

THESIS

ALZHEIMER'S DISEASE AND FAMILY CAREGIVING:  
LOSS OF THE FAMILY CAREGIVER ROLE

Submitted by

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Human Development and Family Studies

In partial fulfillment of the requirements

For the Degree of Master of Science

Colorado State University

Fort Collins, Colorado

Summer 2010

COLORADO STATE UNIVERSITY

April 21, 2010

WE HEREBY RECOMMEND THAT THE THESIS PREPARED UNDER OUR SUPERVISION BY AUDRA GENTZ ENTITLED ALZHEIMER'S DISEASE AND FAMLIY CAREGIVING: LOSS OF THE FAMILY CAREGIVER ROLE BE ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE.

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## ABSTRACT OF THESIS

### ALZHEIMER'S DISEASE AND FAMILY CAREGIVING: LOSS OF THE FAMILY CAREGIVER ROLE

Family caregiving for adults with Alzheimer's disease is an important issue that affects many individuals. When caregivers are no longer caregiving, the loss of the role may impact their life. However, it is unknown in the gerontological literature how the loss of the caregiver role is experienced. The purpose of this research was to understand the loss of the caregiving role of family caregivers who provided assistance to individuals who had Alzheimer's disease. A total of 21 participants, age 41 to 88, participated in one focus group (i.e., three focus groups were conducted with 5 to 10 participants) addressing the loss of their caregiver role. Many participants (i.e.,  $n = 18$ ) were female and were caring for a parent/in-law (i.e.,  $n = 14$ ). A third of caregivers provided care for 5 to 8 years. Qualitative data analysis techniques were used to develop themes and codes to understand the experiences of previous caregivers. Two themes emerged from the data: caregiving journey and standing at a cross-road. Data focusing on the caregiving journey addressed rewards and stumbling blocks of caregiving during and after active caregiving. For example, participants discussed their tools and feelings associated with caregiving.

Standing at a cross-road illustrated four sub-themes: unforeseen happenings, unexpected phase of caregiving, caregiver's sense of self, and grief/sadness. Future researchers should consider examining gender differences and the loss of the caregiver role for children versus spouses. Professionals should consider developing support groups or educational materials focusing on the loss of the caregiver identity.

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## Caregivers for Older Adults with Alzheimer's Disease:

### A Look at the Loss of the Family Caregiver Role

Over the past twenty years, the amount of family caregivers has increased dramatically in the United States (US). Reasons for the increase in the number of individuals providing care include an increase in life expectancy (Maples & Abney, 2006), better health care and medical advancements (Federal Interagency Forum on Aging-Related Statistics, 2004), and decrease use of public services for older adults (Kinsella, 1996). Similar to the rising number of caregivers is the rising number of older adults with Alzheimer's disease (AD) (Maas et al., 2004); please see Appendix A for extended review of the AD literature.

In addition to data focusing on family caregivers for individuals who have AD, since approximately the late 1980s, there has been a remarkable increase in the grief and loss literature focusing on caregivers (Burton, Haley, & Small, 2006; Sanders, Ott, Kelber, & Noonan, 2008; Waldrop, 2007). Loss may be subjective and is characterized when an individual no longer has or experiences something or someone (Bowlby, 1980). Grief occurs as an emotional reaction to the loss of something or someone. Further, bereavement often refers to the state of loss whereas grief refers to the emotional reaction of loss. Kubler-Ross (1969) discusses common stages of grief, which include: denial, numbness, bargaining, depression, and anger. Often times and more recent research suggests (Stroebe, Hansson, Stroebe & Schut, 2001), grief and loss are not linear but multidimensional and complex. Due to the complexity of grief and loss, individuals may exhibit phases versus stages of grief and loss (Cook & Oltjenbruns, 1998). Taken

together, the grief and loss literature is necessary when examining AD family caregiving issues as it has been discussed that family caregivers experience grief and loss.

As previously stated, with the expanding literature, family caregiving and AD have received more attention in communities, in families, and from researchers focusing on gerontological issues (Frank, 2007/2008). However, there has been little attention in the empirical literature around the loss of the caregiving role (Holland, Currier, & Gallagher-Thompson, 2009) and a “call to action” for researchers to study this topic (Berg-Weger & Tebb, 2003-04). More specifically, the loss of the caregiving role after a family member has provided care to someone who had AD. To date, the only research that has been conducted specifically on the loss of the caregiving role focused on caregivers of individuals with cancer and the caregivers’ bereavement process (Schumacher et al., 2008). As a result of the lack of research on this topic, the purpose of this research project is to understand the loss of the caregiving role of family caregivers who provided care to individuals who had AD.

### **Theoretical Perspective**

Role theory and ambiguous loss provides the theoretical lenses for this research project. According to role theorists, a role is a concept that entails a person occupying a social position and his or her behavior is determined by social norms (e.g., dressing professional in an office setting), social positions (e.g., being a mother or a boss), and personal characteristics (Blakely & Dziadosz, 2007). Linton (1936) saw roles from a functionalism perspective with roles remaining static and as prescriptions to life and life’s specific positions. These roles are defined by society and its social structure. For example, roles are usually found in institutions in societies, such as schools, the military,

work places, or in families. There are numerous roles in any given institution and those roles can change with space and time. Finally, it is not uncommon for someone to occupy more than one role at a time (e.g., a daughter, sister, mother, employee, and caregiver to an older parent).

The social structure of institutions helps shape roles and the role definitions (Merton, 1976). For example, in traditional families sons and daughters should listen, be respectful, and obey their mother and father. Roles can also be viewed as subjective. For example, an individual occupying a given role may see his/her role differently than another person in the same role or how an outsider may see that specific role and what the role may or may not entail (Goffman, 1959). Individuals in roles are always interacting with others and testing their concepts of roles (Mead, 1934) by taking on new tasks or positions that may be non-normative (e.g., a grandmother taking on a role as a mother, or students teaching a class session in school).

When discussing role theory, some terms to recognize relating to an individual's role include role-taking, role-making, role-set, role distance, role conflict, and role transition. Mead (1934) saw roles as an outcome of a process of interaction. As described by Mead (1934), role-taking is when an individual takes on the role of another (i.e., children playing teachers or mothers, and young children watching his/her parent on how to care for his/her grandparent). This interaction process can add, take away, or reinforce certain behaviors, questions, or concepts. Role-making refers to when behaviors are created or modified according to interactions and roles are shifted during this process (Turner, 1962). An example of role making is a daughter-in-law cares for her mother-in-law based on the methods and beliefs that she holds and how much time she wants to

spend caring for her (i.e., placing or not the care recipient in a Long Term Care Facility (LTCF), or hand feeding the care recipient). Ron (2006) depicted role-taking as being assigned a role, whereas role-making is where an individual can create his or her own role and make changes according to social norms, social values, expectations, and beliefs. Role distance refers to a person's detachment from a specific role that he or she is performing (Goffman, 1959). Goffman's idea of role distance can be related to commitment and attachment to roles. Role distancing may occur after a care recipient has been placed in a LTCF and the caregiver may no longer provide direct care assistance or during bereavement when a caregiver detaches him or herself mentally from the care recipient. Role conflict can be described as when an individual's roles are being incompatible due to demands from either role or expectations, or when an individual defines his/her role differently than others in the society. Role conflict can often occur for caregivers in middle adulthood who are both caregivers for young children and older adults. Lastly, role transition occurs when an individual is undergoing changes in their life, specifically to roles that they play. For example, when young adult children move out of the home parents often find their role is different. Further, role transitions occur when individuals retire and no longer have the "work" role they once knew. Current literature examining role transition (Ducharme et al., 2009) for caregivers, specifically those who have cared for an older adult with AD, have examined role transition while the care recipient is still alive. Role transition can affect an individual in many different ways and could be referred back to the grief and loss literature. However, the role transition for a family caregiver of an older adult who had AD may be different than the role transition of a retiree or of a parent whose child has left the home.



## Role Strain

Goode's (1960) idea of role strain refers to when an individual can accumulate more than one role until his or her total role obligations become too overwhelming and demanding (Schumacher et al., 2008). As the patient with AD declines in mental and physical health, the family caregiver assumes more responsibilities and more time is needed to care for the patient (Dang et al., 2008). Dautzenberg, Diederiks, Philipsen, and Tan (1999) investigated how multiple roles, competing roles and role strain affected an individual who caregives for someone else. Dautzenberg et al. (1999) referred to the 'sandwich generation' of middle-aged women caring for multiple persons as having the most role strain and taking on the most roles in life. The results of their study showed that the acquisition or the loss of the caregiver role was not associated with higher levels of distress nor the acquisition of multiple roles when compared to those that were not caregiving (Dautzenberg et al., 1999). Ron (2006) also found that the various stressors related to the caregiver role have a *positive effect* on the caregiver's mental health. Role strain is often associated with the caregiving role (Schumacher et al., 2008) and not to those specifically in the 'sandwich generation'. Some caregivers may be caring for more than one individual at a time, which could impact how they viewed their role during the caregiving process and how they view their role once their caregiving role has ended. Furthermore, intergenerational caregivers who have multiple roles show a strong commitment to their caregiving role (Piercy, 2007).

Family caregivers have also been reported to take on the caregiving role spontaneously and with no role orientation or little to no knowledge (Tobin & Kulys, 1980). This rapid accumulation of additional roles and role assumption can be the result

of a crisis, illness, or handicap. With a lack of time to become accustomed to the new caregiving role and lack of role preparation caregivers may feel intense emotional distress around their role (Ron, 2006). In comparison, a rapid decrease in roles and loss of a role can be difficult and stressful, as well. Social roles can diminish with age; however, adults with a lack of roles may find new roles or create roles. Such as retired older adults might start a local book club or volunteer. In addition, the term “roleless”, often used in retirement literature, refers to the lack of defined role characteristics (Price, 2003). A loss of a role can happen if the caregiver’s patient moves into a LTCF, dies, or even experiences better overall health.

In addition, borrowing from the parental loss literature, a loss can be from a variety of causes and can be stressful for the individual, having the individual turn to coping strategies (Schneider & Phares, 2005). During this bereavement stage, a caregiver may have certain behaviors and thoughts that will help him/her through it (Smith et al., 2002). Silverberg (2007) describes that some caregivers go through role denial to help manage the grief and the grief experience. Role denial happens when individuals do not want to embrace their role and carry out the tasks associated with that role. By denying their caregiver role, this coping method may help individuals detach themselves from the patient and that particular role.

As demonstrated by Pierce, Lydon, and Yang (2001), many caregivers who are spouses have a strong commitment to their caregiving role when compared to caregivers of a different relation. In Piercy’s (2007) research, all primary caregivers who had strong commitments to their caregiving role were female and had moral, religious, and affectionate bases. Many participants in Piercy’s (2007) work reported their caregiving

role positively and rewarding by having an opportunity to being able to teach others about compassion. However, participants in the described study were in the caregiving stages and not in bereavement stages. As a result, research needs to address this construct when caregivers are in the bereavement stage.

### **Ambiguous Loss**

The theory of ambiguous loss also provides insight into this research study as it is likely many AD family caregivers experienced ambiguous loss prior to the loss of the caregiving role (Boss, 2006). “Ambiguous losses are physical or psychological experiences of families that are not as concrete or identifiable as traditional losses such as death” (Betz & Thorngreen, 2006, p.359). When losses are not clear-cut, such as losing a child due to a kidnapping or losing a parent due to dementia, this is a type of loss is called ambiguous loss. Ambiguous loss is a unique type of loss where there is an unclear loss, either due to a physical or psychological loss such as in the previous examples. There are two main types of ambiguous losses. The first, a physical absence with psychological presence- such as losing a child due to kidnapping where the child is physical absent but still thought of often; and second, a psychological absence with physical presence- such as a parent with dementia, who is still alive but psychological absent (Walsh & McGoldrick, 2004). Ambiguous loss can be confusing for those around the family member with AD because the physical attachment is still present, but the person they have known is no longer present. Caregivers for individuals with AD often experience ambiguous loss (Frank, 2008). This type of ambiguous loss has also been called “leaving without saying goodbye” (Frank, 2008, p.517). The emotional bond that links the two people is missing or is starting to vanish. Some family members may be frustrated and

wonder if the person who is psychologically absent is even a part of the family anymore because they are not themselves (Betz & Thorngreen, 2006). The memories that linked them are gone.

During times of ambiguous loss role shifts can be questioned (Betz & Thorngreen, 2006) because role reversal is common. This occurs when a daughter is now caring for her mother when it was the mother who usually cared for her daughter. These types of shifts can add to the confusion of ambiguous loss because now the individual may be not only confused about the psychological and emotional loss of the person, but the steady roles have shifted.

Ambiguous loss can be stressful, frustrating, and challenging at times for those experiencing it. It is often characterized by factors that impede the grieving process (Betz & Thorngreen, 2006). This can be seen in AD caregiving because the grieving process cannot be completed because the person with AD is still present physically. With the grieving process interrupted, this can cause extra stress and even exhaustion on the individual and the entire family involved (Betz & Thorngreen, 2006).

### **The Loss of the Caregiving Role**

There are many ways a caregiver may lose the caregiving role. The two most common reasons for no longer being a caregiver is because of the death of the patient or moving the patient into a LTCF. A caregiver's decision for placement in a LTCF relies highly on the quality of life for the individual with AD, and the quality of life of family members of the patient and of the caregiver (Herrman & Gauthier, 2008; Vellone et al., 2008). In addition, a patient's placement in a LTCF does not ensure that there will be a decrease of the caregiving role for the caregiver as the caregiver may often visit the

patient, provide medication and transportation to appointments, grocery shop, purchase clothing, and other merchandise, and may do the care recipient's laundry, among other tasks. Conversely, when the patient dies caregivers may still experience a strong attachment to the caregiving role and have intense physiological, psychological, and emotional distress around the bereavement.

The role of the caregiver involves multiple losses; feelings of loss and grief appear frequently for caregivers of AD (Dang et al., 2008; Frank, 2007/2008). These losses can appear many ways and may be experienced differently for different caregivers. The losses can be summarized into the categories of physical (e.g., loss of appetite), social (e.g., isolation from friends), financial (e.g., out-of-pocket money spent), and psychological loss (e.g., stress or depression).

The demands of caregiving can be so overwhelming that caregivers may spend less time with loved ones in their lives (Dang et al., 2008). Once the patient is dead, the caregiver may begin the bereavement stages. During the bereavement stages of caregiving, caregivers may enter stages of loss, grief, and bereavement (Holland et al., 2009). In the literature, bereavement stages do not specifically refer to the loss of the role of caregiving, but more so the loss of being a caregiver in general (Smith et al., 2002). During the bereavement stages of caregiving, caregivers may experience feelings of relief, feelings of chronic grief, feelings of thankfulness, have a desire to share the legacy of the individual without the impairment of AD, find themselves advocating for other caregivers and AD, and may find a new outlook towards the future (Smith et al., 2002). Grief of caregivers of AD individuals has often been compared and related to caregivers

of patients with cancer, noting that the loss of the individual can be extremely painful (Adams, 2006).

Furthermore, understanding caregivers' loss of role and their bereavement around the loss of the caregiving role may help add to the knowledge around caregiving and how a person deals with and perceives his/her loss of the role. In addition, examining only caregivers of AD patients will add insight to this particular body of literature that will lead to more understanding of the caregiving role as the AD population increases.

### **The Present Study**

Due to the dearth of research on the loss of a caregiving role for those caring for older adults who have AD, I conducted a qualitative study examining this phenomenon. Understanding caregivers' mental health, stress, and coping has been studied in previous literature and has been previously cited in this literature review. Grief and loss are commonly associated with the caregiving role and is prevalent in the caregiving literature. In addition, family caregivers for individuals with AD are growing in numbers. As a result, family caregivers of AD patients were recruited, in comparison to caregivers of other individuals with different impairments (Alzheimer's Association, 2008; Dang et al., 2008; Smith et al., 2002). The goal of this study was to learn more about the experiences and impacts of the loss of the caregiving role for those who were previously caring for individuals with AD. Therefore, the research questions for this project are:

1. How do previous family caregivers describe the loss of their caregiver role?
2. What impact does losing the caregiver role have on individuals?

## **Method**

A general model of qualitative methods (i.e., a model simply used to discover and interpret the perspectives of individuals studied) and data analysis (Merriam, 1998) was used to explain and interpret the experiences of previous family caregivers. Qualitative research has been described as well suited for understanding the complexity of family relationships (Daly, 1992). Furthermore, it also has been portrayed as a way to expand the knowledge researchers have of close relationships (Allen & Walker, 2000).

### **Participants and Participant Recruitment**

Individuals who wished to participate in this research study must have been: (a) at least eighteen years old, (b) been a caregiver to a family member with AD who was deceased for at least 3 months and no more than 5 years, and (c) at a stage during their bereavement process to be comfortable discussing their experiences and the loss of the caregiver role with strangers.

A combined convenience and purposive sample (i.e., a sample easily contacted and met specific requirements) of a total of 21 participants, female ( $n = 18$ ) caregivers and male ( $n = 3$ ) caregivers, participated in this study. A total of 21 participants age 41 to 88 ( $M = 61.14$ ) participated in one focus group (i.e., three focus groups were conducted with five to ten participants) addressing the loss of their caregiver role. Participants were caring for a parent ( $n = 13$ ), an in-law ( $n = 1$ ), or a spouse/partner ( $n = 7$ ). A third of caregivers provided care for 5 to 8 years. The majority of participants ( $n = 18$ ) came from referrals from the Alzheimer's Associations in Fort Collins and Denver, Colorado; while other participants were recruited through word-of-mouth ( $n = 3$ ). The majority of participants ( $n = 17$ ) had stopped being an active caregiver between 3 months and 2 ½

years prior to participating in the focus group. The remaining participants (n = 4) had been an active caregiver between 4 years (n = 3) and 5 years ago (n = 1). All participants reported that they performed IADL's for their care recipients and made a wide variety of decisions (e.g., from grocery shopping to health care decisions) for the care recipient. Nearly half (n = 9) of participants reported they worked for wage at least full-time (i.e., 40 hours per week) for all or some of their caregiving experience, while almost a quarter (n = 5) of participants worked less than 5 hours per week, and the remaining quarter (n = 5) of participants worked between 5 and 30 hours per week. See Table 1 for participant descriptions.

Participant recruitment began after Institutional Review Board (IRB) approval was granted. In an effort to recruit previous family caregivers, different strategies were used. Successful recruitment occurred with the help of Emmalie Connor, Regional Director, Alzheimer's Association, Fort Collins and Pat Holley, Family Services Director, Alzheimer's Association of Colorado, Denver. Participant recruitment also occurred through word of mouth using Colorado Alzheimer's Associations (i.e., snowballing techniques). Lastly, efforts were made to recruit through Hospice of Larimer County, Elderhaus of Fort Collins, Colorado, Golden Peaks Nursing and Rehabilitation Center of Fort Collins, Colorado, and the Evans, Colorado Chapter of the Alzheimer's Association.

Emmalie Connor and Pat Holley identified possible former family caregivers whom they knew through the Alzheimer's Associations. The women contacted potential participants and received their permission to send their names and phone numbers to me. Additionally, the women and other contacted organizations used a recruitment flyer and a



letter addressed to caregiver for participant recruitment purposes. See Appendix B for recruitment materials.

After initial contact from the Alzheimer's Associations, I contacted potential participants directly through e-mail and by telephone to ask a series of screening questions for the study (see Appendix C). A total of 28 participants were recruited by the Alzheimer's Association and through word-of-mouth; 21 caregivers participated in this study, two participants did not show the day of the focus group, two participants contacted me too late to participate in the focus groups, and three participants were unwilling to drive to a nearby city where the focus groups were being held. Screening questions were used to ensure that the potential participant met the criteria to participate in this research project. Another aspect of the screening questions was to help detect if participants were emotionally ready to be in a focus group discussing past family caregiving experiences and their caregiver role. For example, I asked potential participants to "rate their level of comfort (i.e., on a scale from 1 to 10) discussing with strangers about their family caregiving experiences and the loss of the caregiver role." After the participant rated his/her level of comfort, a follow-up question was asked for the participant to "describe what that number means." A common response to the feeling comfortable discussing their caregiving experience in a group of strangers was a rating of "8" or "10" ( $M = 9.29$ ). This meant that the participants believed they would be very comfortable discussing their caregiving experiences with a group of strangers. When I asked the follow-up question, a common response was, "I like sharing my experiences" or "I am very comfortable with talking about it [my caregiving experience] with others". I also asked about the previous caregiver about their "current level of grief or sadness". A

high rating indicated the caregiver had a lot of current grief and a low rating indicated the caregiver had a more minimal amount of grief. There was a broad range of answers between “2” and “10” ( $M = 4.57$ ). When I asked the follow-up question for the meaning of the number, common responses were, “Periodically feelings of depression”, “There are triggers or times that are sadder than normal”, and “I am getting stronger, coping, and letting go”. Rating was a self-measure and was subjective to the individuals. This means that the same number can look or mean something different to each person, which was the purpose for the follow-up question. The screening questions were used to help ensure the participants’ emotional safety and well-being while in the group.

Similarly, individuals who rated themselves high on the bereavement scale or low on the comfortability scale were not excluded from this study, but were told that the scaling questions were asked to help ensure their emotional well-being. These individuals were also told that during the focus group they may be likely to experience emotional distress if they still wished to participate. Only four participants had rated high on the bereavement scale (i.e., rated an “8” or higher) and still wished to participate. All participants reported they were comfortable in a group setting (i.e., rated a “7” or higher). These scales were used to help ensure the participants’ emotional safety and comfort during the focus group; and to give notice to participants that the group may cause some emotional discomfort.

In addition, information to participants about the nature and topic of this study were given at this time (i.e., I described that I was interested in learning about how caregivers of individuals with AD look at the loss of the caregiving role; Smith et al., 2002). Potential participants were notified if they were eligible for this research project

immediately after the screening was performed. Participants in the first two focus groups were given the choice of attending one of two focus group sessions. That is, I provided them with dates for the focus groups and ask them to choose one date to attend. The date and time for the third focus group was predetermined and participants were invited to attend if they met the screening protocol.

## **Procedure**

Due to the exploratory nature of this research project, the primary methods of gathering data were focus group sessions. Focus groups are a qualitative method for collecting data in which a small group of people, normally eight to 10 individuals, gather to discuss a topic they have experienced (Krueger, 1998). For the purpose of this research project, I limited the number of participants in each focus group to five to 10 participants. This allowed for a more intimate setting and a greater opportunity for all focus group members to comment on their attitudes, ideas, opinions, concepts, and reactions to the topic. Additionally, it has been noted, that as little as six people allows for individuals to discuss the topic while bouncing ideas off of each other (Morgan, 1998). The first focus group included eight participants, five caregivers participated in the second focus group, and the third had eight participants. Further, it has been noted that qualitative research, especially focus groups addressing sensitive topics, such as sexuality and drug use, can work successfully (Morgan, 1998). Therefore, this rationale supports this research addressing the sensitive topic of the personal loss of the caregiving role. Furthermore, empirical studies (Borrayo, Goldwaser, Vacha-Haase, & Hepburn, 2007; Lui, Lam, & Chiu, 2006; Meuser & Marwit, 2001) have effectively completed focus groups around the

topic of family caregiving and the unique needs of caregivers of individuals who have AD (Wheeler, 2010).

It was clear that after three focus groups, saturation of the data was met; therefore, participant recruitment stopped. Saturation is the idea that no new information is gleaned from data collection procedures and that as data collection progresses the data gathered fit nicely into what has previously been found (Charmaz, 2000). For this study, the third group reaffirmed, or highlighted, important points during the first two groups that were not as easily noticed. Furthermore, no new significant themes or codes appeared during the third focus group session.

Each focus group took place on one day (i.e., for a total of three different days) over an estimated two hour period. Participants were welcomed to arrive approximately 10 to 15 minutes prior to the start of the focus group to get to know other individuals in the group. Upon arrival, refreshments were available to encourage mingling (Morgan, 1998). In addition, this time attempted to be relaxed and non-directive. Participants were also given name tags, asked to check their contact information on a sign-in sheet, and directed to sit wherever they felt most comfortable. All focus groups were held at the Alzheimer's Associations in the city nearest to participants.

There were one to two individuals in the focus group room to assist with the focus group procedures. These individuals included a moderator (i.e., myself), a note taker (i.e., a trained graduate student), and an observer (i.e., my thesis advisor). The observer attended only the first focus group to monitor and provide constructive feedback to the moderator. Having a note taker was important for this research project to help take notes of what was being stated during each session, who was speaking, and participants' body

language, which could not be seen in an audio tape. In addition, the note taker assisted with paperwork (i.e., passing out and collecting questionnaires), observed the discussion, and provided feedback, observations, and insights of the focus groups (Krueger, 1998) to the moderator. The note taker also allowed the focus group moderator to be the main facilitator during the group discussion and spoke only after the session was over with the moderator during debriefing (Krueger, 1998). In addition, having a second individual involved in the research increased the strength of the project as this person was an initial sounding board and another set of eyes and ears during the sessions. Each focus group session was audio taped to allow for further in-depth investigation after the data gathering session ended.

At the focus groups, after introductions and before the study commenced, signed consent forms were distributed and gathered. During this time, confidentiality and anonymity was addressed on the informed consent form (see Appendix D). I went through the consent form slowly and in detail. I then asked if any sections needed to be clarified to ensure all participants understood the nature of this study. I explained that I would guarantee anonymity as much as I could, however, due to the nature of a group setting other participants knew each others' 'real' names. I asked if participants wished to discuss what was said during the focus group sessions once they left, to keep their discussion at a minimum, and if possible, to not use names of other participants. Lastly, I also asked participants to only share what they are comfortable discussing and if there is other information which they would like to tell me about, but were not comfortable sharing among other people, that they could talk with me individually after the focus group was over. Finally, I explained to participants that to help ensure anonymity, I

would create a pseudonym for each participant before I started to code the data; and would never share their name with others. Parental consent forms were not needed as all participants were 18 years or older.

After participants signed the consent form, I introduced the focus group by welcoming participants and by giving them an overview of the topic and the reasoning of having participants in a focus group. During this time I provided guidelines or ground rules about the focus group session. To start the next part of the focus group, I used an opening activity that asked participants to share whom they were with the group and to choose a miniature (i.e., a small toy/figurine) that represents their caregiving experience, especially as it related to the loss of the caregiver role. I also told participants if there was not a miniature that they believed fit with their feelings, they could draw instead (e.g., I provided markers and colored pencils plus paper for them to use). There were over 40 miniatures available to choose from and a few were of the same miniature, or were a similar miniature. For example, there were two butterflies, two angels, and two elephants that participants had the opportunity to choose from. Other miniatures available included animals (i.e., giraffe, fish, bird, lion, gorilla, etc.), children's fictional characters (i.e., Merlin the Wizard, Princess Cinderella, and superheroes), and construction site tools (i.e., cones, hammer, wrench, etc.). The miniatures were spread evenly and in no particular order on a large table with walking room around the table for participants to clearly see all miniatures available. The opening activity was designed to 'break the ice' and give participants even more of an opportunity to talk and feel comfortable around each other (Krueger, 1998). After the introduction and the 'ice break' activity, a series of questions were asked to allow group participation (see Appendix E).

This study aimed to highlight the importance of looking at a caregiver's experience and well-being from all angles and exploring areas discussed in the literature (e.g., Fruhauf & Aberle, 2007; Smith et al., 2002). The focus group sessions were semi-structured with questions planned, but allowed the participants to use each other's experiences and comments to influence how they might respond to a question or statement. The questions were broad enough to allow the participants to have space to respond to information that they believe is important. Focus group questions were in no particular order and followed the flow and direction of the group; with the exception of the first question and 'break the ice' questions (Smith et al., 2002).

During the focus group, I facilitated group discussion. I kept in mind the idea of 'group think' and attempted to get a sense of what the group as a whole believes by asking if others in the group agree or disagree with statements from participants (Krueger, 1998). I controlled my reactions, such as "That's good", to prevent the group from leading in to one direction and knowing my personal reactions. To control my reactions I gave verbal reactions, such as "Uh-huh" or "Okay", provided direct eye contact, and head nodding. Head nodding was not used as a signal of agreement, but more to elicit additional information and to show that I am listening (Krueger, 1998). I followed Krueger's (1998) list of moderator's body language techniques when conducting the focus group sessions. Also I used my body language to facilitate group discussion without speaking, for example leaning into the table could be interpreted as "I am interested, tell me more" (Krueger, 1998). In addition to being aware of my body language and verbal responses, I allowed time for silence or a pause in the group discussion. To allow the silence gave participants time to think about the question or

comment at hand without me prompting them or giving them a response I wanted. I attempted to engage participants that tended to be quiet by asking for their viewpoint or experience about the question at hand. During the entire focus group sessions, I listened intently by demonstrating head nods, eye contact, and a body position showing “I am listening to you”, such as an open body.

When time was coming to an end, I notified the participants that I had a few final questions remaining to ask them. Once the focus group was over, I thanked participants for attending and allowed time for questions. A demographic questionnaire was given at the end of the focus group. The demographic questionnaire (see Appendix F) was composed specifically for this study and was given to participants at the end of the focus group. This questionnaire included questions such as gender, age, and ethnicity (Ron, 2006). Participants were not excluded from this study because of their gender, ethnicity, religion, or SES. A second separate questionnaire, Family Caregiver Questionnaire (see Appendix G), was also given. This questionnaire covered similar areas that the focus group questions addressed, but differed in being closed-ended questions used for quantitative purposes. Lastly, a referral, in the form of a broacher, was given to each participant to the Colorado State University’s Center for Family and Couple Therapy, if an individual’s wished to see a therapist to discuss personal matters.

### **Plan of Analysis**

Data analysis was employed and various measures of trustworthiness were used to increase the validity and reliability of the research project. Descriptive statistics were reported to provide a summary of the participants that allows for further context of their experiences. Qualitative analyses were conducted by me with the assistance of my thesis



advisor. Using the audiotapes and notes from the note taker, I transcribed each focus group session. This built an additional level of analysis and trustworthiness, as I not only conducted the focus group session but I transcribed the data myself. It also provided an opportunity for me to hear the data twice before sitting down to analyze participants' words. Participants' legal names were not included in the transcribed data and a pseudonym was used in its place.

During analysis of the qualitative data, I kept in mind previous caregiving literature, my research questions, and my theoretical lens. Further, I used an inductive (i.e., not having pre-set codes that the focus group data needed to fit), constant comparison approach (Strauss & Corbin, 1998) to analyze the data. After I read the focus group transcripts (at least twice), I met with my advisor (who read each transcript once) to discuss the data. Notes were taken individually prior to meeting with each other and after initial conversation about what the data was telling us; I then generated a list of codes reflective of the participants' responses that fit the data. Codes are key words or phrases (Smith et al., 2002) depending on the nature of the topic that "assigns a summative, salient, essence-capturing and/or evocative attribute for a portion of language-based or visual data" (Saldaña, 2009, p.3) generated from the participants' voices. After a general list of codes was developed I then consulted with my advisor and began to sort the codes into "like minded codes" or codes that were similar or fell into a particular category. At this time I noticed some codes were repeated and as a result, they were eliminated or revised to fit the data. After further discussion with my advisor and analysis of the data, I started to generate themes following what was believed to be important. A theme is an "outcome of coding" categorization, and analytic reflection"

and usually is a “phrase or sentence describing more subtle and tacit processes” (Saldaña, 2009, p.13).

While coding the data I returned to the coding scheme and made additions and discarded codes when necessary in order to reduce overlap between codes and increase the clarity of the coding scheme. My advisor and I coded one focus group individually and then met to discuss the coded data. During our conversation we discussed passages and codes that we were not certain fit the data. When we could not agree on items we went back to the published literature to consult where items should be coded. After meeting with my advisor, I coded the remaining two focus group transcripts by myself and then met with my advisor again to ask clarifying questions and confirm uncertainties that I had about the data and the coding scheme. After all coding was complete a final version of the coding scheme was produced (see Appendix H).

### **Trustworthiness and Credibility**

The issue of producing research that is both valid and reliable is a concern for all researchers (Merriam, 1998). There has been much debate about whether qualitative research produces valid results and reliable information (Tashakkori & Teddlie, 1998). Alternative approaches to establishing validity and reliability that are appropriate for qualitative research include establishing *trustworthiness* and *credibility* (Merriam, 1998). For this research project I completed the following strategies to ensure trustworthiness of my research. These include: (a) triangulation, (b) member checking, and (c) discussion of my position as a researcher.

Triangulation, the exercise of using multiple methods, researchers, or sources to support findings enhanced the validity of the current study (Merriam, 1998). I

triangulated the data through the focus group discussions, the questionnaires, the notes from the co-moderator, and literature to validate and support the qualitative narrative. As a researcher, it is important to consistently seek support and confirmation of research ideas and results from peers.

To increase trustworthiness and credibility of the coding scheme before going back to code the data, I utilized a technique consist with qualitative work, member checking. I sent the coding scheme, via email, to four focus group participants. These participants were chosen because they contacted me after the focus group to continue discussion and provide feedback of the data and the overall research idea. In particular, I asked the focus group participants to offer thoughts about accuracy of the discussion, clarity of the coding scheme, if they had any thoughts they wanted to add/change/delete from it, and anything else they wanted to let me know before I began coding the data. All participants who reviewed the coding scheme thanked me again for giving a voice to previous caregivers and recognizing the need for research and support in this area of caregiving and of AD transitions. Finally, all participants who reviewed the coding scheme said that what was written was correct and properly highlighted important, or key, aspects of the focus groups. Further, I also asked for feedback from the focus group note taker. Comments from my note taker included to highlight the choice of miniatures chosen by each participant, to note that participants were at different places on their journey (i.e., the third focus group seemed further along than the first and second group), and pointed out key words and phrases stated during the focus groups.

As a researcher is it important that at all times I am aware of my own research bias while keeping in mind my research lens during focus groups and data analysis. My

experience as a granddaughter of my grandmother who had AD first raised my awareness of the effects of AD on individuals and their families. During my undergraduate university years, my grandmother came to live with my family during the early middle stages of AD. I assisted my mother often with my grandmother's IADL's and ADL's while I was at home during the summers. During my grandmother's rapid decline due to AD, my mother placed her into a LTCF and was still an extremely active caregiver. Five months after my grandmother's death I became a caregiver in a memory unit of an assisted living home where I was attending my undergraduate university. I was a caregiver to one wing per night (an average of eight older adults, all with various forms of dementia). My tasks were mostly ADL's and more intense compared to my experiences previously with my grandmother. Due to closeness in time of my grandmother's death and starting my caregiver position, I ended my position at the LTCF. I knew that my grandmother's death was affecting my mental and emotional state of my work at the LTCF and it would be more appropriate for me to resume at a later time.

Lastly, before setting out to conduct this qualitative research project, I had previous experience in quantitative data collection with children under the supervision of a professor during my undergraduate studies. I assisted him (e.g. the professor) with the literature review, the IRB application, participant recruitment, data collection, and data analysis. Upon completion of the project, my professor, my other research team members, and myself presented the research study at an international conference in Chicago, IL in May 2008. As a result, I do have a level of familiarity with research and feel "comfortable" with coding data and analyzing data.

## Findings

“I think it’s such an all-encompassing role. You wake, you dream, you sleep, you think constantly-care. It’s constantly. It does not go away.

When you think you’re not thinking about it, you are thinking about it.

And, you’re deep down worried about it. And, then there’s the added activity.

I have to do this, I have to do this, I have to do that, I have to do that, I have to make sure he’s okay. So, you are really caregiving 24/7 and you’re trying to get ahead of the game.

And you’re thinking, how can I get ahead of the game, um, so that I can prepare for this?

And, so when that goes away, there is a huge gap, a huge gap, and um, thinking, worrying, emotion...Shouldn’t I be someplace (agreement)? Shouldn’t I be doing

[something]? Wait a minute.

I mean it’s always constant.”-Natalie

Natalie was not the only participant in this research study to express the static thoughts running in her mind about the loss of the caregiver role. Similar to Natalie, Catharine stated in an e-mail highlighting important points from the coding scheme:

Nobody can relate to the depth of what it’s like caregiving for an Alzheimer’s disease care recipient...Especially the isolation as a result and loss of directional next steps after his or her death. Some of us require years of self awareness and self development afterwards.

After data analysis procedures from three focus groups, including a total of 21 participants, two main themes emerged from analyzing the data: (a) caregiving journey and (b) standing at a cross-road. The caregiving journey included sub-themes representing rewards of caregiving and challenges associated with caregiving. Standing at

a cross-road included four sub-themes: (a) unforeseen happenings, (b) unexpected phase of caregiving, (c) caregiver's sense of self, and (d) grief/sadness. The following is a discussion of each theme, sub-theme, and the codes describing the loss of the caregiver role. Direct quotes from participants in the focus group sessions support the coding scheme and are provided to help illustrate the complexity of this phenomenon. See Table 2 for positive attributes during and after active caregiving. See Table 3 for challenges during and after active caregiving.

The "ice breaker" not only aided participants in feeling comfortable in the focus group, but was part of the research process. During the "ice breaker" participants were able to hear a little bit about each other's journeys, including struggles and rewards. The miniatures provided a physical object that allowed participants to put their caregiving experience, especially as it related to the caregiver role, into a solid entity and give that miniature a voice. For example, Paige carefully displayed her choice of a clear glass angel and shared, with a quivering voice, "...I picked this for my mom because, um, I know she's in a better place. And it kind of released me to have my life back." In another group, Rachel chose a gorilla with arms open and palms facing up. Rachel told the group,

I picked this gorilla with open arms because I really felt like well, what now?

(makes same posture as gorilla) It was a what now? Yet, also at the same time it was like, I was also feeling like okay. I need to be, that was such an incredible experience that I need to be open to anything that comes my way because I can handle it.

Diana chose an apple core as her miniature and carefully handled it throughout the entire focus group. She often turned the apple core slowly, motioned to it, and held it while

speaking. When Diana did place her miniature down she did so with care. While holding the miniature carefully, she shared part of her journey with the group,

I picked this apple core because um, when my dad first got sick I had no idea how to deal with it...And, when my joy for him not having to go through end-of-life Alzheimer's gave way, shortly after he died, that's exactly how I felt. Like there was nothing left. Like I was down to those poison seeds and I did not have any idea how I was going to cope with it.

In a different focus group Hillary chose a two-headed dragon. Unlike, Diana, Hillary did not handle it with as much care and did not refer back to it during the focus group.

However, Hillary still described a strong tie to the miniature, "I picked the two headed creature, whichever it is, because it all, I was taking care of my husband. You needed an extra person to figure out what he wanted, what he needed, and what everybody else needed too."

After all participants shared the reasons why they chose their miniature, comments and discussion was encouraged between caregivers. Throughout all focus groups participants described agreeing with what other participants had said about their experience in relation to their miniature. For example, Olivia said,

I like what you said too about the decision making because there are a lot of decisions to be made, but there is no manual of how to make those you know. So, I think it is difficult to know sometimes what direction to go.

In agreement with many others in her focus group, Margret affirmed, "Well, what was said resonates with me pretty well." Similarly, during the third focus group, Natalie said, "Only that I can identify with what everyone says." In response, all participants agreed

with head-nods, smiles, and stating, “Exactly.” This strong agreement and response that appeared while sharing the miniatures, is an example of the process and journey of being a caregiver. The miniatures also may have allowed participants to share and open up about their experience in a non-threatening way.

### **Caregiving Journey**

“We were the lucky ones. We were. We really were the lucky ones to know that [caregiving experience with a care recipient who had AD].” -Emily

“Yeah, my feeling [about lack of family support] was like they’d splash around fairy dust to get it [helping the care recipient] to look right in their eyes.” -Diana

When speaking about their caregiving experiences, caregivers discussed both positive and negative aspects of being a caregiver, which can be seen from the previous statements from Emily and Diana. Participants started the conversation by describing how they became a caregiver, obstacles they met along the way, support they received, tools and resources that were helpful, and their feelings throughout the experience.

When asked, “In one word, how would you describe your caregiving experience?”, during the first focus group, Catherine summed it up by stating, “That it was a journey”. During all focus groups other participants discussed their journey as being “a privilege”, “priceless”, and “difficult”. They only stated that they were “blessed” to have been a caregiver and that it was a “treasure” because it was “love” that brought them to the caregiver role. Similarly, during the third focus group, Jenna described the hardships of being a caregiver and then said, “...I am very happy that I was capable of doing this journey”. Caregivers referred to all of their caregiving experiences, during and after active caregiving (i.e., when the care recipient who had AD was alive), as part of



their caregiving journey. In addition to their experiences, feelings were often associated with each part of their caregiving journey. In sum, the caregiving journey refers to experiences and feelings associated with a caregiver's experience.

**Rewards.** During the focus groups, participants often discussed their experiences caregiving when the care recipient was alive while at the same time sharing their experience of the loss of the caregiver role. Rewards of caregiving illustrated two main areas: (a) during active caregiving and (b) after active caregiving. Rewards encompass tools and feelings associated with the caregiver role.

A 'tool' is something that helped the caregiver role through their journey. For example, when discussing their caregiving journey, participants said having "strength", "support", and knowledge, or "education", was helpful and at times, invaluable to them as caregivers. "Strength" or "support" sometimes appeared in the form of religion, "family", or "resources", such as the Alzheimer's Association or hospice. The participants own dedication to their caregiver role also added to their "strength" which was helpful during their journey, especially through hard times. While discussing "strength" and "support", Diana shared:

This process for me to gain the strength to be a caregiver and step into this situation...it [educational support] was the information I needed to be able, I didn't know, I didn't have a clue what I was supposed to be doing, and if you give me some information I can use it.

In addition to tools, participants shared many feelings experienced during their caregiving journey. Caregivers felt that humor, "joy", and "love" guided them through

their journey; while “appreciation” for being a caregiver made the experience positive.

For example, when specifically discussing the caregiving journey, Kelly disclosed:

The journey with my dad was an amazing, was just an amazing journey and while it was incredibly difficult seeing him, cause he ran the course of the disease, I mean it went until the end. And, while it was hard to see that, I mean, there was just amazing gifts through it all. It was just the most blessed experience.

During the caregiving journey, many tools and feelings used during active caregiving continued after the care recipient died. Because participants were comfortable in a group setting, they shared memories of their journey, expressed “gratitude”, enjoyed “sharing” with each other and the “support” felt during the focus group. Being comfortable was seen during the second focus group when Ned stated:

You know, people see you in certain lights, and I know you know what I’m talking about here. And, you don’t see yourself like that, but, you feel an obligation you have to. You have to uphold what they expect. I don’t feel, I feel really comfortable to be able to talk here because you people already know what to expect.

Ned spoke about holding up “a front” in front of others who may not understand the journey caregivers go through. Being comfortable in the focus group appeared many other times during all focus group sessions.

Similar to during active caregiving, feelings were often expressed during the focus groups for after active caregiving. Participants showed appreciation for their caregiving experiences and felt it was a “blessing”, a “joy”, “grace”, a “treasured” or

“priceless” experience. Caregivers felt a “connection” with each other often leading to the ability to speak freely. For example, Catherine shared:

You know what, it is a difficult thing that, my mom was so....everything was so fresh and so new. The prettiest flower she had ever seen was just you know so those are the little gifts that you get. And, you are forced to slow down and really, and really enjoy the moment. And, you know, if everything were healthy and I would have missed out on those things. So, it’s best when you can slow down.

Catherine’s statement illustrates the feelings of appreciation, joy, priceless, and having a connection with the care recipient. She also demonstrates being comfortable enough in the focus group to share her experiences and her dedication to her care recipient through the caregiving journey. Further, these feelings were supported and confirmed at the end of each group by many participants through statements of gratitude for discussing this topic, enjoyment, and feelings of connection found at the focus group.

Participants also provided support to one another during the focus groups and helped point out that caregivers who felt vulnerable, defeated, or worried were just “surviving”. As a participant discussed feeling “embarrassed” and “fragmented”, Hillary responded by stating, “No, you’re surviving. That’s all you can say is that you’re surviving until you can figure out what it is that you’re going to do with the rest of your life.” Hillary’s response shows strong group support with emotions and self-purpose. Group support occurred in every focus group and by every participant, either through their spoken words, head nodding, smiling, laughter, or body gestures.

**Challenges.** Similar to rewards of caregiving, challenges associated with caregiving illustrated two sub-themes: during active caregiving and after active

caregiving. Both of these sub-themes also represent stumbling blocks and feelings caregivers experienced. During active caregiving, there were many “decisions” that had to be made about the care recipient and “caring for myself [the caregiver]”. For about a third of participants, these “decisions” created family conflict and feelings of “worry” or guilt. For example, Kim was sharing what was going through her mind while her care recipient was in a LTCF, “...When he went in there it was so hard because I guess, I was taking care of him as best as I could and when he went in there and somebody else is going to be looking after him...” Paige helped finish Kim’s sentence, “And, you worry about him every day.” Kim answered, “Yes, either is he doing alright? Is he okay?” Similarly, Olivia commented on decision-making and said:

So, I think it is difficult to know sometimes what direction to go...But still, it is a difficult, you know, you never felt like you know [if] that was a good decision. You always feel up in the air about everything; about was it the right, the wrong, or do we need to make a decision about this. So, it’s always, you always feel like you are kind of floundering...

During active caregiving all participants shared there were many hard decisions to make relating to the care recipient and their personal life. When discussing her miniature during the ice breaking activity, Olivia said, “...you know their [Mr. Potato Head] ear can be facing this way, and the other ear, and one eye can be out, so I just kind of felt pulled in a lot of different directions [when I was caregiving].” Like so many other participants in this study, during active caregiving, Olivia was making decisions related to the entire family, was caring for multiple people in the family, was not always quite

sure about the decisions she made related to her caregiver role, and her own self-care started to suffer.

In a different focus group session Kim shared, “[to] make decisions, um, I’d ask him [my care recipient] to help me make it because, ‘you were stronger than me, I know you.’ [He would say] You can figure it out and do it. And, keep going.” Kim’s statement illustrates that there were many hard decisions for her to make and that she was not always confident about the decisions she made. She wanted her care recipient’s support and input. Furthermore, for Kim, her care recipient was a positive source of strength that helped her continue her caregiving journey. Participants further discussed wishing there was some sort of universal manual for caregiving that would work for caregivers, doctors, educators, and more. Rose stated, “I wish the doctors had a manual...that it’s all the same. There were so many things that were such a struggle and disappointment and frustration and, somehow there needs to be a concise something that can direct you to different things.” Rose’s statement is one example of many frustrations and wishes for the medical and professional world.

Furthermore, Natalie also mentioned difficulties and frustrations with those in the professional world whom interact with individuals with AD and their caregivers. Natalie stated, “...so and that was a negative piece in my caregiver role was to try to advocate well in an industry that I think is suffering, ill-trained, ill-equipped, uh, no money and all those kind of things, so that was a piece that was a real drag on the momentum.” In addition to Natalie and Rose’s frustrations and concerns many other participants expressed similar ideas and feelings.

Caregivers expressed feeling accountable, or “responsible”, for the care recipient’s health and well-being. While feeling “responsible”, caregivers articulated feelings of “guilt”, and caregiving being “difficult” and “tiring”. Jealousy also appeared as participants discussed losing part of their caregiving role to formal, or professional, caregivers and other family members who had stepped-in to give the participant some relief. During the second focus group Frances and Ned discuss what it is like making hard decisions around hiring professional help:

Ned: Did you find that you were the bad guy?

Frances: Absolutely.

Ned: Boy.

For Frances and Ned, making hard decisions also came with feelings of guilt, it’s [caregiving] hard, and feeling accountable, or responsible, for their care recipients’ physical/mental health, and overall well-being. Similar feelings from participants appeared numerous times throughout all focus groups and were often accompanied by tears and agreement (i.e., head nods and vocal cues).

In addition to active caregiving, participants discussed stumbling blocks associated with after active caregiving. Participants said there were many hard “decisions” during their caregiving journey and some were associated with family conflict and diminished self-care. Frustration with lack of education and sensitivity with resources, such as hospice or LTCF, was one of the primary stumbling blocks. For example, Rachel affirmed, “it [part of the negative experience] was more about the facility, there was some frustrations.” Further, Rachel’s frustration with the LTCF was associated with her “worries” for her care recipient. Participants also shared feelings of

emptiness, “regret”, “fear”, “anger”, being “unprotected”, and “overwhelming” in the caregiver role. For example, regret and worry can was seen when Paige shared, “My biggest challenge on not having the caregiver role is like getting rid of the ‘if-only’s’. If only I’d done this better.” Feelings of fear for participants mainly appeared around the possibility of having AD themselves, or for other family members. For example, Jenna stated, “I think Alzheimer’s is the most feared disease out there,” and Tracy had to call Alzheimer’s the “A-word” on request of the care recipient. Participants in all focus groups discussed the “lack of education” about AD and caregiving. This “lack of education” for family and friends added to the fear of “getting” or “catching” AD, whereas for participants, because they were knowledgeable about the disease, were anticipating their own AD diagnosis in the future.

Stumbling blocks such as decisions and resources along with feelings of not being relieved, anger, and worries appeared multiple times, particularly, when discussing the lack of education and knowledge about AD and caregivers in professional settings. This was evident when Natalie said, “It’s inexcusable the lack of training,” all other seven participants in the focus group nodded in agreement when discussing LTCF and some physicians. Rachel stated something similar when she disclosed, “just those insensitivities” and lack of common sense bothered her.

### **Standing at a Cross-Road**

“And, so, sort of an unexpected feeling to find myself lost, and being very at a loss, and just kind of like now what? Now what? And kind of searching and exploring...

This is the first time in my life, I think ever, that I’ve been alone.” –Emily

Emily's statement sets the stage for discussing the second and final theme: standing at a cross-road. This theme includes four main sub-themes: (a) unforeseen happenings, (b) unexpected phase of caregiving, (c) caregiver's sense of self, and (d) grief/sadness. After analyzing the data it was clear that the sub-theme, caregiver's sense of self, had three main coding categories: (a) caregiver's sense of personal direction, (b) caregiver's sense of personal purpose, and (c) caregiver's sense of self-identity. Data from the grief/sadness sub-theme revealed that there were two coding categories: (a) beliefs and (b) feelings.

The theme of standing at a cross-road was first considered to be: standing at a cross-roads with no map. However, after saturation and further review and analysis of the data, it was clear that some caregivers believed that they had a map and a way an end-point, but not always a clear direction. For example, Emily's statement, "...find myself lost...and just kind of like now what? Now what? And, kind of searching and exploring..." demonstrated the group of participants that felt they were standing at a cross-roads with no map. During the third focus group it became clear that some caregivers did have a map, or direction after time had passed. Jenna stated, "I call my plan the bucket list because, you know, I don't want to wait until I have that disease. I want to dance and be happy in this moment..." Jenna's statement implies that she was standing at a cross-road with no clear direction, but had a plan, or map, to know where to go and what to do next in her life. Therefore, standing at a cross-road is an appropriate theme representing this data.

The theme of standing at a cross-road refers to the caregiver's sense of self where there is a temporary loss of direction, purpose and identity. Catherine discussed what it



was like to be standing at a cross-road, "...one foot is still dragging and there is one arm still really focused and determined to go forward." Her statement embodies much of the coding categories and codes for this section, such as personal direction, personal purpose, self-identity, and not prepared or uncertainty under unforeseen happenings. Standing at a cross-road is the most significant theme from this study for the reasons of it encompassing personal direction, purpose, and self-identity and because this data is new to the caregiving literature. Adding to the significance, this theme was also highlighted and emphasized multiple times by all participants throughout all focus group sessions.

**Unforeseen happenings.** As the first sub-theme, unforeseen happenings included ideas from the data representing caregivers not having a "choice" in being a caregiver, and for some, losing the caregiver role. This was best described when Hillary stated, "My husband received the diagnosis and so, that's what you do." All other seven participants in the first focus group nodded in agreement. Hillary further discussed the importance of taking on the caregiving role and how others may not view it in the same way, "Well, I didn't have a choice because some people feel they are not able to be a caregiver, and that is understandable, but uh, I didn't feel like there was any choice. And, I didn't want, I didn't want anyone else taking care of him."

Caregivers also described unforeseen happenings as not being "prepared" to no longer be a caregiver and the experiences that are associated with the loss of the caregiver role. Jenna disclosed, "...I don't feel like he, like I'm prepared, for those moments [grief and hardship], and um, letting yourself know that's it's okay if those moments come along and you work through." Not being prepared often lead to "uncertainty" with the

loss of the caregiver role which was discussed by Margret when she said, “So you wonder what we are supposed to do with the rest of our lives.”

Finally, and possibly the most important, is that the loss of the caregiving role is “unexpected.” As a result, many participants reported feeling they did not prepare for many aspects of the caregiving journey. Some said they reached out for educational and emotional support from friends, family, and professionals. Frances said, “I look back on it, the times that feel real I wasn’t prepared. He died so far down the road and I just didn’t understand.” Frances did have some educational and emotional support through her journey, however, it is clear she thought additional support would have been helpful to help her be more prepared. Other participants in the same focus group as well as other focus groups supported Frances’ thoughts, where they could have used more educational and emotional support. Further, many participants did not believe they were prepared for the loss of the caregiver role once their care recipient died. As a result, participants expressed a need for additional support. One excellent example that captures these thoughts was a discussion during the first focus group:

Margret: Well, you know I did, want to focus on, it has been 5 months today since I have lost my husband and so, my head is still searching for which direction I want to go to. And, you know, that is good to hear you say that because I didn’t want to give that up. I feel so blessed with the help I had along the way. And so, right now I am not knowing which direction that is so... (laughter) it is good to know...

Catherine: Me either, that’s why I am glad you [gesturing to researcher] did this [research study].

Hillary: You do feel like a fish out of water; just not knowing which way to go. Margret, Catherine, and Hillary's discussion did not explicitly ask for help, but alluded to needing a direction and support through this time of uncertainty.

One unforeseen happening that appeared throughout all focus groups was not being prepared for the loss of the caregiver role. Almost all participants answered they believed they "lost the caregiver role once their care recipient died." A more specific example was when Frances shared, "When I lost my mom, I lost the caregiving role and it's also this feeling." However, a few caregivers answered differently. In the third focus group, Rachel shared she lost the caregiver role before her care recipient died. For example, Rachel shared, "...[When] another person come in and if I was in an emergency situation and couldn't be there...that was the first time for me that it was like, 'Oh, that's my job. This is my job. What am I going to do?' It's like what am *I* going to do?" For Rachel, she believed she first lost the caregiver role when a professional caregiver, or formal caregiver, was hired to help with caregiving tasks.

After some discussion about when participants thought they lost the caregiver role, about half of the participants stated they did not lose the caregiver role. For example, during the third group Natalie stated, "Once again, I don't think the caregiver role ends though." Many other caregivers in the group nodded in agreement with Natalie. Similarly, Rachel disclosed, "I'm still a caregiver, you know I just have one less person that I'm caregiving for I guess. But, it's shifted to other people too. It's just who I am. I will always be that way." Jenna, Harry, and Tracy nodded in agreement with Rachel's statement. Another example, during the first focus group, was when Lilly claimed, "Women are always caregivers..." and Olivia responded, "My mom still is too because

she still goes to meetings and caregives to other people who are going through it. You know they haven't lost the person they are taking care of." Lastly, during the second focus group, Paige had previously stated she lost the caregiver role once her care recipient died. She then shared, "I made sure her will was carried out the way she wanted it carried out. And, all of that legal stuff, and you know, it was even after she [died] I still took care of her."

**Unexpected phase of caregiving.** Even if the caregiver role does not end for some individuals, many participants expressed the journey after active caregiving ended as unexpected. For example, the caregiving journey after active caregiving was "unexpected" and allowed time to "volunteer" for some. Others were more able to focus on the care of themselves. For example, Tracy shared:

...I can do that [relax] because it is okay. Because no one is depending on me to do something, and I can go out dancing you know, stuff I didn't do before [and it] is really fun. And, I feel like you know, it's okay to do this.

Other participants also discussed another caregiving phase that occurs after the care recipient dies. When discussing the unexpected phase of caregiving, Catherine said, "...that somebody recognizes that there is an issue to me is very powerful....that after caregiving is another phase of-" Stacy helped finish her sentence by saying, "of caregiving." Catherine responded with, "of caregiving. Yeah. And, why isn't there anything about that? Where do we turn?" Catherine and Stacy's discussion of an unexpected phase of caregiving appeared in all groups, however, in different ways. Over a third of participants expressed they were currently volunteering in some way to help fill the space of the caregiver role. For example, Kelly stated, "Would I want anyone to go

through it [hardships of the caregiving journey]? No. But having been through it, ... I guess now for me, it's just like, I want to be an advocate.”

The idea of “another phase of caregiving” is a phase that almost all participants reported not being prepared for, not knowing that it was coming, and needing help to navigate it. As Kelly and other participants found, volunteering and advocating helps to find a path. In a way, participants are agreeing that the caregiver role does not end, it just changes; and for some individuals, another phase of caregiving. Participants said these experiences were unforeseen, and at times were associated with feelings of guilt and still feeling like a caregiver; but, overall, the journey was a “blessing” and “priceless”.

During the third focus group I summed what I had heard so far as it relates to the general support of comments from the participants. I stated:

I'm hearing a lot of agreement that the role didn't go away and it just transforms ('uh-huh', all but one person nodded in agreement) into something different. And, maybe find a different purpose, and different way to be a caregiver. (A lot of head nodding)

In response, Harry said, “I think you become more of an advocate at that point. You are still doing caregiving, but you have to advocate for what they can't say to the people that are helping to care for them.” Harry started to define the unexpected phase of caregiving as an advocate-type role or phase. Diana disagreed with Harry through shaking her head ‘no’ and stating, “I don't know.” Tracy supported Diana's disagreement and uncertainties by stating, “Well yours [Diana's caregiver role] did [end] because your dad died. When my husband died my caregiving role went away.” Diana responded in agreement, “Yeah.” Tracy continued to share:

And, your caregiving role. And, I was, um, as I said before grieving the loss of all the caregiving hours, you know, everybody. And, I grabbed on to it by becoming, well I guess I was already a support group leader, um, but saying with that, with the Alzheimer's Association, I was sort of able to continue to be a caregiver in steps. And, you know, helping other people.

**Caregiver's sense of self.** Under the sub-theme of caregiver's sense of self, was a coding category of caregiver's sense of personal direction. Similar to other codes of caregiver's sense of self, caregiver's sense of personal directional appeared multiple times throughout all focus groups. All participants mentioned directly or alluded to their personal direction during the discussions. Some participants reported they felt "alone" and a "loss of direction" which leads to restructuring their life without the primary care recipient. Personal direction tied closely with the concept of caregiver's sense of personal purpose. Participants who were standing at a cross-road often discussed feeling confused about their personal purpose. In contrast, participants who were confident in their current direction and path had a clearer vision of their personal purpose. Participants described they felt "invisible" now that their active caregiving role ended and started to rethink and redefine their caregiver role. Many participants reported "volunteering" and giving service to organizations and new care recipients to help fill their sense of purpose.

A common topic that appeared throughout all focus groups was self-identity. Caregivers believed they had become "fragmented" and were "floundering" trying to figure out their purpose and redefine their identity. Participants also thought they lost a part of themselves once the caregiver role ended. Emily stated, "you've died too." When discussing about "the self" during the loss of the caregiver role, Catherine disclosed:

So, it's embarrassing. I don't know how to word it. I can't explain what I'm doing. We're fragmented (lots of agreement) I guess. Invisible is probably a good word. Or, lost is another good word...How do you explain why you're doing that and you're not a caregiver anymore? So, why aren't you having a good time? (laughter) Yeah.

In sum, self-identity was discussed at lengths and in detail in all focus groups. In the first focus group participants were discussing what their caregiver role means to them now that their care recipient passed away. During the discussion Catherine shared, "But you do have to recreate yourself..." and Natalie helped Diana during the focus group with self-identity and sense of purpose by saying, "You're still caregiving." Tracy agreed, "Yeah." Diana's mother, Grace, agreed further by saying, "Very much so." Tracy responded by stating, "But you're not doing *that* caregiving role." Rachel helped explain the loss of the caregiver role and self-identity further by saying, "It's different." In response, Diana agreed, but said that the new caregiver role is different and is one that she does not know how to navigate. For these participants in the third focus group, self-identity and purpose were strongly tied to the caregiver role. Participants who helped Diana see her new role were trying to help her recreate her identity.

During the first focus group, Rose added to and supported the idea of self-identity and sense of purpose when she shared, "I hadn't thought about caregiving I guess. I am still sort of hanging on to that (laughs); not wanting to give it up maybe. I don't know." Further, within the second focus group, Wes expressed loss of self-identity, especially loss of self or part of self, and feelings of fragmented or floundering in the second focus group. Wes revealed, "Yeah, it [no longer having the caregiver role] makes kind of a big

empty place in my heart- not being able to do that anymore...” For Wes, being a caregiver was not a just a job or task, being a caregiver became part of who he was (i.e., his identity), how he saw himself, and possibly gave him direction or a sense of purpose.

When asked the question, “How do you define the loss of your caregiver role?”, many participants agreed on feeling mixed emotions. Some shared feelings of relief, being overwhelmed, and many shared feelings of floundering and loss of direction. For example, Grace shared, “Well, my role it just seemed like it was over and I had to have help with...and, all that was gone. And, I think, why am I still here? You know, what is my job now? I’m not sure what my job is, other things I know.” Feelings of loss of direction, uncertainty, and needing guidance are evident in Grace’s statement. Similarly, Catherine said, “I guess I don’t know which direction I’m heading, but it is, um, unknown I have to make the very best to, because I don’t know how long I have. And, I want to make the very best of what I have at this point, because life is just so fragile.”

Another example occurred during the first group, when Rose stated, “It’s a huge void.” During the third group, Natalie similarly shared, “Almost a purposelessness comes over you.” All eight participants in the third focus group session agreed with Natalie’s statement and then started to share how they have adapted to the feeling of purposelessness. An example occurred during the second focus group discussions when Paige disclosed a loss of personal purpose and direction “drifting” whereas Ned shared, “now, having a direction and personal purpose.” Their dialogue continued:

Paige: I think you feel a loss of purpose. I just felt, like I was just drifting around, I was like oh, what do I do now? You know. It,

Ned: You still feel that way?



Paige: Sometimes.

Ned: For a very short period of time I felt like that but now I think I have a direction because of what I, I'm doing, for the people.

Thus, as previously stated, when the care recipient died many participants filled that space of caregiving for that individual with caring for others, advocacy, and other types of volunteering. For example, Grace states, "I even volunteer" as she responded to what does she do with her time. Similarly, Ned tells a fellow caregiver who is struggling with the feeling of purposelessness and void, "You know, volunteer work really does help a lot, and here, obviously I can see that 100%. You need somewhere to go to and focus and concentrate that level of energy that you had and gave your mother." Ned's statement holds true for many previous caregivers in the focus groups where their energy has been building up and been put to use, often for years. Then, all of a sudden once the care recipient dies, there is nowhere to place their energy and skills previously devoted to caring for a person.

There is a need for a place to direct this energy, or dedication, which is still in movement. For Ned and Grace, volunteering fits their needs. However, many others are still feeling lost and in need of a direction. Emily revealed:

I don't think anything ever again in our lives will feel as important and as huge, special, privileged, as our roles as caregivers and what that was for us... But, it's a hard thing to fill the emptiness of that all by ourselves... But, something that is out there that says, 'Hey, you still matter.' It's just different now, and we'll take that commitment that you made, and that energy, and that love that you had for doing that and we'll help you redirect it...

Emily had a strong connection with organizations during her active caregiving role and now noticed an emptiness that appeared once the active caregiving ended. This need to fill the empty space is strong in almost all participants. In response to feelings of loss of purpose, Lilly added, “As tiring as it was, and as hard as it was, sometimes you wish you had it [the caregiving role] back.” To fill the empty space, in some ways, one might argue is having your caregiver role back. It is redefining and recreating your caregiver role in your life. It is changing how it used to be into something that you can do now without the care recipient in your life. During the third focus group, Rachel states, “Oh yes. It [the caregiver role]....” Natalie agreed with Rachel by helping to finish her sentence, “Changed.”

**Grief/sadness.** Finally, the theme of grief/sadness had two main codes: (a) beliefs and (b) feelings. As participants discussed their caregiving journey, grief and sadness appeared multiple times. Caregivers shared thoughts about death, their frustrations for the misunderstanding of their grief by those who are not caregivers, feeling that their world is “silent”, and stating they experienced two losses: (a) loss of the care recipient and (b) loss of the caregiver role. Ned shared some of his experiences of grief, “I’m happy for him [care recipient] that he’s not suffering any longer, but I feel sorry for myself sometimes because the loss, he was very big part of my life...” Ned’s statement is an example of thoughts about death and sadness. Participants in the first focus group also discussed death and their experience with two losses (and possibly multiple losses):

Catherine: I found when I lost my husband...I grieved for his loss, he lost seeing his grandchildren grow up, he lost retirement, he lost all of those, and then I started grieving for myself because I lost a companion, I lost my love. And, you

know, so it's a bit, that is a strange journey too. Because there are two losses there. (Many other participants, in agreement): uh-huh, yeah.

Emily: There are, there are two causalities when somebody dies from Alzheimer's or dementia. And, you don't hear about that, you know. All the organizations that are, that are setting up to support and understand. I just don't see that in the conversation, in the approach... There really are two causalities involved or more.

Hillary: Actually there's more. My granddaughters that have lost their grandfather...

Hillary has highlighted that AD affects the entire family, not just the caregiver. Further, there are two types of ambiguous loss being described in the focus groups. The first and most commonly discussed, losing the care recipient mentally but not physically, and losing the care recipient physically but still remaining in the caregiver's mind. The second, and most significant for this study, losing the care recipient physically but still remaining in the caregiver's mind and caregiver losing part of his/her self because of the loss of the caregiver role. Additionally, Tracy shared not just two losses, but more specifically, losing her caregiver role more than once:

For me there was two places where I lost the caregiver role. One was when I placed my husband in a facility and that was hard. The freedom went... And, the second giving it up was when there was no advocacy to do for him.

For Tracy, losing the caregiver role twice added to the hardships of the caregiving journey, making it a "difficult" journey.

Grief appeared many times throughout all groups and in different forms. However, one of the most powerful ideas about grief that came out was the idea of

having a “silent world” and the experience of “two losses”. During the first group, Emily shared about what it has been like in her life since her active caregiving role ended. “...It just got so silent in my world. Nobody calls me. Nobody writes. Nobody wonders. You just feel like, you know, you’ve died too. So, it’s tough.” A silent world for Emily is a lack of connection and support from other people who once supported her. Many participants shared Emily’s lack of connection and support from others, including organizations (e.g., the Alzheimer’s Association and Hospice), family, friends, co-workers, and neighbors that were supportive when the care recipient was alive.

During discussions of grief and sadness feelings of “emptiness”, “alone”, and “you’ve died too” appeared. As previously stated, Ned shared, “I’m happy for him [care recipient] that he’s not suffering any longer, but I feel sorry for myself sometimes because the loss, he was very big part of my life...” not only shows an example of grief, but also feelings. Ned demonstrated positive feelings such as relief and release, while demonstrating feelings of sadness, pain, loneliness, and emptiness. Feelings of being alone and emptiness were also apparent in Emily’s statement about a silent world and “you’ve died too”, due to the lack of support. In response to Emily, others shared:

Rose: That’s really true.

Olivia: I did not expect that part, I don’t think I was prepared for that.

Hillary: They come to the memorial and then they, and that’s it.

Rose and Emily: That’s it

Hillary: I don’t know whether they don’t know what to say or how to relate, or ah, but all of a sudden you are alone.

In another discussion participants again tied together the themes of not being prepared and grief. Rose stated:

And, [to] experience the whole package all at one of these feelings, the anger and all these things, and I, so I thought, well I'm really over all that. But, it doesn't, it just isn't that way. I mean, it's hard, hard, hard. No matter. No matter what. We think we're being prepared, but it's just not.

Throughout the caregiving journey there are “joys”, “dedication”, “decisions”, family conflict, “support”, and education to be learned. Along with the experiences come feelings of sadness, “grief”, “worry”, “guilt”, “loneliness” on one end; and feelings of gratitude, “blessing”, “love”, comfort, relief, and looking back on the journey as a “treasure”. Participants discussed the loss of the caregiver role as unexpected and not prepared for what was ahead. For some, the role did not end but merely transformed into a different type of caregiver role. The loss of the role caused confusion and a redefining of life's purpose and the caregiver role. Many participants felt the loss of the caregiver role caused feelings of being “fragmented”, “purposelessness”, and loss of direction; which affected the caregiver's self-identity.

### **Discussion**

Three focus groups were conducted, with a total of 21 participants, to examine the loss of the caregiver role. Two research questions guided this study: (a) How do previous family caregivers experience and describe the loss of their caregiver role? and (b) What impact does losing the caregiver role have on previous family caregivers? In this discussion section, I will focus on (a) answers to the research questions, (b) theoretical

implications, (c) future research directions, (d) limitations of this study, and (e) implications for practioners.

The first research question, how do previous family caregivers experience and describe the loss of their caregiver role, is answered by understanding that a large part of the participants' focus group discussion address experiences during active caregiving (i.e., when the care recipient was alive). Participants discussed helpful tools and challenges, or obstacles, during their caregiving journey (i.e. resources, support) and feelings associated with during and after active caregiving. In the present study and in past research, family caregivers discussed the tools including various resources (e.g., programs such as The Savvy Caregiver Program, Powerful Tools for Caregivers, and hospice support groups- for immediate loss of care recipient) (Holland et al., 2009). Participants in this research project often referred to 'active' caregiving and 'after' caregiving during the focus groups. As previously described in this study, the definition of 'active caregiving' refers to day to day caregiving, caregiving that may be 24 hours a day for seven days a week, and while the care recipient is still alive. The term of 'after caregiving' is related to more of a 'passive' caregiving experience. Passive caregiving may be a paradox as it appeared in the forms of participants focusing on advocacy or volunteering and refers to the caregiver caring for someone different (i.e., other than the care recipient who had AD), and further performing different care related tasks for themselves and even the community. Passive caregiving means that caregiving may not be on the previous caregiver's mind daily, but the caregiver still defines him or herself as a 'caregiver', without a clear, defined receiver or care recipient. This type of caregiving might also not be about performing ADL's or IADL's for a care recipient, but instead

caregiving in a different or unique way (i.e., serving as an advocate for current individuals in the active caregiving role). In sum, caregivers experienced the loss of the caregiver role through sharing and describing tools and feelings and the impact this had on their identity as a caregiver in the active or passive caregiving role. It might have also lead some caregivers to question their life's purpose and the next step of caregiving. Participants called their experience a journey, and after reviewing the data it also appears that their experience is a processes and not just an event. A process is a progression or development, whereas an event is an occasion or a result. The caregiving journey and standing at a cross-road is not a final destination, but rather a continuing roller coaster or circle of events. The events that occurred during the process may not be the same for each caregiver, yet similarities were discovered.

As previously discussed, caregivers discovered tools and skills during their caregiving experience and discussed having no place to put their energy or skills. After the care recipient died, many caregivers wanted a place to continue using their caregiving knowledge and skills, and to share with others. This feeling of 'being put on hold' seemed to add to the loss of purpose. Because participants want a place to utilize their energy and skills, they discussed wanting additional support groups and mentoring for the loss of the caregiver role. Another impact of the loss of the caregiver role is the feeling of loss of direction or purpose. In some ways, a void is a loss of purpose. It is a space that appears in your heart and life. In response to this void and loss of purpose, many participants in this research project discussed trying to fill that space through volunteering and advocacy opportunities on behalf of caregivers.

Participants described the loss of the caregiver role as having lost their self-identity and sense of purpose. Caregivers also described the loss as encompassing unexpected experiences. This addresses the second research question, what impact does losing the caregiver role have on previous family caregivers. Caregivers discussed that the loss of the caregiver role is a transition to where they are going next on their journey. For many participants, the caregiving journey does not end, but merely changes or evolves over time along with changes in the caregiver's roles and purpose. As caregivers described losing their caregiver role, participants used descriptive words such as "fragmented", "floundering" and "Who am I?" which imply feeling lost, not having a defined purpose and searching for their self-identity. This is consistent with previous identity research that suggests self-images transform as a result of changes in life circumstances and roles (Whitbourne, 1987; Whitbourne & Connolly, 1999). It can be inferred that some participants felt an identity crisis after the loss of their care recipient. However, this study did not ask questions related to self-identity during focus groups, therefore, this should be cautiously inferred and future research should examine this area further.

All participants mentioned the frustrations and struggles arising from the lack of resources and support for after the active caregiving role ended. Previous literature discusses family caregivers not being prepared to provide care (i.e., during active caregiving) (Ron, 2006). This study discovered that substantial issues arise when family members are not prepared for the loss of the caregiver role. Having an unexpected phase of caregiving adds to the caregiver not being prepared for 'what happens next' and the rainbow of feelings that are connected to the caregiver role. Family caregivers had not



given much thought to their life once the caregiver role was gone. When an individual has prepared for a next phase in life, such as retirement (Richardson, 1993; Wang, 2007) or in this case being a caregiver, the literature has shown that the transition may be easier. However, researchers need to further examine the phenomenon of role transition when a caregiver unexpectedly no longer is a family caregiver versus those whom have been planning for life after caregiving.

### **Implication for Theoretical Perspective**

This qualitative study has only begun to add to the theoretical perspectives used to support the research topic. Therefore, interpretations of the data for the theories are not as strong, or supportive, for this study. As it pertains to role theory, there are numerous roles in any given institution and those roles can change with space and time. For example, for those caregivers whose care recipient died 3 months to 1 year ago may experience role change differently than those whose care recipient died 4 to 5 years ago. Caregivers where more time elapsed since the death of their care recipient may have had a clearer sense of self than those who had lost their care recipient more recently. Although this was not examined in depth through the interview questions, participants who had more time to grieve the loss of the care recipient and their caregiver role may have better direction because of the time to figure out their next steps or their purpose. In support, grief literature has also shown that grief and sadness are stronger closer to the death of the individual (i.e., in this case the care recipient) (Frank, 2007/2008). Therefore, it is likely that participants with more time elapsed since their active caregiving experience went through more phases of grief as it relates to the loss of the caregiver role.

During the grief process caregivers start to redefine their identity, family structure, and social roles. They begin to question the decisions they made during their caregiving journey and start to define their current identity, without the care recipient. Some caregivers in this research study, lost their identity or part of themselves and their purpose. A person's identity is strongly tied to and shaped by their social roles, attitudes, beliefs, and ideas (Berger, 1966). Identity is also maintained or altered depending on their interaction with others (Hayes, Boylstein, & Zimmerman, 2009) and personal experiences. As caregivers lose one of their social roles (i.e., the caregiver role) there is a need, or struggle, to start to redefine their identity.

According to Shapiro (1994), "Grief is a crisis of both attachment and identity, disrupting family stability in the interrelated domains of emotions, interactions, social roles, and meanings" (p. 17). Relating to the present study, it is evident that the grief processes includes a search for identity and a missing bond, or attachment. Further, participants also discussed family disruptions and remaking social roles, or the meaning of their caregiver role.

As previous stated, roles are subjective; therefore, each caregiver may have a different caregiving experience. In this study, all participants spoke from their personal experience and shared many similar experiences throughout the caregiving journey. Two mother-daughter dyads participated in this study and, at times, one of the daughters helped to describe the mother's experiences and feelings. This may be the daughter's role in the family structure, her caregiving experience, or personality traits/characteristics. On the other hand, the other daughter did not speak as much for her mother. Miller, Shoemaker, Willyard, and Addison (2008) reference that the death of a parent is

extremely difficult for a child. Often times the death of a parent is a time for the child to recreate or redefine their identity as an individual and may not use their parent for support, or if both parents have died, recreate their identity as an orphan. Furthermore, as previously stated, ambiguous loss role shifts can be questioned (Betz & Thorngreen, 2006) because role reversal is common among caregivers. In this case, a daughter was now caring for her father when historically it was the father who had cared for his daughter. This type of role shift may have added to the confusion of ambiguous loss because of emotional loss and roles shifting. This research project did not allow for this type of investigation, therefore, conclusions cannot be made about mother-daughter caregiving experiences and interactions.

Participants experienced role strain during active caregiving, primarily when caregivers had many roles in their life or took on the role with little to no orientation or knowledge (Tobin & Kulys, 1980). Caregivers discussed positive resources and accumulation of knowledge (i.e., Alzheimer's Association and hospice) as helpful, but also described areas of improvement. For example, caregivers said these same organizations should provide resources and support for the loss of the caregiver role. This could include caregiver support groups around the loss of the caregiver role or a mentor program, or caregivers who have recently lost the caregiver role. Having these additional resources, support, and knowledge should help decrease role strain. Caregivers may see the work outside of active caregiving simply as an extension of their relational role (O'Connor, 2007).

Another aspect of role strain is lack of preparation. Not being prepared (e.g., knowledge or education, time to give, money, "a plan") may contribute to distress during

active caregiving (Ron, 2006). In this study, role strain was apparent after active caregiving. For example, participants found the loss of the caregiver role “hard”, “difficult”, and for many, not wanting to let their role go. As related to role strain the loss of a role can be difficult and stressful at times (Piercy, 2007). Caregivers who may not have had previous caregiving experiences, especially for individuals with AD, found their role more “difficult” than others.

All participants in the current study, at some point during the focus groups, regarded their previous caregiver role in a positive way (i.e., “joy”, “priceless”, “love”). For many, the caregiver role did not end but transformed into a different type of caregiver role through advocacy, volunteering, and being involved in community activities. As previously stated Piercy (2007) found that caregivers reported their caregiving role positively by having an opportunity to being able to teach others about compassion. Further, Smith et al. (2002) research supports this finding as caregivers in this study would advocate for other caregivers and AD, and often found a new outlook towards the future. Participants in Piercy’s work (2007) were in the active stages of caregiving, whereas this study found similar feelings and actions after the active caregiver role had ended. This finding is profound and is related to the lack of support and resources for caregivers after their caregiver role ended.

Many participants agreed that there were numerous losses related to their caregiving experiences. Specifically, participants found ambiguous loss to be difficult and at times, a challenge. Alzheimer’s disease has numerous victims which was described during the focus groups. Caregivers described ambiguous loss during caregiving and two losses after the care recipient dies- the care recipient and the caregiver

(Dang et al., 2008). One participant stated that only after the care recipient died did she finally have time to grieve for herself. The mental loss of a loved one to AD can be devastating and impact the caregiver even after the care recipient dies. The severity of the loss before the person dies can be confusing and hurtful for the caregiver, adding to participants thinking two losses occurring when caring for an older adult with AD.

### **Limitations of the Current Study**

The present study has several limitations that should be noted. Although 21 caregivers agreed to participate in this study, the self-selection of participants adds to the limitation of the studies' generalizability. Only 75% of potential participants contacted ultimately attended the focus groups. Additionally, caregivers that did not seek help through the Alzheimer's Associations (AA) did not have the opportunity to participate in this study. There may be differences between caregivers who seek help from the AA, than those who welcome assistance, support, etc. from other agencies, and those who seek no help at all. Another limitation was the use of convenience and purposive sample of participants through the Alzheimer's Associations, looking for a specific type of caregiver. The experiences of the participants selected may not be generalizable to a larger population and those caregivers who did not participate in this project may be inherently different than the participants of this study.

Further limitations of this research are related to participant demographics. The majority of participants in this research were female, non-Hispanic/White, middle-aged, and from the Northern Colorado region. A wider range, or type, of participants can increase the generalizability to different populations and areas of the country. Therefore, the findings from this research are limited to the characteristics of the 21 participants.

## **Future Research and Directions**

This research study focused only on previous family caregivers of individuals who had AD. Therefore, the ideas for future research and directions are directly related to this population. However, it could also be noted that future research and directions could be applicable for other previous family caregivers, regardless of the care recipients' diagnosis.

Future researchers should consider examining gender differences and spouses' experiences compared to sons'/daughters' experiences as it relates to the loss of the caregiver role. Further examination of the loss of the caregiver's identity and purpose after the loss of the caregiving role should also be considered. In addition, investigation of needed resources and how to help with redefining previous caregivers' personal direction, purpose, and self-identity after active caregiving may also be warranted.

The loss of the caregiver role occurs when care recipients are placed in LTCF, or when "a professional" comes in the home for relief. Therefore, future research should also examine how caregivers experience the loss of the caregiver role when their care recipient enters a LTCF or a formal caregiver enters their home. Because this population (i.e., when the care recipient is still alive) was not the focus of this research study, future researchers should examine this population separately from the current population examined, as their experiences are likely different.

Future researchers may also want to investigate the loss of the caregiver role not solely for caregivers who provided care for an older adult with AD, but other diseases as well. Lastly, this research study had limits related to elapsed time of caregiving for participants. Participants had to have provided care between 3 months and 5 years prior

to participating to qualify for this study. Due to the large temporal difference, future researchers should consider examining time differences as it relates to the loss of the caregiver role, especially in smaller segments of time. For example, gathering data on caregivers 3 months to 5 months, 1 year to 2 years, etc. This gives more definition and separation to time, which may have played a difference in experiences discussed between participants.

Another area future research could examine is the different losses in participants' lives and the effects of other losses on the loss of the caregiver role. This might be important because having multiple losses, especially close together, could impact how the caregiver views loss of the caregiver role and adjustment to that loss.

As shown from the focus groups, resources for caregivers, such as hospice and the Alzheimer's Association, may want to provide additional services to meet the loss of the caregiver role and still recognize previous caregivers. These services should help meet the loss of the caregiver role after the care recipient has died and may want to help with caregivers' sense of purpose, direction, and self-identity. Almost all participants showed a strong desire to continue working with organizations and to continue some type of caregiving role. Organizations could offer mentoring programs, support groups, and ways to continue, or start, involvement in the organization (i.e., through volunteering, fundraising, Alzheimer's and caregiving awareness, education, and advocacy) for months to years after the care recipient has died.

### **Implications for Practitioners**

Due to the increasing number of family caregivers it is likely that many practitioners (i.e., physicians or nurses, formal caregivers, therapists or counselors, those

working or volunteering in the caregiving or Alzheimer's disease field) will interact with current or previous caregivers. Practitioners, who are currently working with, or may work, with active caregivers, or previous caregivers, should consider a variety of implications the loss of the caregiving role has on individuals' lives. These could include, but is not limited to, feelings of frustration, anger, being lost or alone and wanting more direction and support from professionals.

During the focus groups, almost all of the participants stated support groups or talking to others about the loss of the caregiver role would be extremely helpful and should be more readily available to previous family caregivers. Participants believed that hearing different perspectives, ideas, and advice from caregivers was helpful. In addition, participants said having someone (i.e., the researcher) who recognized this loss was supportive and powerful. Some participants also stated that they believed they were less invisible and more recognized as caregivers because of this research study.

When meeting with family caregivers, practitioners should acknowledge the act of caregiving (Fruhauf & Aberle, 2007) and, when appropriate, the loss of the caregiver role. Family caregiving is very personal and takes the caregiver's time, energy, health, and much more (Dang et al., 2008). By just acknowledging this act and/or loss may show care and support. In addition, practitioners should be open to hear all aspects of the caregiving journey, both positive and negative, to show additional support to the caregiver.

Participants discussed redefining, or needing to redefine, their sense of self (e.g., direction, purpose, and self-identity). During active caregiving, a caregiver's sense of self starts to shift and starts to redefine as a caregiver. After active caregiving, there is a sense



of, “What now?” Helping previous caregivers find a new path, or redirect their path of direction, purpose, and self-identity, may be useful and supportive during the caregiver’s journey.

In an effort to provide direction, practitioners could offer tools and resources, both during and after active caregiving, to caregivers to help guide them through their journey and caregiver path. Tools could be ideas or thought-provoking questions about the caregiver’s sense of self. Resources may be ways to re-direct the caregiving energy through volunteering and advocacy for caregivers and AD or offering support groups or peer to peer support in their community (Wilks & Croom, 2008).

Due to the grief and loss that appears during and after active caregiving, practitioners may want to consider further grief and loss training to be better equipped to meet with family caregivers. Continued education is recommended in many fields and grief and loss training should be considered when looking for ideas and directions for continued or practicing education. As it relates to this research, grief and loss can look many different ways and appear at many times during the caregiver journey. Grief and loss in this research study appeared as: loss of time, loss of friends and family, loss of career, loss of energy, loss of sense of self (e.g., direction, purpose, and self-identity), and the loss of the care recipient both mentally and then physically. After the care recipient dies, participants then experience a loss of the caregiver role and a misunderstanding of grief from family and friends, which may lead to feelings of emptiness and being alone. Practitioners must recognize that after the care recipient dies, for many caregivers, caregiving does not end and instead their caregiving role changed.

## **Conclusion**

Caregiving does not end after the care recipient dies; it is another phase of the caregiving journey. This additional phase of caregiving is an important event in a caregiver's life and is minimally discussed in the literature. Therefore this topic needs greater attention. Because of the uncertainty of the next phase, many previous family caregivers feel lost. Other caregivers may not be necessarily lost, but have a plan. However, caregivers do not always have a clear direction about how to carry out their plan. The loss of the caregiving role is another part of caregiving where individuals experience a loss of identity. This may be unique to individuals caregiving for older adults with AD because of the complexity of their caregiving experience. For example, the likelihood that caregivers experience ambiguous loss before the care recipient died, the high level of care provided to the care recipient, the toll caregiving for AD can take on the caregiver's social, financial, emotional, and physical well-being, and the roller-coaster of emotions associated with caring for someone who has AD.

Programs, resources, and support should be made for the preparation for after active caregiving ceases. There needs to be more discussion to address how the caregiver finds direction after the care recipient dies. Further, the definition of 'after active caregiving', or passive caregiving, is a point that was discussed often among previous caregivers. As Harry said, "It [the caregiver role] changed." The caregiving role is different after the care recipient dies, and so is the loss of the caregiving role. Future researchers should extend the caregiving literature to further examine findings from this study as an effort to support and meet the needs of previous family caregivers.

## References

- AARP Public Policy Institute. (2007, November). *Valuing the invaluable: A new look at state estimates of the economic value of family caregiving (data update)*. Washington, DC: Author.
- Adams, K. B. (2006). The transition to caregiving: The experience of family members embarking on the dementia caregiving career. *Journal of Gerontological Social Work*, 47(3/4), 3-29.
- Allen, K. R., & Walker, A. J. (2000). Qualitative research. In C. Hendrick & S. S. Hendrick (Eds.), *Close relationships: A sourcebook* (pp. 19-30). Thousand Oaks, CA: Sage.
- Alzheimer's Association. (2008). 2008 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 4, 110-133.
- Alzheimer's Association & National Alliance for Caregiving. (2004). *Families care: Alzheimer's caregiving in the United States*. Retrieved January 10, 2007, from <http://alz.org/national/documents/Caregiver.pdf>. Abstract obtained from Wilks & Croom, 2008.
- Berger, Peter L. (1966). *Invitation to sociology: A humanistic perspective*. Middlesex, UK: Penguin Books.
- Berg-Weger, M., & Tebb, S. S. (2003-2004). Conversations with researchers about family caregiving: Trends and future directions. *Generations*, 27(4), 9-16.
- Betz, G., & Thorngren, J. (2006). Ambiguous loss and the family grieving process. *The Family Journal*, 14(4), 359-365.
- Blakely, T. J., & Dziadosz, G. M. (2007, December). Social functioning: A sociological common base for social work practice. *Journal of Sociology & Social Welfare*, 34(4), 151-168.
- Bogdan, R. C., & Biklen, S. K. (1998). *Qualitative research for education: An introduction to theory and methods*. Boston, MA: Allyn and Bacon.
- Borrayo, E. A., Goldwaser, G., Vacha-Haase, T., & Hepburn, K. W. (2007). An inquiry into Latino caregivers' experience caring for older adults with Alzheimer's disease and related dementias. *Journal of Applied Gerontology*, 26(5), 486-505.
- Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss*. New York, NY: W.W. Norton.
- Bowlby, J. (1980). *Loss: Sadness and depression*. New York, NY: Basic Books.

- Burton, A. M., Haley, W. E., & Small, B. J. (2006). Bereavement after caregiving or unexpected death: Effects on elderly spouses. *Aging & Mental Health*, 10(3), 319-326.
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds., 2<sup>nd</sup> ed.) *Handbook of Qualitative Research* (pp. 509-535). Thousand Oaks, CA: Sage.
- Cook, A. S., & Oltjenbruns, K. (1998). *Dying and grieving: Lifespan and family perspectives*, 2<sup>nd</sup> ed. New York, NY: Delmar Thomson Learning.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23(9), 929-936.
- Daly, K. (1992). The fit between qualitative research and characteristics of families. In J. F.
- Dang, S., Badiye, A., & Kelkar, G. (2008). The dementia caregiver-A primary care approach. *Southern Medical Journal*, 101(12), 1246-1251.
- Dautzenberg, M. G. H., Diederiks, J. P. M, Philipsen, H., & Tan, F. E. S. (1999). Multigenerational caregiving and well-being: Distress of middle-aged daughters providing assistance to elderly parents. *Women and Health*, 29(4), 57-74.
- DeFries, E. L., McGuire, L. C., Andresen, E. M., Brumback, B. A., & Anderson, L. A. (2009). Caregivers of older adults with cognitive impairment. *Preventing Chronic Disease: Public Health Research, Practice, and Policy*, 6(2), 1-10.
- Dilworth-Anderson, P., Williams, S. W., & Cooper, T. (1999). Family caregiving to elderly African Americans: Caregiver types and structures. *Journal of Gerontology: Social Sciences*, 54, 237-241.
- Ducharme, F., Beaudet, L., Legault, A., Kergoat, M. J., Lévesque, L., & Caron, C. (2009). Development of an intervention program for Alzheimer's family caregivers following diagnostic disclosure. *Clinical Nursing Research*, 18(1), 44-67.
- Federal Interagency Forum on Aging-Related Statistics. (2004). *Older Americans 2004: Key indicators of well-being*. Washington, DC: Author.
- Ferrara, M., Langiano, E., Di Brango, T., De Vito, E., Di Cioccio, L., & Bauco, C. (2008). Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health and Quality of Life Outcomes*, 6(93), 1-5.

- Frank, J. B. (December 2007/January 2008). Evidence for grief as the major barrier faced by Alzheimer caregivers: A qualitative analysis. *American Journal of Alzheimer's Disease & Other Dementias*, 22(6), 516-527.
- Fruhauf, C. A., & Aberle, J. T. (2007). Women caring for partners with dementia: A contextual model. In D. Linville & K. M. Hertlein (Eds.), *The Therapist's Notebook for Family Health Care* (157-164). Binghamton, NY: The Haworth Press.
- Fruhauf, C. A., & Orel, N. A. (2008). Developmental issues of grandchildren who provide care to grandparents. *The International Journal of Aging and Human Development*, 67(3), 209-230.
- Gilgun, K. Daly, & G. Handel (Eds.), *Qualitative methods in family research* (pp. 3-11). Newbury Park, CA: Sage.
- Goffman, E. (1959). *The presentation of self in everyday life*. Garden City, NY: Doubleday Anchor.
- Goode, W. J. (1960). A theory of role strain. *American Sociological Review*, 25, 483-496.
- Hayes, J., Boylstein, C., & Zimmerman, M. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies*, 23(1), 48-59.
- Herrmann, N., & Gauthier, S. (2008). Diagnosis and treatment of dementia: 6. Management of severe Alzheimer disease. *Canadian Medical Association*, 179(12), 1279-1987.
- Holland, J. M., Currier, J. M., & Gallagher-Thompson, D. (2009). Outcomes from the resources for enhancing Alzheimer's caregiver health (REACH) program for bereaved caregivers. *Psychology and Aging*, 24(1), 190-202.
- Keeling, M. L., Dolbin-Macnab, M. L., Hudgins, C., & Ford, J. (2008). Caregiving in family systems: Exploring the potential for systemic therapies. *Journal of Systemic Therapies*, 27(3), 45-63.
- Kinsella, K. (1996). Aging and the family: Present and future demographic issues. In R. Blieszner & V. H. Bedford (Eds.), *Aging and the family: Theory and research* (pp. 32-56). Westport, CT: Praeger.
- Krueger, R. A. (1998). *Moderating focus groups*. Thousand Oaks, CA: Sage.
- Kübler-Ross, E. (1969). *On death and dying*. New York, NY: Macmillan.

- Linton, R. (1936). *The study of man: An introduction*. New York, NY: Appleton.
- Lui, V. W. C. , Lam, L. C. W., & Chiu, H. F. M. (2006). Validation of a memory inventory for the assessment of awareness of memory deficits in Alzheimer's disease in Chinese elderly. *International Journal of Geriatric Psychiatry*, 21(10), 917-923.
- Maas, M. L., Reed, D., Park, M., Specht, J. P., Schutte, D., Kelley, L. S., Swanson, E. A., Tripp-Reimer, T., & Buckwalter, K. C. (2004). Outcomes of family involvement in care intervention for caregivers of individuals with dementia. *Nursing Research*, 53(2), 76-86.
- Maples, M. F., & Abney, P. C. (2006). Baby boomers mature and gerontological counseling comes of age. *Journal of Counseling & Development*, 84, 3-9.
- Mead, G. H. (1934). *Mind, self and society*. Chicago, IL: Chicago University Press.
- Merton, R. K. (1976). *Sociological ambivalence and other essays*. New York, NY: Free Press.
- Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: Jossey-Bass.
- Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41(5), 658-670.
- Miller, K., Shoemaker, M., Willyard, J., & Addison, P. (2008). Providing care for elderly parents: A structurational approach to family caregiver identity. *Journal of Family Communication*, 8(1), 19-43.
- Morgan, D. L. (1998). *The focus group guidebook*. Thousand Oaks, CA: Sage.
- O'Connor, D. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*, 21(2), 165-174.
- Penrod, J. D., Kane, R. A., Kane, R. L., & Finch, M. D. (1995). Who cares? The size, scope, and composition of the caregiver support system. *The Gerontologist*, 35, 489-497.
- Pierce, T., Lydon, J., & Yang, S. (2001). Enthusiasm and moral commitment: What sustains family caregivers of those with dementia. *Basic and Applied Social Psychology*, 23, 29-41.
- Piercy, K. W. (2007). Characteristics of strong commitments to intergenerational family care of older adults. *Journal of Gerontology*, 62 (6), 381-387.

- Price, C. A. (2003). Professional women's retirement adjustment: The experience of reestablishing order. *Journal of Aging Studies, 17*, 341-355.
- Richardson, V. E. (1993). *Retirement counseling: A handbook for gerontology practitioners*. New York: NY: Springer.
- Ron, P. (2006). Caregiving offspring to aging parents: How it affects their marital relations, parenthood, and mental health. *Illness, Crisis, & Loss, 14*(1), 1-21.
- Saldaña, J. (2009). *The coding manual for qualitative researchers*. London, England: Sage.
- Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies, 32*, 495-523.
- Schneider, K. M., & Phares, V. (2005). Coping with parental loss because of termination of parental rights. *Child Welfare, 84*(6), 819-842.
- Schulz, R., McGinnis, K. A., Zhang, S., Martire, L. M., Hebert, R. S., Beach, S. R., Zdaniuk, B., Czaja, S. J., & Belle, S. H. (2008). Dementia patient suffering and caregiver depression. *Alzheimer Disease & Associated Disorders, 22*(2), 170-176.
- Schumacher, K. L., Stewart, B. J., Archbold, P. G., Caparro, M., Mutale, F., & Agrawal, S. (2008). Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncology Nursing Forum, 35*(1), 49-56.
- Shapiro, E. (1994). *Grief as a family process*. New York, NY: Guilford.
- Sherman, C. W., & Bauer, J. W. (2008). Financial conflicts facing late-life remarried Alzheimer's disease caregivers. *Family Relations, 57*(4), 492-503.
- Silverberg, E. (2007). Introducing the 3-A grief intervention model for dementia caregivers: Acknowledge, assess and assist. *OMEGA, 54*(3), 215-235.
- Smith, A. L., Folan, T. K., & Haaland, C. D. (2002). Connecting practitioners with the progression of Alzheimer's caregiving. *Journal of Systemic Therapies, 21*(4), 86-100.
- Stephens, M. A. P., & Franks, M. M., & Townsend, A. L. (1994). Stress and rewards in women's multiple roles: The case of women in the middle. *Psychology of Aging, 9*, 45-52.
- Strauss, A., & Corbin J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, NJ: Sage.

- Stroebe, M. S., Hansson, R. O., Stroebe, W., & Schut, H. (2001). Introduction: Concepts and issues in contemporary research on bereavement. In M. S. Stroebe, R. O. Hansson, W. Stroebe, and H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 3-22). Washington, DC: American Psychological Association.
- Tashakkori, A. & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.
- Tebes, J. K. & Irish, J. T. (2000). Promoting resilience among children of sandwiched generation caregiving women through caregiver mutual help. *Journal of Prevention & Intervention in the Community*, 20(1/2), 139-158.
- Tobin, S. S., & Kulys, R. (1980). The family services. In C. Eisdorfer (Ed.), *Annual review of gerontology and geriatrics* (Vol. 1; pp. 370-399). New York, NY: Springer.
- Tsolaki, M., Paraskevi, S., Degleris, N., & Karamavrou, S. (2009). Attitudes and perceptions regarding Alzheimer's disease in Greece. *American Journal of Alzheimer's Disease and Other Dementias*, 24(1), 21-26.
- Turner, R. H. (1962). Role taking: Process versus conformity. In A. M. Rose (Ed.), *Human behavior and social processes* (pp. 20-40). Boston, MA: Houghton Mifflin.
- U.S. Department of Health and Human Services: Administration on Aging. (2004). *The older Americans act national family caregiver support program (Title III-E and Title VI-C)*. Retrieved April 6, 2009 from Administration on Aging via [http://www.aoa.gov/AoARoot/Program\\_Results/docs/Program\\_Eval/FINAL%20NFCSP%20Report%20July22,%202004.pdf](http://www.aoa.gov/AoARoot/Program_Results/docs/Program_Eval/FINAL%20NFCSP%20Report%20July22,%202004.pdf)
- Vellone, E., Piras, G., Talucci, C., & Cohen, Z. M. (2008). Quality of life for caregivers of people with Alzheimer's disease. *Journal of Advanced Nursing*, 61(2), 222-231.
- Waldrop, D. P. (2007). Caregiver grief in terminal illness and bereavement: A mixed-methods study. *Health and Social Work*, 32(3), 197-206.
- Walsh, F., & McGoldrick, M. (2004). *Living beyond loss: Death in the family* (2<sup>nd</sup> ed). New York, NY: W. W. Norton.
- Wang, M. (2007). Profiling retirees in the retirement transition and adjustment process: Examining the longitudinal change pattern of retirees' psychological well-being. *Journal of Applied Psychology*, 92, 455-474.



- Wheeler, B. K. (2010). Using qualitative research to indentify and address the unique needs of caregivers of persons with Alzheimer's disease. *The Weekly Qualitative Report*, 3(10), 54-59.
- Whitbourne, S. K. (1987). Personality development in adulthood and old age: Relationships among identity style, health, and well-being. In K. W. Schaie (Ed.), *Annual review of gerontology and geriatrics* (Vol. 7, pp. 189-216). New York, NY: Springer.
- Whitbourne, S. K. & Connolly, L. A., (1999). The developing self in midlife. In S. L. Willis & J. D. Reid (Eds.), *Life in the middle: Psychological and social development in middle age* (pp. 25-45). San Diego, CA: Academic Press.
- Wilkins, C. H., Wilkins, K. L., Meisel, M., Depke, M., Williams, J., & Edwards, D. F. (2007). Dementia undiagnosed in poor older adults with functional impairment. *Journal of the American Geriatrics Society*, 55(11), 1771-1776.
- Wilks, S. E., & Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Ageing and Mental Health*, 12(3), 357-365.
- Yilmaz, A., Turan, E., & Gundogar, D. (2009). Predictors of burnout in the family caregivers of Alzheimer's disease: Evidence from Turkey. *Australasian Journal on Ageing*, 28(1), 16-21.

## Appendix A: Extended Review of Literature

In 2000, there were approximately 411,000 new cases of individuals with AD and that number is expected to increase to 454,000 by 2010 (Alzheimer's Association, 2008). It is roughly projected that every 71 seconds someone in the US develops AD and by 2050 that number is expected to increase to every 33 seconds (Alzheimer's Association, 2008). This increase is likely because of increased knowledge about the signs and symptoms of AD and a greater awareness and education among individuals about AD. As a result of these trends in the US, one particular group of family caregivers that should receive more attention in the gerontological literature is individuals who provide care to older adults who have AD.

Not only does AD affect family caregivers in the US, the empirical literature indicates that this phenomenon is not specific to the US alone. Globally it is known that family members are the main sources of care for individuals with AD. For example, 80-90% of individuals in Italy with AD are cared for by family caregivers (Vellone, Piras, Talucci, & Cohen, 2008) and caregivers are usually (64%) female with the mean age of caregivers at 56.1 years old (Ferrara et al., 2008). Ferrara et al. (2008) also found most (70.5%) of the family caregivers in Italy are daughters of the patients with AD. This is similar to other parts of Europe. For example, in Greece, 50% of caregivers are sons or daughters and 32% are partners for those with AD (Tsolaki, Paraskevi, Degleris, & Karamavrou, 2009). Yilmaz, Turan, and Gundogar (2009) examined caregivers in Turkey where 80% of their sample population were females, with daughters making up 50% of the total sample. In addition Yilmaz et al., (2009) found (84%) of their caregiver sample preferred to care for the older adult with AD at home. Seeing as AD affects many

populations, families, and individuals around the world, AD caregiving deserves further attention.

### **Alzheimer's Disease**

Alzheimer's disease (AD), one of many forms of dementia, affects the lives of thousands of individuals and families around the globe. AD currently affects 5.2 million older adults in the US, which is 6 to 10% of those ages 65 and above and 30 to 50% ages 85 and above; making it the most common form of dementia and the 6<sup>th</sup> leading cause of death for adults in the US (Alzheimer's Association, 2008; Maas et al., 2004).

Unfortunately, it is estimated that the numbers of individuals with AD will only increase and by the year 2050, that is, it has been estimated that 11 to 16 million individuals in the US will have the prognosis of AD (Alzheimer's Association, 2008). In addition, AD is degenerative, irreversible, and fatal (Smith, Folan, & Haaland, 2002); it is not a "normal" part of aging.

Individuals who develop AD are impacted physically, socially, psychologically, emotionally, and financially (Frank, 2007/2008). Individuals experiencing AD may have symptoms including: gradual memory loss, decline in the ability to perform routine tasks, loss of language skills, impairment of judgment, problems with abstract thinking, often misplacing things, change in personality, a change in mood or behavior, disorientation, and a loss of initiative (Alzheimer's Association, 2008). With AD, the patient may become psychologically absent while still being physical present. This ambiguous contradiction can create high amounts of distress for individuals around them, specifically those closest to them (i.e., often the caregiver) (Frank, 2007/2008).

Sadly, the average survival period for those with AD ranges between 2 to 20 years from the first sign of symptoms (Alzheimer's Association, 2008). Previous research has shown that approximately one-third of the survival period with AD is spent in the severe stages of the disease (Herrmann & Gauthier, 2008). During the last stages of AD, an individual's memory continues to worsen, behavior and personality may change, he/she may need help eating, walking, dressing, and bathing, may lose the capacity to speak, and may wonder (Alzheimer's Association, 2008). Those with AD will need long-term care over time due to the devastating nature of the disease (Sherman & Bauer, 2008). As a result, there are many types of care for those with AD, family caregiving being one of the most popular and usually the first choice for families.

### **Family Caregiving**

The US health care system relies heavily on family caregivers to assist individuals with a disease, a disorder, disability, or other handicap (Keeling, Dolbin-Macnab, Hudgins, & Ford, 2008; Sherman & Bauer, 2008) that limits the ability for individuals to care for themselves. In 1997, approximately 23% of households had a person caregiving for an older adult in the family and in 2007 approximately 34 million caregivers were caring for an older adult (Piercy, 2007; Tebes & Irish, 2000). In 2007, 9.8 million family caregivers were providing care for individuals with AD or another form of dementia; totaling 8.4 billion hours of care (Alzheimer's Association, 2008).

Aside from the number of family caregivers, researchers have defined a family caregiver as a person (i.e., family or close friend) who provides care, usually informal, unpaid care, to a person in need of assistance (Alzheimer's Association, 2008; Tebes & Irish, 2000). Family caregivers are usually female and are the daughters, grand-daughters,

daughter-in-laws, and wives of care recipients (Alzheimer's Association, 2008; Piercy, 2007). Further, individuals take on the caregiving role for various reasons. In particular, family caregivers often take on the caregiving role to keep the care recipient within the family home, to possibly save on formal long-term care expenses, and to continue a close relationship with the care recipient. Further, family members may become a caregiver at any point in their lives. For example, research indicates that family caregivers can be as young as age seven (Fruhauf & Orel, 2008) and as old as 80 years (U.S. Department of Health and Human Services, 2004). The average age of caregivers for individuals with AD in 2008 was 48 years old (Alzheimer's Association, 2008). In 2008 there were approximately 250,000 American children (i.e., under age 18) acting as caregivers for a person with AD or other dementia; making up 18% or 1.4 million family caregivers (Alzheimer's Association, 2008). Caregivers provide an average of 70 hours of care per week and may be on-call (i.e., always available and responsive to their patient) seven days a week, 24 hours per day, and without relief (Dang, Badiye, & Kelkar, 2008; Frank, 2007/2008). The long hours can be described as being exhaustive and tiresome for caregivers, especially when there is no break.

While acting as a caregiver for someone with impairments, individuals may perform a variety of tasks. Caregivers complete tasks that include, but are not limited to, activities of daily living (ADL's) such as toileting, hygiene, grooming, dressing, walking, and feeding; and instrumental activities of daily living (IADL's) such as shopping, driving, managing finances, and performing housework tasks (Alzheimer's Association, 2008; Wilkins, Wilkins, Meisel, Depke, Williams, & Edwards, 2007). ADL's and IADL's can look differently depending on the impairment of the patient, which is no

different for individuals caring for an older adult with AD. Finally, the economic value of the time caregivers give and the care-related tasks family caregivers provide has been estimated to be over \$350 billion annually (AARP Public Policy Institute, 2007).

Needless to say, family caregivers are much needed and provide a necessary role in society and in the lives of care recipients. In addition to the tasks family caregivers provide, there are different types of caregivers. For example, in the family caregiving literature scholars often discuss primary, secondary, and tertiary caregiving. Primary caregiving occurs when an individual provides the majority of the caregiving tasks; these caregivers are, usually female (Piercy, 2007). Men are most often secondary caregivers (Piercy, 2007) who provide assistance to the primary caregiver with hands-on tasks and decision-making for the care recipient (Penrod, Kane, Kane, & Finch, 1995). Finally, tertiary caregivers are caregivers who provide care to the care recipient periodically (i.e., on summer vacations), or when more help is needed (Dilworth-Anderson, Williams, & Cooper, 1999). Tertiary caregivers do not usually need to complete decision-making-tasks or hands-on tasks, but more hands-off tasks, such as mowing the lawn or grocery shopping (Dilworth-Anderson et al., 1999).

### **Family Caregiving and Alzheimer's Disease**

It is estimated that there are currently over 10 million caregivers who provide unpaid care to those with AD (Alzheimer's Association, 2008). AD affects not only the patient with AD and their caregiver, but the entire family as well (Ferrara et al., 2008), giving AD the term a "family disease" (Dang et al., 2008). Primary caregivers of individuals with AD tend to be closely related, such as a close family member or a close friend (Alzheimer's Association, 2008; Piercy, 2007; Smith et al., 2002; Vellone et al.,

2008). Since individuals with AD can live with the disease between 2 and 20 years, family caregivers give care to loved ones an average of five years (Dang et al., 2008).

It has been well established that the majority of older adults with AD are cared for by family caregivers, and most of the care is primarily done in the home (Yilmaz et al., 2009). Caring for an individual with AD has been described as a burdensome, exhausting, and a devastating experience, and is well documented in the literature (DeFries, McGuire, Andresen, Brumback, & Anderson, 2009; Vellone et al., 2008; Wilks & Croom, 2008). The stress of caregiving for an individual with AD is unique to dementia and has been described as being particularly difficult when compared to caregiving for other illnesses (Wilks & Croom, 2008). The cascading losses of the body and mind make AD a particular challenge for family caregivers (Herrmann & Gauthier, 2008; Sherman & Bauer, 2008). For example, “Compared with other caregivers, the type of care they [caregivers of AD] provide is more physically and emotionally demanding and more time consuming, and it takes a heavier toll on work and family life” (Alzheimer’s Association & National Alliance for Caregiving, 2004, p. i). As a result, family caregivers (along with those with AD) also face great emotional, physical, psychological, financial, and social strain on many aspects of their lives (Cooper, Katona, Orrell, & Livingston, 2008; Dang et al., 2008; Maas et al., 2004; Schulz et al., 2008; Smith et al., 2002). Caregivers may experience an increase in blood pressure and a decrease in their immune system. It has also been reported that close to one-third of caregivers experience depression and close to half of caregivers reduce their hours at work, while an estimated 18% quit their jobs (Cooper et al., 2008; Dang et al., 2008). Other dimensions of well-being that may affect AD caregivers include self-esteem, relationship strain, life satisfaction, time spent of

social activities and time spent on the caregiver's self (Frank, 2007/2008). Successful communication between the caregiver, the patient, and the physician treating the patient is imperative to the well-being of the caregiver and the patient (Dang et al., 2008).

Not only does family caregiving for someone with AD affect the mental and physical health of individuals, but because of this caregivers have been described as the "hidden victims" or "hidden patients" of AD as it affects and encompasses many aspects of their lives (Dang et al., 2008; Yilmaz et al., 2009). Furthermore, some family caregivers have described their caregiving role as their "career". Family caregivers perceiving their caregiving role as their "career" may be due to the constant care (i.e., 24 hours a day) for their care recipient, loss of their "real" job or hours cut back, loss of social life, the stress of caring for an individual with AD, and not giving time for anything else other than caring for the care recipient (Frank, 2007/2008). In summary, the impact of caregiving for an individual with AD is often great and intense which affects many areas of the caregiver's life (Frank, 2007/2008). This impact supports the need to further the growing literature related to caregiving and AD.

Receiving proper care and medication for the individual with AD adds to the financial losses of both the caregiver and the patient. In addition to the patient's rapidly declining health, medical costs are often associated with AD (Sherman & Bauer, 2008) and unfortunately, caregivers take the brunt of it. There are "significant cost implications related to AD and other dementias including an estimated \$148 billion annually in direct (Medicare/Medicaid) and indirect (e.g., caregiver lost wages and out-of-pocket expenses) costs" (Alzheimer's Association, 2008, abstract). Not included in that figure, are the estimated 10 million caregivers in the US who provide \$89 billion in unpaid services to



individuals with AD annually (Alzheimer's Association, 2008). Family caregivers worked an estimated 8.4 billion hours with care valued at \$10.58 per hour, all unpaid (Alzheimer's Association, 2008). The Alzheimer's Association (2008) actually found that family caregivers averaged \$219 out-of-pocket caregiving expenditures a month. Lastly, the majority of the time the family caregiver assumes decision making for the finances and medical costs for the individual with AD (Sherman & Bauer, 2008). If a decision is made for the patient with AD to be placed into a long-term care facility (LTCF), costs can be around \$152 for an 8-hour day of care, averaging \$3,000 per month (Alzheimer's Association, 2008). Assisted living care is expensive, which may be a reason many family members take on the caregiving role.

In contrast to the negative aspects of caregiving for an individual with AD, many individuals experience a variety of positive aspects to their care related responsibilities. Some caregivers experience a sense of meaning or a purpose in being a caregiver. Other caregivers feel an emotional closeness and enjoy being emotionally nearer to their care recipient than perhaps previously (Stephens, Franks, & Townsend, 1994). Also, many caregivers have reported an overall improved quality of their interpersonal relationship with the patient they are caring for and find great satisfaction in being a caregiver. In addition, some caregivers want to help and educate others in the community and in their family about family caregiving and AD and believe they are better equipped to deal with everyday problems, including those associated with AD. Lastly, caregivers may feel more proficient as a caregiver as time passes due to gained experience in a caregiver role (Dang et al., 2008; Frank, 2007/2008; Piercy, 2007).

## Appendix B: Recruitment Materials

### Letter to Caregivers



**Human Development and Family Studies**  
*"Families are Earth's Orchards: Tend Them Carefully"*  
102 Gifford Building  
Colorado State University  
Fort Collins, CO 80523  
(970) 491-5558

January 25, 2010

Dear Caregiver:

We are writing to inform you of a thesis project being conducted. You have received this letter because you have been identified as being a previous family caregiver for an individual with Alzheimer's disease.

The purpose of this research project is to understand the loss of the caregiving role of family caregivers who provided care to individuals who had Alzheimer's disease. We hope to use the results to bring awareness to the topic of family caregiving and Alzheimer's disease, as well as, expand the literature on these topics.

Your participation in the research project is voluntary. You will be asked to participate in one focus group that should last no longer than two hours, and complete two short questionnaires. It is our hope that you will choose to participate in one of two focus groups being held at the Alzheimer's Association to discuss your experiences as a family caregiver for an older adult who had Alzheimer's disease and the loss of the caregiver role. The focus groups will be compiled of others in the community who have had similar experiences to yours. There will be between 6 and 10 people in each focus group. During the focus group, you will have the opportunity to respond, react to, elaborate on, agree with, or disagree with other's responses. There is no right answer, so we will not be trying to come to a consensus. Basically, I want to hear all opinions.

If you decide not to participate in this project, you will not experience any decline in the amount of services you currently receive or be penalized in any way. If at any time, you wish to stop participating in this research project, you are free to do so as well and, again, will not experience a decline in services available to you or be penalized. Your responses to questions asked during the focus group are not confidential and you will not remain anonymous due to the nature of a focus group. However, I will urge those participating to please keep what is said in the focus group confidential as well as others who are participating. When I start to write what was said in the focus group, you will be identified by a pseudonym.

Should you have any questions, please call Audra Gentz at (928) 814-8328 or Christine Fruhauf at (970) 491-1118. Questions about participants' rights may be directed to Janell Barker at (970) 491-1655. Thank you for considering this opportunity.

Sincerely,

Christine Fruhauf  
Principal Investigator  
Audra Gentz  
Co-Principal Investigator

## Appendix C: Screening Form

### Screening Form

*As you know, I am conducting a study about the loss of the family caregiver role. Before we set-up an interview, I'd like to tell you about the project and ask you a few questions. If after the screening interview you qualify to participate in the study and you voluntarily wish to do so, I will then ask for your contact information and set-up a time for us to meet. The purpose of this project is to understand the loss of the caregiving role of family caregivers who provided care to individuals who had Alzheimer's disease. In order to understand your experiences, I will conduct focus groups with previous family caregivers.*

1. *Did you provide previous care for a family member who had Alzheimer's disease?*

Yes

No (If no, stop interview now)

2. *If yes- What was your relationship to the care recipient?*

(If the relationship is other than family or close friend, stop the interview)

---

3. *How long ago were you a caregiver? (If more than 5 years, stop interview)*

---

4. *How old are you? (If under age 18, stop screening interview)*

---

5. *On a scale of 1-10, one being no grief or sadness and ten being the most sadness you can imagine, what would you say your current level of grief is?*

Number Given: \_\_\_\_\_

*What does that (the number given) look like or mean to you?*

Notes:

*On a scale of 1-10, one being not open or comfortable at all and ten being extremely open and comfortable, how open would you be in a group of strangers discussing your caregiving and the loss of your caregiving role?*

Number Given: \_\_\_\_\_

*What does (the number given) look like or mean to you?*

Notes:

*At this time I believe you are eligible to participant in the study. Would you like to participate in a focus group?*

Yes                      No

(If no, stop interview now and give referral for CSU's Center for Family and Couple Therapy)

If yes: *I would like to inform you that audio taping will be occurring at the focus group for data analysis purposes only. Strict confidentiality will always be maintained and a pseudonym name will be given for you. At this time do you have any questions? Would*

*you still feel comfortable participating?*

Yes

No (If

no, stop interview now)

Notes:

If yes: *Can I please have your name?*

\_\_\_\_\_

*Phone number where you can be reached?* \_\_\_\_\_

*Mailing*

*Address?* \_\_\_\_\_

*Preference date for focus group:* \_\_\_\_\_

*Preference time for focus group:* \_\_\_\_\_

*Place for focus group:* \_\_\_\_\_

*Any other questions that I can answer for you before you go?*

*You can contact me at [afgentz@colostate.edu](mailto:afgentz@colostate.edu) or at 928-814-8328 if you have any further questions. Thank you for your time and I look forward to seeing you soon.*

Appendix D: Informed Consent Form

**Consent to Participate in a Research Study  
Colorado State University**

**TITLE OF STUDY:** Caregivers for Older Adults with Alzheimer's Disease: A Look at the Loss of the Caregiver Role

**PRINCIPAL INVESTIGATOR:** CHRISTINE A. FRUHAUF, PH.D.; 105 GIFFORD BUILDING;  
COLORADO STATE UNIVERSITY; FORT COLLINS, CO 80523 ; 970-491-1118;  
[CFRUHAUF@CAHS.COLOSTATE.EDU](mailto:CFRUHAUF@CAHS.COLOSTATE.EDU)

**CO-INVESTIGATOR:** AUDRA GENTZ; 928-814-8328; [AFGENTZ@COLOSTATE.EDU](mailto:AFGENTZ@COLOSTATE.EDU)

**WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH?** You have been asked to participate in this research project because you have been identified as being a previous family caregiver for an individual with Alzheimer's disease.

**WHO IS DOING THE STUDY?** Audra Gentz is conducting this research project, with the assistance of Dr. Christine A. Fruhauf.

**WHAT IS THE PURPOSE OF THIS STUDY?** The purpose of this research project is to understand the loss of the caregiving role of family caregivers who provided care to individuals who had AD.

**WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?** The study is going to take place in a classroom/conference room at the Alzheimer's Association of Fort Collins, CO and will last approximately an hour and a half to two hours.

**WHAT WILL I BE ASKED TO DO?** You will be asked to participate in one focus group session held during November or December. A focus group is a group discussion about a particular topic or product. During this time I will ask you a series of questions that pertain to your experiences about being a family caregiver for an individual with Alzheimer's disease and about the loss of your caregiver role. In addition, the focus group session will be audio taped for analysis purposes only and a pseudonym will be used in data reporting.

For each question you will have the opportunity to respond, react to, elaborate on, agree with, or disagree with other's responses. There is no right answer, so we will not be trying to come to a consensus. Basically, I want to hear all opinions.

**ARE THERE REASONS WHY I SHOULD NOT TAKE PART IN THIS STUDY?** You should not take part in this study if you are under the age of 18 years, have not cared for a family member or close friend with Alzheimer's disease, if your care recipient passed away less than 3 months ago or more than 5 years ago or is not in long-term care, and do not feel comfortable discussing your experiences in a group setting.

**WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?** Slight distress is a normal reaction when discussing personal experiences about family caregiving. However, it is anticipated that the risks will be minimal.

It is not possible to identify all potential risks in research procedures, but the researcher(s) have taken reasonable safeguards to minimize any known and potential, but unknown, risks. If you do experience distress please feel free to contact Colorado State University's Center for Family and Couple Therapy (CSU CFCT) at (970) 491-5991. CSU's CFCT has a \$17 rate for students and a sliding fee scale for community members starting at \$22.



**WILL I BENEFIT FROM TAKING PART IN THIS STUDY?** There are no direct benefits in participating; however, participating in a focus group session may provide you with useful ways to cope with the stress of being a previous family caregiver for an individual with Alzheimer's disease. Participating in the focus group sessions will allow you a chance to share your caregiving experiences and your experiences, attitudes, and reactions to the loss of the caregiver role. Thus, this process of participating in a focus group will allow you to share your experiences with others in the community and hear similar stories.

**DO I HAVE TO TAKE PART IN THE STUDY?** Your participation in this research is voluntary. If you decide to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

Page 1 of 2 Participant's initials \_\_\_\_\_ Date \_\_\_\_\_

**WHAT WILL IT COST ME TO PARTICIPATE?** No financial cost is associated with this research study. The only cost to you is your time. Each session will last at an estimated 90 minutes (an hour and a half) to two hours.

**WHO WILL SEE THE INFORMATION THAT I GIVE?**

We will keep private all research records that identify you, to the extent allowed by law.

Your information will be combined with information from other people taking part in the study. When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will only be identified in these written materials by a pseudonym. We may publish the results of this study; however, we will keep your name and other identifying information private.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from your research records and these two things will be stored in different places under lock and key. You should know, however, that there are some circumstances in which we may have to show your information to other people.

Further, because of the format of this research study, focus group, the PI and Co-PI cannot provide 100% assurance that participants will not discuss the information outside of the focus group session. Please be advised that it is your right to share information or not to share information during the focus groups session. If you would like to share something with the Co-PI and not the entire focus group you may do so at the end of the session.

Lastly, there may be certain situations in which a mandated reporter is legally bound to reveal information obtained during confidential times to other persons or agencies without your permission. These situations are defined as a **"threat of serious harm to yourself or others."** This includes suspected child abuse or neglect, elder abuse or neglect, suicide, homicide, or a threat to national security. In rare circumstances, a court of law may also order the breaking of confidentiality.

**WILL I RECEIVE ANY COMPENSATION FOR TAKING PART IN THIS STUDY?** No compensation will be given to you as a result of participating in this research study.

**WHAT HAPPENS IF I AM INJURED BECAUSE OF THE RESEARCH?** The Colorado Governmental Immunity Act determines and may limit Colorado State University's legal responsibility if an injury happens because of this study. Claims against the University must be filed within 180 days of the injury.

**WHAT IF I HAVE QUESTIONS?** Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the co-primary investigator, Audra Gentz at [afgentz@colostate.edu](mailto:afgentz@colostate.edu) or at 928-814-8328; or

the primary investigator, Christine A. Fruhauf at [cfruhauf@cahs.colostate.edu](mailto:cfruhauf@cahs.colostate.edu) or at 970-491-1118. We will give you a copy of this consent form to take with you.

Questions about participants' rights may be directed to Janell Barker, Human Research Administrator at (970) 491-1655. This consent form was approved by the CSU Institutional Review Board for the protection of human subjects in research on September 21, 2009.

Your signature acknowledges that you have read the information stated and willingly sign this consent form. Your signature also acknowledges that you have received, on the date signed, a copy of this document containing two pages.

\_\_\_\_\_  
Signature of person agreeing to take part in the study

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of person agreeing to take part in the study

\_\_\_\_\_  
Signature of Research Staff

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of person providing information to participant

Page 2 of 2 Participant's initials \_\_\_\_\_ Date \_\_\_\_\_

## Appendix E: Focus Group Questions

### Focus Group Questions

**Purpose:** In an effort to understand the experiences of previous caregivers about the loss of the caregiver role, the purpose of this focus group is to generate discussion among all of you (who were once assisting someone with Alzheimer's disease) about the loss of your caregiver role.

#### ***\*(Research Questions)***

- 1. How do previous family caregivers experience and describe the loss of their caregiver role?*
- 2. What impact does losing the caregiver role have on previous family caregivers?*

#### **Ground Rules for the Focus Group:**

- No put downs
- Please respect each other
- One person talks at a time (emphasize this...not only out of respect for each other, but for recording purposes)
- If you need to take an emotional break, please feel free to excuse yourself for the amount of time that you need
- It is okay not to answer a question
- It is okay to disagree
- There are no right or wrong answers

#### *Activity:*

To begin the discussion, I would like you to choose a miniature from the table that describes your experience as a family caregiver, especially as it relates to the loss of your caregiving role. After a few minutes we will go around the room and have each person introduce him/herself and share the meaning of his/her miniature.

Would anyone like to make a comment or reaction to anything that was stated as people described their miniatures.

#### *Possible Probes:*

- Has anyone had a similar experience?
- How has this made a difference for you?
- Do others agree or disagree?

*Questions:*

1. Tell me about the circumstances around how you became a caregiver.
  - a. Was there a crisis associated with how you became a caregiver?
2. How did you respond to caregiving on your best day?
3. How did you respond to caregiving on your worst day?
4. If you could describe your role as a caregiver in one word- what would it be?
5. How did you know that you no longer had a caregiver role?
6. How do you define the loss of the caregiver role?
7. What has the effect been like of no longer having the caregiving role in your life?

Are the changes positive, negative, or even neutral?

  - a. Such as a weight lifted, more sleep, loss of sleep, more time for friends
8. What are the benefits to you of the loss of your caregiver role?
9. Tell me about any grief or sadness you have felt around the loss of your role?
10. What concerns do you have around the loss of your caregiver role?
11. What could/do you need help with around the loss of the caregiver role?
12. Who has helped you achieve a negative experience related to the loss of being a caregiver?
13. Who has helped you achieve a positive experience related to the loss of being a caregiver?
14. Is there anything else you (participants) would like to tell me about your loss that you have not already stated?

Before we end, I would like to ask-

15. What do you think are the most important elements of today's discussion

We have finished the focus group session, but before we end today, the note taker will ask any clarifying questions she may have.  
Thank you for your time. I greatly appreciate it.

## Appendix F: Demographic Questionnaire

### Demographic Questionnaire

First Initial: \_\_\_\_\_, Last Name: \_\_\_\_\_

**Please check one answer for each question, or fill in the blank.**

**If you have been a caregiver for more than one individual with Alzheimer's, please think about your most recent care recipient.**

1. Birthdate: \_\_\_\_\_ , \_\_\_\_\_ , \_\_\_\_\_  
MONTH DATE YEAR

2. Gender

- ☐ Male
- ☐ Female

3. Race/Ethnicity (*Check all that apply*)

- |                                                        |                                                        |
|--------------------------------------------------------|--------------------------------------------------------|
| <input type="radio"/> African American/Black           | <input type="radio"/> Hispanic/Latino                  |
| <input type="radio"/> Caucasian/Anglo/White/           | <input type="radio"/> Native Alaskan/ Pacific Islander |
| <input type="radio"/> Asian                            | <input type="radio"/> Other- Please Specify _____      |
| <input type="radio"/> Native American/ American Indian |                                                        |

4. What category *best* describes your total gross household income?

- |                                            |                                            |
|--------------------------------------------|--------------------------------------------|
| <input type="radio"/> \$19,999 or less     | <input type="radio"/> \$60,000 to \$79,999 |
| <input type="radio"/> \$20,000 to \$39,999 | <input type="radio"/> \$80,000 to \$99,999 |
| <input type="radio"/> \$40,000 to \$59,999 | <input type="radio"/> \$100,000 or more    |

5. Relationship Status

- ☐ Single
- ☐ Living with Partner
- ☐ Separated/Divorced
- ☐ Committed Partnership/Married
- ☐ Widowed

6. On average, how often did you work for wage (not including your family caregiver role) during your caregiver role?

- ☐ Less than 5 hours per week
- ☐ 5-10 hours per week
- ☐ 10-20 hours per week
- ☐ 20-30 hours per week
- ☐ 30-40 hours per week
- ☐ Full-Time (40 hours per week)
- ☐ More than Full-Time (Over 40 hours per week)

7. Did you and your care recipient share a household at any point?

- ☐ Yes
- ☐ No

8. How many people live in your household, including yourself?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7 or more

9. How would you rate your health?

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Excellent

10. Have you had previous experience in counseling/therapy related to the loss of the caregiver role?

- ☐ Yes
- ☐ No

Appendix G: Family Caregiver Questionnaire  
Family Caregiver Questionnaire

First Initial: \_\_\_\_\_, Last Name: \_\_\_\_\_

**Please check one answer for each question, or fill in the blank.**

**If you have been a caregiver for more than one individual with Alzheimer's, please think about your most recent care recipient.**

1. What was your relationship to the care recipient? He/ She was my:

- |                                         |                                                 |
|-----------------------------------------|-------------------------------------------------|
| <input type="radio"/> Spouse/Partner    | <input type="radio"/> Cousin                    |
| <input type="radio"/> Sibling           | <input type="radio"/> Niece or Nephew           |
| <input type="radio"/> Parent            | <input type="radio"/> Great-Aunt or Great-Uncle |
| <input type="radio"/> Grandparent       | <input type="radio"/> In-Law                    |
| <input type="radio"/> Great Grandparent | <input type="radio"/> Close Friend              |
| <input type="radio"/> Aunt              | <input type="radio"/> Other- Please Specify     |
| <input type="radio"/> Uncle             | _____                                           |

2. How long were you a caregiver?

- |                                            |                                       |
|--------------------------------------------|---------------------------------------|
| <input type="radio"/> Less than six months | <input type="radio"/> 3-5 years       |
| <input type="radio"/> Six months to 1 year | <input type="radio"/> 5-8 years       |
| <input type="radio"/> 1-3 years            | <input type="radio"/> 8 years or more |

3. How much of that time was the care recipient in a long-term care facility (LTCF) (i.e. an assisted living home or nursing home)?

- |                                            |                                                            |
|--------------------------------------------|------------------------------------------------------------|
| <input type="radio"/> Less than six months | <input type="radio"/> 5-8 years                            |
| <input type="radio"/> Six months to 1 year | <input type="radio"/> 8 years or more                      |
| <input type="radio"/> 1-3 years            | <input type="radio"/> Not applicable (Never lived in LTCF) |
| <input type="radio"/> 3-5 years            |                                                            |

4. Did you perform activities of daily living (e.g. bathing, dressing, etc.) for the care recipient?

- |                           |                          |
|---------------------------|--------------------------|
| <input type="radio"/> Yes | <input type="radio"/> No |
|---------------------------|--------------------------|



5. Did you perform instrumental activities of daily living (e.g. housecleaning, errands, cooking, etc.) for the care recipient?

- ☐ Yes ☐ No

6. Did you make decisions for the care recipient (i.e., general, such as: groceries, laundry; or legal/health decisions, such as: health care, living arrangements)?

- ☐ Yes ☐ No

7. If yes, to #6- What kind of decisions did you make?

---

---

8. How often did you provide care for the care recipient?

- ☐ 8 hours or less per week ☐ 32-40 hours per week  
☐ 8-20 hours per week ☐ 40 or more hours per week  
☐ 20-32 hours per week

9. What illness(es) did the care recipient have? **Mark All That Apply**

- |                                                    |                                            |
|----------------------------------------------------|--------------------------------------------|
| <input type="radio"/> Alzheimer's Disease/Dementia | <input type="radio"/> HIV/AIDS             |
| <input type="radio"/> Arthritis/Carpeltunnel       | <input type="radio"/> Huntington's Disease |
| <input type="radio"/> Asthma                       | <input type="radio"/> Hypo/Hyperthyroid    |
| <input type="radio"/> Blindness                    | <input type="radio"/> Lupus                |
| <input type="radio"/> Cancer                       | <input type="radio"/> Parkinson's Disease  |
| <input type="radio"/> Deafness or Hearing Impaired | <input type="radio"/> Paralysis            |
| <input type="radio"/> Diabetes                     | <input type="radio"/> Other_____           |
| <input type="radio"/> Heart Disease                |                                            |

10. How would you rate your adjustment to the loss of the caregiver role?

- ☐ Poor ☐ Fair  
☐ Good ☐ Excellent

## Appendix H: Coding Scheme

### Coding Scheme: Final Draft

#### ***I. Caregiving Journey***

##### ***a. Rewards of Caregiving***

##### ***i. During Active Caregiving***

###### ***1. Tools***

- a. Being a friend/ friendship
- b. Dedication
- c. Intuition
- d. Knowledge/ education
- e. Religion
- f. Resources
- g. Strength
- h. Support

###### ***2. Feelings***

- a. Appreciation
- b. Humor
- c. Joy
- d. Love
- e. Not a burden

##### ***ii. After Active Caregiving***

###### ***1. Tools***

- a. Appreciation
- b. Being a friend/ friendship
- c. Comfortable in group
- d. Connections
- e. Dedication
- f. Gratitude
- g. Humor
- h. Knowledge/ education
- i. Memories
- j. Religion
- k. Resources
- l. Sharing
- m. Strength
- n. Support

## **2. *Feelings***

- a. A privilege
- b. Appreciation
- c. Blessing
- d. Comfort
- e. Dedication
- f. Grace
- g. Gratitude
- h. Growing up
- i. Joy
- j. Love
- k. Not a burden
- l. Precious/Priceless/Treasure(d)
- m. Relief
- n. Surviving
- o. Wishful
- p. Connection

## ***b. Challenges Associated with Caregiving***

### ***i. During Active Caregiving***

#### **1. *Stumbling Block***

- a. Anticipation of AD
- b. Care of self
- c. Decisions
- d. Parent vs. Spouse
- e. Personal hardships
- f. Family Conflict
- g. Want Help
- h. Resources/Lack of Training

#### **2. *Feelings***

- a. Fear
- b. Feel accountable
- c. Guilt
- d. It's hard
- e. Overwhelming
- f. Personal hardships
- g. Tiring
- h. Worries
- i. Denial
- j. Jealousy

***ii. After Active Caregiving***

***1. Stumbling Block***

- a. Anticipation of AD
- b. Decisions
- c. It's hard
- d. Legal frustration
- e. Personal hardships
- f. Family Conflict
- g. Still a caregiver
- h. Care of Self
- i. Resources

***2. Feelings***

- a. Emptiness
- b. Fear
- c. Fragmented
- d. Invisible
- e. Not relieved
- f. Overwhelming
- g. Personal hardships
- h. Regret
- i. Silent world
- j. Still a caregiver
- k. Unprotected
- l. Worries
- m. You've died too
- n. Guilt
- o. Anger
- p. Pain

***II. Standing at a Cross-Road***

***a. Unforeseen Happenings***

- i. Loss of self/ part of self
- ii. No choice
- iii. Not prepared
- iv. Predestined
- v. Time
- vi. Uncertainty
- vii. Unexpected
- viii. You've died too

***b. Unexpected Phase of Caregiving***

- i. Being recognized
- ii. Care of self
- iii. Complex
- iv. Have it back
- v. Implications for practitioners
- vi. Population specific
- vii. Release
- viii. Time
- ix. Volunteer
- x. Sense of purpose

***c. Caregiver's Sense of Self***

***i. Caregiver's Sense of Personal Direction***

- 1. Alone
- 2. Loss of Direction
- 3. Restructuring your life

***ii. Caregiver's Sense of Personal Purpose***

- 1. Invisible
- 2. Rethinking caregiver role
- 3. Sense of purpose
- 4. Service
- 5. You've died too

***iii. Caregiver's Sense of Self Identity***

- 1. Floundering
- 2. Fragmented
- 3. Identity Crisis
- 4. Invisible
- 5. Loss of self/ part of self
- 6. You've died too

***d. Grief/Sadness***

***i. Beliefs***

- 1. Death
- 2. Misunderstanding of grief
- 3. Silent world
- 4. Two losses

***ii. Feelings***

1. Alone
2. Emptiness
3. Grief
4. You've died too

Table 1. Participant Demographics

<b>Name*</b>	<b>Relationship to Care Recipient</b>	<b>Age</b>	<b>Time Elapsed Since Caregiving</b>	<b>Length of Caregiving</b>	<b>Hours Worked for Wage</b>	<b>Rating of Health<sup>a</sup></b>	<b>Rated Adjustment to Loss of Role<sup>a</sup></b>
Group 1							
Emily	Parent	45	1 Year	5-8 Years	Full Time (40hrs/week)	Good	Fair
Rose	Spouse/Partner	65	5 Months	8 Years or More	Full Time (40hrs/week)	Good	Fair
Olivia	Parent	52	5 Months	1-3 Years	10-20 hrs/week	Good	Good
Margret	Spouse/Partner	76	1 ½ Years	5-8 Years	Did not work	Fair	Fair
Lilly	Parent	62	5 Years	3-5 Years	Full Time (40hrs/week)	Good	Good
Hillary	Spouse/Partner	76	1 Year	8 Years or More	More than Full Time (+40hrs/week)	Good	Good
Stacy	Parent	64	7 Months	3-5 Years	Full Time for 3 years, then quit work for full-time caregiver	Excellent	Good
Catherine	Parent	63	4 Years	8 Years or More	Less than 5hrs/week	Fair	Good
Group 2							
Wes	In-Law	54	11 Months	5-8 Years	Less than 5hrs/week	Fair	Excellent

Frances	Parent	60	11 Months	5-8 Years	Less than 5hrs/week	Fair	Fair
Ned	Parent	64	3 Months	5-8 Years	Full Time (40hrs/week)	Fair	Good
Kim	Spouse/Partner	75	7 Months	3-5 Years	Full Time (40hrs/week)	Good	Fair
Paige	Parent	55	1 ½ Years	1-3 Years	10-20 hrs/week	Good	Excellent
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Group 3 Jenna	Parent	55	1 Year	3-5 Years	Full Time, then quit work for full-time caregiver	Fair	Fair
Grace	Spouse/Partner	88	11 Months	8 Years or More	Full Time (40hrs/week)	Good	Good
Diana	Parent	59	11 Months	1-3 Years	Less than 5hrs/week	Fair	Poor
Rachel	Parent	46	11 Months	5-8 Years	Less than 5hrs/week	Excellent	Good
Kelly	Parent	41	1 ½ Years	8 Years or More	5-10 hrs/week	Excellent	Good
Harry	Spouse/Partner	66	2 ½ Years	1-3 Years	10-20 hrs/week	Excellent	Good
Natalie	Parent	57	4 Years	3-5 Years	20-30 hrs/week	Good	Excellent
Tracy	Spouse/Partner	61	4 Years	5-8 Years	10-20	Excellent	Good

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hrs/week

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\*Pseudonym names (not actual names of participants). <sup>a</sup>Rating 4-point scale; poor to excellent.

Table 2: Positive Attributes During and After Active Caregiving

<b>During Active Caregiving</b>	<b>After Active Caregiving</b>
<b><i>Tools</i></b>	<b><i>Tools</i></b>
Being a friend/ friendship	Appreciation
Dedication	Being a friend/ friendship
Intuition	Comfortable in group
Knowledge/ education	Connections
Religion	Dedication
Resources	Gratitude
Strength	Humor
Support	Knowledge/ education
	Memories
	Resources
	Sharing
	Strength
	Support
<b><i>Feelings</i></b>	<b><i>Feelings</i></b>
Appreciation	A privilege
Humor	Appreciation
Joy	Blessing
Love	Comfort
Not a burden	Connection
	Dedication
	Grace
	Gratitude
	Growing up
	Joy
	Love
	Not a burden

	Precious/Priceless/Treasure(d)
	Relief
	Surviving
	Wishful

Table 3: Challenges During and After Active Caregiving

<b>During Active Caregiving</b>	<b>After Active Caregiving</b>
<b><i>Stumbling Blocks</i></b>	<b><i>Stumbling Blocks</i></b>
Anticipation of AD	Anticipation of AD
Care of self	Care of Self
Decisions	Decisions
Family Conflict	Family Conflict
Parent vs. Spouse	It's hard
Personal hardships	Legal frustration
Resources/Lack of Training	Personal hardships
Want Help	Still a caregiver
	Resources
<b><i>Feelings</i></b>	<b><i>Feelings</i></b>
Denial	Anger
Fear	Emptiness
Feel accountable	Fear
Guilt	Fragmented
It's hard	Guilt
Jealousy	Invisible
Overwhelming	Not relieved
Personal hardships	Overwhelming
Tiring	Pain
Worries	Personal hardships
	Regret
	Silent world
	Still a caregiver

	Unprotected
	Worries
	You've died too