"It Gets Easier, Not Better": Ambiguous Loss and Resiliency in Adult Children Caring for Their Parent with Alzheimer's Disease

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Abstract

ABSTRACT

AMBIGUOUS LOSS AND RESILIENCY IN ADULT CHILDREN CAREGIVING FOR THEIR PARENT WITH ALZHEIMER'S DISEASE

Maria Balintona, LCSW

Ram Cnaan, PhD

Background

Alzheimer’s Disease is characterized by a decline in cognitive function, memory retention, and thinking skills directly affecting one’s ability to perform activities of daily living. Alzheimer’s disease is fatal, though for many this is its lesser curse. The loss of humanity and the emotional pain of caregiving can be devastating. Today, an estimated 15 million American adults provide uncompensated personal care to their loved ones with Alzheimer’s Disease (Alzheimer’s Association, 2017). As life expectancy increases, the number of elderly are expected to grow and consequently an increase in incidence of Alzheimer’s Disease is anticipated.

Alzheimer’s Disease impacts both the individual diagnosed and the family caregivers. Caregivers are profoundly impacted by increasing care requirements as the disease advances. Alzheimer’s Disease (AD) progresses imperceptibly and creates unforeseen challenges to partners, adult children, family systems, loved ones, and friends. Caregivers often face years helping their loved one and experience a multitude of emotional responses ranging from anger to sadness, not to mention the physical and financial strain of the disease on the family system. Often, adult children simultaneously strive to raise their own families, face job-related demands, and limited fiscal resources.

With no known cure, this problem has led me to the question of how adult children, providing care for their parent with Alzheimer’s Disease, experience ambiguous loss and resilience.

Methods

This study employed qualitative methods and the outcomes may be used to further enhance our understanding of their experience. Twelve in-depth, semi-structured, face-to-face interviews lasting 60-90 minutes were conducted with adult children who have served as caregivers to their parent.

Results

Key results of the research suggest that feelings of loss change through the disease trajectory and increased social supports are needed early in the disease trajectory to address emotional loss, and adjustments in the shared attachment. Resilience was experienced as increased self-knowledge, self-care, and improved adaptive capabilities. Additional use of social supports and family connections increased resilience in the face of day-to-day care challenges and coordination.

Discussion

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This research points to the need to bolster social supports and information for the caregiver when their parent is in the early stages of Alzheimer’s Disease. Increasing social support, self-care strategies, and education early on can mitigate feelings of isolation and ambiguous loss. Limitations include the homogeneity of the participants, different ranges in their parent’s stage of Alzheimer’s disease. Additionally, this study was conducted in a rural area.

*Keywords:* Ambiguous loss, caregiving, Alzheimer’s Disease, adult children, qualitative research, phenomenological theory.

**Degree Type**
Dissertation

**Degree Name**
Doctor of Social Work (DSW)

**First Advisor**
Dr. Ram Cnaan

**Second Advisor**
Dr. Lina Hartocollis

**Keywords**
Alzheimer’s Disease, Ambiguous loss, Resiliency, Adult Children, Qualitative

**Subject Categories**
Social and Behavioral Sciences | Social Work

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“IT GETS EASIER, NOT BETTER”: AMBIGUOUS LOSS AND RESILIENCY IN ADULT CHILDREN CARING FOR THEIR PARENT WITH ALZHEIMER’S DISEASE

Maria L. Balintona

A DISSERTATION

In

Social work

Presented to the faculties of the University of Pennsylvania

In

Partial Fulfillment of the Requirements for the Degree

Doctor of Social Work

2018

Ram Cnaan, PhD
Dissertation Chair

John L. Jackson, Jr., PhD
Dean, School of Social Policy and Practice

Dr. Lina Hartocollis
Second Advisor
Dedication

This dissertation is dedicated to the participants caring for their parent with Alzheimer’s Disease who generously gave of their time to provide insight into their experiences. They reexamined events and emotionally taxing circumstances during their journey as caregivers. Their motivation to participate in this study was to help other adult children experiencing the loss of their parent to Alzheimer’s Disease. My greatest appreciation for your time and insights.
Acknowledgements

I would like to first thank Dr. Ram Cnaan for his scholarly advice and steadfast guidance through this process. His quick help, feedback, and information arrived at perfect intervals to provide motivation and keep me on track. His support was invaluable! My sincere gratitude to Dr. Lina Hartocollis for helping fulfill my dream to attend school at SP2, complete the DSW program, and her encouragement along the way. To Dr. Phyllis Solomon...thank you so much for teaching me the first semester and believing in me. You are an incredible teacher.

My father, a medical social worker himself, has provided feedback, guidance, and most of all love. Many, many thanks to my mother for her unrelenting belief in me and my abilities to exceed through years of education and life’s various challenges. She is an inspiration in innumerable ways. To my sister: thank you for being such a fabulous friend. My sincere appreciation to my supervisor, Ginger, and my phenomenal colleagues who covered for me when I needed to leave for class. To my mentor, Selva, for your support for the past 10 years at the hospital, I owe a debt of gratitude. My running buddies who logged many miles with me and kept asking me about the dissertation...thank you for your unwavering patience. To Cheryl—thank you for our many talks, the years of shared friendship, and your belief in me. Thank you to the SP2 DSW 2016 Cohort for all the friendship, laughs, and support!

Lastly, to my husband, John, who has been an inspiration for this journey and in life. Because of his support and belief in me, I was able to dedicate long hours while he kept the home fires burning and full of laughter at just the right times to make it all bearable. He traveled to Philadelphia for every immersion and went out of his way to express support. Thank you from the bottom of my heart. To my sweet Ana, you are an inspiration and by far the best daughter a mother could imagine.
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This research points to the need to bolster social supports and information for the caregiver when their parent is in the early stages of Alzheimer’s Disease. Increasing social support, self-care strategies, and education early on can mitigate feelings of isolation and ambiguous loss. Limitations include the homogeneity of the participants, different ranges in their parent’s stage of Alzheimer’s disease. Additionally, this study was conducted in a rural area.

**Keywords**: Ambiguous loss, caregiving, Alzheimer’s Disease, adult children, qualitative research, phenomenological theory.
CHAPTER 1
Introduction and Statement of Purpose

Alzheimer’s Disease is a life changing, debilitating disease impacting more than 5.4 million adults and their families this year alone (Alzheimer’s Association, 2017; National Institute on Aging, 2016; National Institutes of Health, 2016). Alzheimer’s disease will impact one in every five women and one in every ten men (Khan, 2016). With the aging of the baby boomer population, increased longevity, and enhanced provision of medical care, the annual incidence of Alzheimer’s Disease is expected to grow to an anticipated 13.8 million by 2040 (Cummings et al., 2016; Reitz & Mayeaux, 2011). Alzheimer’s Disease (AD), which is considered the most common cause of dementia, accounts for an estimated 60-80 percent of overall dementia diagnosis in the United States (Alzheimer’s Foundation of America, 2017; National Institute on Aging, 2016).

During the course of Alzheimer’s Disease (AD), the memory, mental functions, and physical body decline over time (Mayo Clinic, 2016, National Institute on Aging, 2016). Patients diagnosed with AD experience harrowing consequences including cognitive impairments, decreased language capabilities, and difficulty with their activities of daily living during the course of disease progression (Alzheimer’s Association, 2017; Masliah & Salmon, 2016). Likewise, caregivers for people with Alzheimer’s (PWA) Disease also experience associated physical, emotional, and mental side effects in the process of caring for their loved one. For example, caregivers for PWA experience a higher incidence of depression than peers their age, physical exhaustion in provision of care needs, insomnia rates two times higher than caregivers for all other diseases, increased financial strain due to lost time at work, and social withdrawal
related to the intensity and severity of illness progression (Boss, 2006; Boss, 2010; Cox, 2007; National Alliance for Caregiving, 2015; National Institute on Aging, 2016).

Alzheimer’s Disease is the predominant cause of physical dependency among elderly in high and low income families where the bulk of care is shouldered by uncompensated family carers who remain the cornerstone of assistance (World Health Organization, 2012). With decreased insurance coverage for long term care, the burden of caregiving increasingly falls upon families and their resources (Alzheimer’s Association, 2016; Boss, 2011, National Alliance for Caregiving, 2015). In 2016, an estimated fifty-seven percent of those providing care for people with Alzheimer’s (PWA) Disease are simultaneously working full-time jobs and providing care to their loved ones for an overall average of five years (American Association of Retired People, 2015; National Alliance for Caregiving, 2015).

A considerable body of knowledge has found that caregiving for a family member with Alzheimer’s Disease is challenging and stressful to the family system (Boss, 2007; Dupuis, 2002; Beach, Schulz, Yee, & Jackson, 2000). The primary caregivers, typically spouses and adult children, tend to the daily provision of care aimed at providing quality of life, dignity, and respect to their loved one. As the care needs for their loved one progress and symptoms increase, many caregivers experience a sense of sadness over the absence of emotional and physical connection with the person they once knew. Loved ones caring for persons with Alzheimer’s Disease have been entitled “the hidden victims” (Zarit, 1985). The bereavement experienced by caregivers for people with Alzheimer’s (PWA) prior to death has been likened to the intensity of grief experienced after a loved one has died (Boss, 2007). Caregiving for PWA entails new family roles, responsibilities in caring for their parent, coping with the emotional loss of their
loved one, and numerous unfamiliar tasks in provision of physical care (Toepfer, Foster, & Wilz, 2014).

Imagine a parent asking their adult child “who are you?” or having their parent run an errand only to return four hours later and have no idea where they went or be able to account for their time. Unfortunately for many caregivers for PWA, these types of occurrences are commonplace, thereby creating an indescribable sense of loss. “Dementia creates ambiguous loss. The duality of your loved one being absent and present at the same time is confusing and finding meaning (or making sense of your situation), becomes immensely challenging. Without meaning, it becomes hard to cope” (Boss, 2011, p.2).

Drawing on her extensive research and clinical experience, the theory of ambiguous loss was developed by Pauline Boss. The theory of ambiguous loss details the loss of family members who are simultaneously physically present and psychologically absent, which is the case with those caring for a loved one experiencing Alzheimer’s Disease (Boss, 2006; Boss, 2016). As Alzheimer’s Disease progresses through the symptom trajectory, caregivers experience a powerful sense of progressive, unrelenting grief and loss. The confusion for the caregivers lies in the pain of loss associated with the unpredictable and uneven advancement of the disease. The context of the disease process, not the caregiver or the person with Alzheimer’s Disease are the issue. Many adult children, serving in the role of caregiver for their parent with AD, may not understand the unresolved loss they are experiencing or how to increase their resilience to endure the many care demands of their parent.

Social workers, by nature of their training and role, address numerous dimensions of family care in outpatient and inpatient settings. Given the vast impact AD has on the patient, care partners, extended family, and society, social workers are uniquely positioned to be responsive to
the needs of those caring for PWA. With the expected number of elderly increasing, the National Association of Social Workers chose the Older Americans Act to assist caregivers with support of elderly as one of the seven key policy issues that they will working on in the 115th congressional session (NASW, 2017). Similarly, The American Academy of Social Work and Social Welfare has identified the advancement of long and productive lives for our older citizens as one of their Twelve Grand Challenges (American Academy of Social Worker and Social Welfare, 2016).

With adult children accounting for one third of the caregivers for PWA, garnering a greater understanding of their experience can inform and enhance care delivery. Therefore, the purpose of this study is to explore how adult children, who are caregivers for their parent with Alzheimer’s Disease, experience ambiguous loss, create meaning, and develop resilience across the disease trajectory. The aim is to enhance our understanding of their loss while giving voice to their subjective experiences. Due to the sheer number of hours of care required, the length of the AD trajectory, and the sense of loss, researchers want us to better understand how to enhance delivery of social work services to families while caring for their loved one with Alzheimer’s Disease.

This problem has led me to the question of how adult children, providing care for their parent with Alzheimer’s Disease, experience ambiguous loss and resilience. This study employed qualitative methods and the outcomes may be utilized to further enhance our understanding of their experience. Twelve semi-structured face-to-face interviews lasting 60-90 minutes were conducted with adult children who have served as caregivers to their parent. The goal of this research is to examine their experiences of caregiving, ambiguous loss, and resilience. The dissertation literature review that follows will provide the history of Alzheimer’s
Disease and the diagnostic implications. Understanding the historical concepts and current day medical components offer a foundational explanation of the Alzheimer’s Disease process. Often the disease progresses insidiously and can be overlooked by family members during the initial stages because it appears as normal age-related memory changes. Use of neuropsychological testing can assist in identifying an initial diagnosis and offer a concrete cognitive baseline. Related to changes in familial structures and increased longevity, caregiving for people with Alzheimer’s can be an unrelenting road to travel. The last segment of the next chapter will review the nature of ambiguous loss and set the backdrop for conceptualizing the feelings often encountered by caregivers.
CHAPTER 2
Review of Literature

In the introduction, the care for people Alzheimer’s Disease and its impact on adult-child caregivers was identified as a critical, understudied issue of pressing societal importance. The literature review that follows will begin with an examination of the background elements of Alzheimer’s Disease to include the historical identification of the disease in 1906 to the current day DSM-V diagnostic criteria used by practitioners. I then move onto describe the various stages of disease progression followed by the limited treatment options. The nature of societal perceptions regarding people with Alzheimer’s Disease has created stigma for both the person diagnosed and their caregiver. Caregiving has changed over the last century and due to changed family structures, the pressures to provide care with limited societal supports has strained the family system. The final segment of this chapter will address the history of caregiving to provide background knowledge of caregiving in families.

Historical Context

The phenomenology of memory loss was first described by the Egyptians as inability to participate in civilian activities or legal proceedings, along with an increased need for societal supports (Cohen, 2002; Perry, Avila, Kinoshita, & Smith, 2006). For many centuries, aging was understood as a natural continuum of the human life cycle and dementia was couched in terms like ‘softening of the brain’, ‘imbalances in body fluids’, ‘vague mental decline’ or mania.

Alois Alzheimer (1864-1915) was born in Bavaria, Germany and while attending medical school developed an interest in the cortex of the human brain (Alzheimer’s Association, 2016; Alzheimer’s Disease International, 2016; Hardy, 2006). During an internship in psychiatry and
neuropathology at a state asylum in Frankfurt, he accepted a research post with Emil Kraeplin, who established a new laboratory for brain research and enabled Alzheimer to lay the groundwork for his studies (Alzheimer’s Disease International, 2016).

In 1906, Alzheimer noticed his patient, Auguste D, who was first institutionalized at age 51, exhibited signs of memory loss and erratic behavior prior to her death (Cox, 2007; Hardy, 2006). In working with his patient, he became curious about the causes of her memory deterioration. During a post-mortem brain autopsy of Auguste D, he identified the presence of what he described as neuritic plaques and neurofibrillary tangles (Jacques & Jackson, 2000). As he furthered his laboratory research, he discovered that neuritic plaques were commonly found in the brains of patients who experienced later life memory loss. Alzheimer became “preoccupied with finding the neuropathological corollary to progressive dementia in older patients” (Cox, 2007; Toodayan, 2016). Later, in 1910, he reported on his findings at a medical conference with little response or recognition from his colleagues in psychiatry. During the five years following his identification of this disease, he continued to examine brain structures, conduct research, and translate his findings into other languages (Berchtold, & Cotman, 1998; Whitehouse, Maurer & Ballenger, 2003). Alois Alzheimer laid the groundwork for researchers who followed him with baseline scientific descriptions that are still used today.

Over the course of many decades through the 1970’s until present, scientists continue to investigate and examine patterns of neurofibrillary tangles and plaques, transmitter deficits, and amyloid in abnormal locations of the brain which can be attributed to Alzheimer’s Disease (AD) (Jacques & Jackson, 2000). According to the National Institutes on Aging, these plaques and tangles identified over 100 years ago, are essential elements of AD (2016) causing loss of connection between neurons in the brain, thereby creating difficulties transmitting messages to
other parts of the body (National Institute on Aging, 2016). Although the history of memory loss
dates back to ancient times in rather nebulous terms occurring with advance age, with our
scientific and medical advancements there are now clearer clinical guidelines and approaches for
treatment that can help patients and families. (Alzheimer’s Association, 2016; Berchtold, &
Cotman, 1998; Cox, 2007).

**Description of Alzheimer’s Disease**

Alzheimer’s is a clinical syndrome characterized by impairment and deterioration in
multiple cognitive domains such as language, spatial awareness, memory recall, behavior, and
judgement which impact activities of daily living (Alzheimer’s Association, 2016; Alzheimer’s
Foundation of America, 2017; Camicioli, 2014; Cox, 2007; Deb, Thornton, Sambamoorthi, &
Innes, 2017, Kahn, 2016). At present, scientists and physicians have no ability to stop disease
progression or cure Alzheimer’s Disease (Mace & Rabins, 2011; National Institutes on Aging,
2015).

A healthy brain has an estimated 100 billion neurons, which are elongated branch
extensions creating connections with other neurons. The communication networks of the brain,
composed of these 100 billion nerve cells, also called neurons, process stored information and
communicate with other cells (Alzheimer’s Association, 2017; National Institute on Aging,
2016). Widespread deterioration of neurons in AD create neurofibrillary degeneration and
tangles in the brain composed of a protein called amyloid. As the brain shrinks, the physical
body, behavior, cognition, and memory are impacted (Jacobsen, 2011; Jacques & Jackson,
2000). The most common cause of damage to the neurons in the brain is from accumulated
amyloid plaques, also referenced as ‘senile plaques’, which get tangled, diffused, or in the walls
of the blood vessels of the brain.
Although the exact cause of AD remains unknown, risk factors such as diabetes, hypertension, and high cholesterol are a few of the more common comorbid medical conditions believed to contribute to symptom development (Alzheimer’s Association, 2016; Cox, 2007; Jacques & Jackson, 2000). Patients who have the presence of numerous co-morbid medical conditions can make the diagnostic process complex and thereby affect the clinical course. In some cases, the symptoms which appear to be AD could be caused by a different underlying medical issues (Jacques & Jackson, 2000). Disease progression, diagnosis, and symptoms are different for each individual; therefore, the course of the disease and treatment needs to take into consideration the baseline functioning of the patient (Whitehouse, Maurer, & Ballenger, 2003).

Medical Definition

The World Health Organization established an overall description of AD defined as:

A syndrome in which there is deterioration in memory, thinking, behavior and the ability to perform everyday activities. Although dementia affects many older people, it is not a normal part of aging. Alzheimer’s Disease, the most common type, accounts for 60-70 percent of cases. Dementia is a major cause of disability and dependence among older people. Dementia has physical, psychological, social, and economic impact on caregivers, families, and society (World Health Organization, 2016).

The revised Diagnostic and Statistical Manual 5 (American Psychiatric Association, 2013), a reference manual commonly used by psychiatrists and social workers, characterizes AD under the heading major or mild neurocognitive disorder due to Alzheimer’s Disease with a diagnostic category of 331.0 and explains the disorder as:
Insidious onset and gradual progression of impairment in one or more cognitive domains which can include complex attention, executive function, learning and memory, language, perceptual motor or social cognition (American Psychiatric Association, 2013, p.611).

Moreover, the DSM-V proposes probable diagnostic criteria for AD if either of these two criteria are met:

- Evidence of a causative Alzheimer’s Disease genetic mutation from family history or genetic testing.
- All three of the following are present:
  a. Clear evidence of decline in memory and learning and at least one other cognitive domain (based on detailed history or serial neuropsychological testing).
  b. Steadily, progressive, gradual decline in cognition without extended plateaus.
  c. No evidence of mixed etiology (i.e. absence of other neurodegenerative or cerebrovascular disease, or another neurological, mental or systemic disease or condition likely contributing to cognitive decline). (American Psychiatric Association, 2013, p. 611-613).

An important addition in the DSM V (2013) definition is the acknowledgement that Alzheimer’s entails a progressive deterioration in memory over time. The DSM lays the groundwork for psychiatrists and clinical social workers to distinguish between normal memory loss associated with aging and those experiencing Alzheimer’s Disease.
Challenges and Implications of Diagnosis

One of the many challenges associated with diagnosing AD is its insidious onset. Alzheimer’s Disease is not one single biologic condition, but a variety of heterogeneous processes which occur, thereby creating trouble with distinction between AD and the natural progression of the aging process (Whitehouse & George, 2008). Research over the past 40 years has revealed information about possible factors leading to AD, however scientists do not know exactly how AD develops (Whitehouse & George, 2008). Criteria have been established to assist in identifying AD at an earlier stage in an effort to increase treatment options and provide parameters with regard to diagnosis. An interview and general examination by a medical provider can start the process to determine if AD is the primary diagnosis. Often times, a patient will present to their provider with increased forgetfulness and concerns about memory loss.

Advanced age is considered the most common risk factor associated with AD and Dementia. Incidence of AD is proportional to increasing age. An assessment of cognitive functioning and impairment is essential to defining the level of impairment and may include measurements of attention span, orientation, memory, and executive function capabilities among others in PWA (Perry et al., 2006). The physician will often order tests to rule out other unidentified medical issues by checking labs such as combined blood count (CBC), thyroid stimulating hormone, chemistry panels, and check spinal fluids to identify any acute infections to determine if other sources could be contributing to memory impairment. Additionally, both MRI and CT scans can clarify pre-existing structural concerns through brain imaging (Camicioli, 2014).

AD most commonly has presenting symptoms to caregivers and loved ones as memory decline and decreased participation in activities of daily living. Cox (2007) argued that “The
symptoms that an individual with dementia expresses are a direct result of the neuropathology in specific brain regions that control those cognitive functions and behavior” (Cox, 2007, p. 53). Up to this point, research trials have not yet led to a cure for AD (Alzheimer’s Association, 2017).

If the person with Alzheimer’s (PWA) is in denial of their memory changes, the family members may likewise ignore the symptoms until behaviors are so obvious that they no longer can be disregarded. Moreover, in the initial stages of AD families struggle with how to inform their loved one of the changes they are observing with memory or behavior. Given the diagnostic complexity, some couples in long term relationships who have shared close quarters may not realize the small, insidious changes over time, resulting in delayed use of prescriptive medications and behavioral interventions to address or alleviate symptoms for a brief time (Cox, 2007; Fauth et al., 2012).

**Stages of Alzheimer’s Disease**

Although each person with Alzheimer’s (PWA) will experience a different array of symptoms, there are typical features, phases, symptoms, and behavioral concerns (Borenstein & Mortimer, 2016). As the condition progresses, the neurofibrillary tangles and amyloid plaques which are forming deep within the entorhinal cortex or folds of the brain will begin to show symptoms akin to early disease process. Brain changes often begin an estimated 20 years prior to the onset of noticeable symptomology (Ferreira et. al, 2017; Huynh & Mohan, 2017; Mortamais, Ash, Harrison, Kaye, Kramer, & Randolph, 2017).

The earlier a patient is diagnosed with AD, the more effective the medications will be at slowing the accumulation of plaques and tangles (Alzheimer’s Association, 2017). Alzheimer’s Disease is typically separated into three stages entitled mild, moderate, and advanced. Although
these stages are categorized, progression through the stages is not always a linear or predictable process.

In 2011, the guidelines for AD diagnosis broadened to include preclinical phases of pathologic brain changes prior to the symptom onset (Alzheimer’s International, 2016; Dubois, Hampel, Feldman, Scheltens, Aisen & Andrieu, 2016). “Pre-Alzheimer’s” is the broadened term entitled by the Mayo Clinic to examine symptoms prior to onset (Alzheimer’s Association, 2017; Mayo Clinic, 2016). Given that PWA can function normally in the early stages of AD without much awareness by family around them, PWA are typically diagnosed well into the moderate stages of dementia (World Health Organization, 2015). Early signs of Alzheimer’s Disease can include:

1. Forgetfulness regarding events that just occurred
2. Difficulty recalling words while in conversation
2. Misplacing items
3. Losing track of the day or time
4. Decreased level of activity
5. Increased isolation and solitariness
5. Decreased interest in social activities previously enjoyed
6. Depression or anxiety symptoms
7. Difficulty following through on activities
8. Forgetting how to complete familiar tasks
9. Rapidly cycling mood changes

(Adejare, 2017; Alzheimer’s Association, 2016).

Moderate or middle staged Alzheimer’s is evidenced by symptoms including:

1. Beginning to get lost at home or within the community
2. Continued challenges with speech or word recall
3. Assistance with numerous activities of daily living
4. Requiring considerable support to live safely at home
5. Beginning to wander
6. Asking the same question(s) repeatedly
7. Changes in sleep patterns

(LoboPrabhu, Molinari, & Lomax, 2008). In most circumstances, a diagnosis can accurately be identified during the middle stages as the features are more pronounced and the family can offer a history of memory changes over time.

In the final stages, advanced AD is characterized by:

1. Complete dependence upon others
2. Inactivity
3. Difficulty understanding their surroundings
4. Disorientation
5. Incontinence
6. Decreased ability to ambulate
7. Behavioral changes
(Yeaman, Ford, & Kim, 2012). During this stage, family may require professional paid care interventions for respite or consideration of institutional care if adequate help is not available within the home. Many nursing facilities offer both memory care and palliative care units which would be suitable when families require extra assistance. With impaired ability to complete their own self-care, dignity among PWA may be compromised throughout the disease trajectory at various point.

There is great variability in disease progression, however medical issues can involve increased susceptibility to infection, nutrition, hydration, and skin integrity which are all usually comprised in advanced AD. For example, some PWA in the later stages refuse to eat or drink, thereby the family have to consider feeding tubes to maintain sustenance. Some families choose palliative care or hospice services to assist in provision of comfort to their loved one near the end of life. In the final stages of Alzheimer’s, the National Institutes of Health (2015) estimated that medical care costs a quarter of a million dollars per person, which is approximately 50% more than any other disease. Patient’s experiencing Alzheimer’s Disease and their families may notice plateaus in disease progression. For instance, social functioning (social interaction with family or friends) and procedural memory (e.g. cooking, tying a shoe, turning on television) may continue to operate for a prolonged period of time, thereby making memory decline uneven (American Psychiatric Association, 2013). The remote memory, which is associated with long term memory processes and associated with childhood events, can remain intact through much of the disease process.

Given the insidious onset of AD, the PWA may have limited insight regarding their memory loss or may blame their forgetfulness on a loved one or family members. If the PWA has awareness of the memory changes, they may experience humiliation, depression or
frustration among other emotional responses. Commonly, the PWA will have disease progression that lasts an average of 10 years (American Psychiatric Association, 2013) as the ability to function decreases and dependence upon unpaid and paid caregivers increases.

**Incidence and Prevalence**

By age 65, an estimated 15-20 percent of elderly in the U.S. will have what is classified as Mild Cognitive Impairment (Alhurani, Vassilaki, Aakre, Mielke, Kremers & Machulda, 2016). As society ages, the incidence of Alzheimer’s increases correspondingly. Between 5-20% of those over age 65 experience mild cognitive impairment (Alzheimer’s Association, 2016). Moreover, research has demonstrated that 10-15% of older people with Mild Cognitive Impairment (MCI) go on to develop AD within a span of 10 years (Alzheimer’s Society, 2015; Dubois, et al., 2016). In 2011, the Alzheimer’s Association, in conjunction with the National Institutes of Aging suggested that mild cognitive impairment could be considered an early stage of AD or some form of dementia (Alzheimer’s Association, 2016). Data suggest that almost two-thirds of those impacted by AD are women with a higher incidence in African American and Hispanic populations, who are nearly twice as likely to be affected than their white counterparts (Alzheimer’s Association, 2017).

In 2016, one in every seven Americans, totaling 44.7 million, are over the age of 65 (US Census Bureau, 2016). The aging population of baby boomers have been described as threat to healthcare services with titles of the baby boomer population terms like the “Silver Tsunami”, because of an estimated 10-14 million US citizens over the age 65 (Buckley, 2010). The Alzheimer’s Association (2016) estimates that by 2030, approximately 8.4 million Americans will be experiencing some form of dementia. In addition to age, other risks associated with Alzheimer’s Disease include a history of traumatic brain injury, vascular factors, and Trisomy
21. Down’s Syndrome (Trisomy 21) is a known risk factor associated with AD and those affected by Down’s Syndrome commonly experience symptoms of AD at mid-life (National Institute on Aging, 2016).

**Medical Treatment Options**

Alzheimer’s disease is the only major disease that has yet to uncover a treatment regimen proven efficacious or disease modifying (Adejare, 2017; Alzheimer’s Association, 2017). Although there is no known cure yet, some drugs on the market are believed to offer temporary treatment of symptoms but with variable response to intervention (Adejare, 2017). Addressing the diagnosis and presenting symptoms with medication is believed to provide the PWA a sense of dignity, peace of mind, and independence for an increased duration than would occur without the use of medication (National Institutes on Aging, 2016).

Medications intended to treat the initial stages of Alzheimer’s Disease, entitled Cholinesterase inhibitors, are utilized to slow the development and decrease symptoms for a limited period of time (National Institutes of Aging, 2016). Research suggests that Cholinesterase inhibitors may slow the destruction of acetylcholine, a neurochemical important for thinking and retention of memory. With the progression of AD over time, the brain manufactures decreasing levels of acetylcholine, and the effectiveness of the medications wane. Between 2002-2012, the NIH conducted clinical trials of 244 drugs for AD and only one passed FDA approval (Cummings et. al., 2016). Five medications are approved by the Federal Drug Administration in 2017 as medications indicated to possibly slow the progression of symptoms.

The first FDA approved drug, in 1996, was Donezpid, which is known under the trade name Aricept on the pharmaceutical market, and works to inhibit breakdown of acetylcholine,
thereby enhancing the synaptic transmission in the central nervous system (Adejare, 2017; Khan, 2016). Other AD prescriptive medications such as Namenda (Metamine) and Rivastigmine (Exelon) work similarly to Aricept in slowing the deterioration of neurotransmitters. Namenda may be able to assist PWA in preserving the ability to maintain use of the bathroom independently or other related activities of daily living (National Institutes on Aging, 2016). Metamine, the latest FDA approved drug regimen in 2014, is used in moderate to severe stages of Alzheimer’s and works to decrease the release of a neurotransmitter called glutamate (Adejare, 2017; Kahn, 2016). Metamine is intended to preserve some of the daily functioning of the PWA. Researchers suspect a combination of drug regimens, such as used with other chronic illnesses like AIDS, may be required to treat specific neurotransmitters and slow the effects of progressive brain damage (Khan, 2016). Current efforts in research are geared to identify biomarkers in PWA to increase specificity and accuracy of AD diagnosis and efficacy of treatments (Khan, 2016; Perry, et al., 2016).

As with any medication, there are side effects which can be physically limiting to PWA to include gastrointestinal upset, insomnia, muscle cramps, and diarrhea among other. With higher dosages of medication, the likelihood of side effects increases. Additionally, the average cost per year for medications is $3000.00, despite prescription drug coverage, which creates financial burden for most families (Alzheimer’s Association, 2017).

Often neuropsychiatric symptoms, such as aggression, agitation, anger, or verbal outbursts occurring later in the disease process can be spurred by small changes in caregiving arrangements. Examples of some adjustments that could create strain include travel, houseguests, moving, or going to a long-term care facility (Alzheimer’s Association, 2016). It is safe to assume that small changes within the environment create stress and fear in the PWA, thereby
exacerbating behavioral issues. Unfortunately, the FDA does not have any market approved drugs to treat behavioral issues associated with AD yet. Some medical providers utilize atypical antipsychotics, although not intended for this use with AD, which can provide relief in some situations (Adejare, 2017). With that in mind, clinical interventions need to be multifaceted to address family strain and behavioral issues as they arise during the course of caregiving encounters. Behavioral techniques, employed by CG, can diffuse some of the behaviors.

**Social Perception**

An estimated 1 in 4 people with Alzheimer’s Disease prefer to conceal their memory issues or diagnoses because of stigma associated with AD (Alzheimer’s Disease International, 2015). A combination of fear and judgement attached to the diagnosis of AD can impede diagnostic workups and care seeking (Alzheimer’s Disease International, 2015). Left, in many situations with a probable diagnosis, the PWA and the family members involved may have misconceptions or worries. The social perception of Alzheimer’s is often stigmatizing for both the PWA and their family.

The World Alzheimer’s Report released in 2015, determined that 75% of those with dementia and 64% of family caregivers expressed concerns regarding stereotypes about AD which delayed their decision to seek care (World Health Organization & Alzheimer’s Disease International, 2015). On a global scale, 2 out of 3 Alzheimer’s patients feel that there is a lack of understanding and provision of public education in their country about AD (Alzheimer’s Association, 2017; Alzheimer’s Disease International, 2015).

This section provided an overview of the diagnostic and physical components of Alzheimer’s Disease. The next section will examine the history of caregiving in the United
States, definitions of informal caregiving, burdens of caregiving, and the tasks involved in care provision when engaged with their loved one experiencing AD.

**Caregiving**

Over the course of the last century, caregiving has become a local, state, and national issue. Increased longevity, cost of care, changes in family structure, social policy, and social constraints have heightened the awareness and need for unpaid care (Beach et al., 2000; Brumgamin & Hirn, 2006). Historically speaking, in 1900, 75% of people died before they reached the age of 65 (Administration on Aging, 2014). At the turn of the 20th century the average life expectancy was 48 years of age for women and 46 years for men. However, during the second half of the 20th century, with improvements in care, clean water sanitation systems, and better antibiotic regimens, people are living longer with the average life expectancy now of 79 years of age. Traditionally, families have typically provided the bulk of care for their older loved ones, however in the previous centuries care duration was usually short lived.

Simultaneously, while longevity was improving, families were moving farther apart from one another into the suburbs of larger cities and the U.S. was becoming an industrialized nation. This created a change in patterns of caregiving, thereby complicating caregiving arrangements related to geographic distance (Bureau of Labor Statistics Data, 2016; Gillies, 2011). While family size was shrinking, women, who were frequently caregivers, launched into the workforce. In 1935, social security was introduced and provided financial assistance to the elderly. Medicare, Title XVIII under the Social Security Act, came into effect in 1965 and is now the single largest payer for medical care in the U.S. (Blevins & McClintock, 2001). Typically, most seniors are automatically enrolled in Medicare Part A, which covers hospital stays, home health, hospice and skilled nursing. However, the typical non-skilled nursing assistance utilized to
provide respite for caregivers of PWA, is not a covered benefit under the Medicare programs. People with Alzheimer’s who meet the state poverty threshold can, in many cases, qualify for both Medicare and Medicaid programs, thereby experiencing less financial strain for some out of pocket costs (Centers for Medicare and Medicaid Services, 2016; Gillies, 2011).

The great burden and trajectory of AD requires substantial amounts of caregiving by family (Adejare, 2017). The CDC (2014) determined that there are an estimated seven possible caregivers per adult in year 2014, however by year 2030 there will be four careers per adult. With the number of aging persons anticipated to grow exponentially, coupled with lower birth rates in later generations, a shortage of family careers is predicted. The Interagency Forum on Aging (2016) identified over 18 million informal caregivers assisting at home, of which 11.1 million are women and 6.9 million men with the majority of caregivers between the ages of 45-64 years of age.

Many older Americans shoulder the cost of medical and caregiving expenses themselves, which can prove challenging. AARP (2015) national research identified out of pocket expenditures for care needs, on average, equate to $6956.00 per year, thereby creating financial hardship for most families. In 2016, the items Medicare covered most were hospital related costs, home health nursing, and skilled rehabilitation services. In January 2017, the Centers for Medicare and Medicaid enacted legislation entitled the HOPE act for Alzheimer’s Disease, which offers coverage for the cost of Alzheimer’s diagnostics and care planning including advice on treatment options, interventions, and emotional issues related to diagnosis.

With an estimated 15 million unpaid caregivers who offer 18 billion hours of care to PWA, the value in calendar year 2016 for the unpaid care given to PWA was 230 billion dollars (Alzheimer’s Association, 2017). Forty percent of unpaid caregivers hold a college degree or
higher (Alzheimer’s Association, 2017). Caregivers for PWA spend an average of 1-4 years longer in the provision of care than caregivers for any other disease (National Institute on Aging, 2015). Due, in large part to shifts in social policy, the concept of family care with supplemental personal care has become a preferred choice for many families in the 21st century (Gillespie & Moore, 2013).

**Informal Caregivers**

The term informal caregiver can be operationalized as someone providing unpaid care to a family member with a physical or cognitive impediment (Bensadon, 2015; LoboPrabhu, Molinari, & Lomax, 2008). Caregiving becomes more complex with increases in symptom severity and progression through the stages of AD (Fisher et al., 2011; Liu, Kim & Zarit 2015).

In 2015, the Health and Human Services, AARP, and the Family Caregiver Alliance found that the largest number of informal caregivers are between the ages of 50-64 providing unpaid care to their parent. As the stages of AD progress, the care tasks required adjusted in both type and intensity, thereby requiring more assistance from CG (Dupuis, 2002; Frank, 2008; LoboPrabhu, Molinari, & Lomax, 2008). Frequently, during the initial stages, the caregiver may be involved in household duties, managing medical information, financial and legal organization, or thoughtful consideration of simple tasks including cooking, cleaning and periodic physical assistance (LoboPrabhu, Molinari & Lomax, 2008; National Institute on Aging, 2016; Zarit, Lee, Barrineau, Whitlatch, & Femia, 2013). Among caregivers, with increased need for concrete physical assistance in simple activities of daily living, the greater the experienced burden by CG. Caregivers relate that some of the most challenging activities associated with caregiving include incontinence, changing diapers, showering, and assisting with toileting, all of which typically occur during the later stages of AD (Health and Human Services, 2014).
**Care Provision by Adult Children**

With changes in family structure, rising divorce rates over the past few decades, decreased government funding for care, and increased longevity, more PWA are turning to their adult children for assistance in their care (Chen, Clayton, & Chodosh, 2017; Szinovacz, Maximilane & Davey, 2007). Role changes are inherent amongst adult children and their parent with AD and they continue to change through disease progression. Being dependent and interdependent can have multiple meanings among family members and cultures (Brumagin & Hirn, 2006).

Many elderly couples living together today may experience physical challenges or frailty as they age, thereby looking to their adult children or extended family for physical, emotional, and occasional financial support. Because women outlive men statistically, most often it is the mother who requires care from their adult child later in life (Szinovacz & Davey, 2007). Among adult children in the caregiving role, Matthews and Rosner (1988) have identified common levels of involvement as caregivers for their parent which include:

- Routine assistance with provision of regular daily care or shared care amongst sibling caregivers
- Back up care provision offering care on an “as needed” basis when the regular caregiver is unavailable
- Circumcised assistance providing limited care to parent for specific requests
- Sporadic assistance involving care shared between siblings

Commonly, adult daughters who are unmarried, younger in age, not working full-time, and live in close proximity to their parent absorb the responsibilities of caregiving, although this
varies based on family structure (Szinovacz & Davey, 2007). Maintaining employment at a full or part-time job, while providing an average of 20 hours of care per week, creates strain among caregivers. Some adult children of parents with AD relate that they often go to work late, take family leave of absences, leave during their work mid-day to check on their loved one, depart work early, turn down promotions, and may decide to leave the workforce in order to offer care to their parent with AD (American Association of Retired Persons, 2015; National Alliance of Caregivers, 2015).

Siblings often help one another throughout the course of the disease. Both quantitative and qualitative studies examining how adult siblings negotiate the caregiving roles point out that the adult child’s decision to assist in the provision of care is typically based on:

1. Filial responsibility
2. Ability to assist
3. Willingness to help,
4. Family structure
5. The characteristics of the parent with Alzheimer’s Disease

(Finch & Mason, 1993; Hequenbourg & Brailer, 2005) Ford and Collins (2010) pointed out that activation of the caregiving system within the family occurs in two situations: (1) when someone in the family is facing a stressful situation, experiencing fear, is actively requesting assistance or it is obvious they would benefit from help and (2) when a loved one has the opportunity to seek learning, advancement or mastery, and needs help to make the most of the opportunity. Under either of these circumstances, the system is activated to respond to a loved one with the aim of assistance and advancing the welfare of their loved one. Adult children vary greatly in their decisions about how to adjust to the care demands, loss, and changes associated with caregiving.
The Nature of Caregiving and Ambiguous Loss

The changing nature of Alzheimer’s Disease creates ongoing stressors and repeated incremental losses (Meuser & Marwit, 2001; Zarit, Gerstorf, & Infurna, 2013). The provision of care for a PWA often has both physical and emotional effects to include higher levels of depression than peers their age who are not involved as caregivers, a higher incidence of comorbid medical conditions, increased difficulty sleeping, and financial pressures (Bookwala, Yee & Schulz, 1998; Cox, 2007; Fauth et al., 2011). The social impact of caring for a PWA include decreased socialization, unmet needs, and physical exhaustion. Caregiving for a person with Alzheimer’s Disease is unique because the intensity of the illness places significant strain on pre-existing bonds between loved ones (LoboPrabhu, Molinari, & Lomax, 2008). Moreover, as the intensity of care needs increase, the sense of burden and grief increase likewise (Health and Human Services, 2014). Caregivers have identified that behavioral symptoms in the PWA present the greatest challenges while caregiving (Fisher et. al., 2011).

Loss among caregivers for PWA is a common experience and can be understood as the physical and psychological deprivation of someone or something that is of value. In their book The 36 Hour Day, Mace and Rubin (1981) first referenced this sense of loss experienced by caregivers for PWA pointing out that “grief is a natural emotional response to loss and is a normal experience for people who love a person with a chronic illness” (p.221).

Social work professionals have long worked with clients experiencing bereavement and loss, however the loss experienced by caregivers of PWA presents a unique challenge as the grief is not typically expressed in the commonly understood clinical frameworks, stages, or models. Moreover, the losses associated with Alzheimer’s are not limited to the physical and emotional aspects, but extend to the social network of both the PWA and the caregiver when friends or
family feel uncomfortable in the presence of the PWA, or the caregiver is unable to pursue previously enjoyed hobbies. The duration of care required, combined with lack of effective medical treatments available to PWA, differentiates Alzheimer’s Disease from other chronic illnesses. As PWA and caregivers work to adjust to one loss, another incremental loss could arise unexpectedly during disease progression (LoboPrabhu, Molinari, & Lomax, 2008). Loss includes the physical, emotional, and mental reactions to the disease process. The Alzheimer’s Disease Education and Research Center (2017) identified common emotions caregivers of PWA experience to include a sense of loss, depression, abandonment, and frustration with their loved one’s changes in cognition. If the caregiver cannot control the many tides of change they face, one option is to build a better system for adapting to change or expanding resilience to stay the course under challenging circumstances.

**Resilience**

Despite the numerous adversities faced while caring for a loved one with AD as mentioned above, resilience posits that adaptation by families and caregivers is possible (Aldwin, 2012, Boss, 2006; Walsh, 2015). The ability to continually adjust to the many stressors of caregiving and ambiguous loss requires a healthy amount of resilience. Resilience is operationalized as the developmental process of reflective adaptation when faced with adversities and consequent return to an equal or improved level of functioning than prior to the event (Garmezy, 1993; Walsh, 2015).

Historically, teachings on resiliency first emerged in the 1960’s and 1970’s when researchers in the fields of child development, psychiatry, and psychology began to question how adverse childhood events such as abuse, divorce, or poverty stall growth and disrupt emotional equilibrium during the early years. One pioneer in the field of resilience was Norman Garmezy
who, while studying patients with schizophrenia at the University of Minnesota, began to question why some of his patients seemed to function well in the face of their diagnosis, maintain family life, and employment, whereas other patients were unable to function well outside institutional-level care (Garmezy, 1993). His robust research led him to examine how cognitive skills and motivation act as protective mechanisms against stress and consequent resilience.

Similarly, Masten, who studied under Garmezy, continued resiliency research and later discovered that resilience is a commonplace phenomenon; a function of basic human adaptation systems (Masten, 2014). When these systems are functional, people will not only be able to face life’s difficulties, but overcome such challenges. Conversely, if adaptation systems are dysfunctional, the developmental processes through time are halted. In dysfunctional family systems, the ability to withstand stressors is limited. Resilience cannot be boiled down to an individual trait, although Masten (2016) identified certain characteristics which can influence resilience to include “problem-solving skills, cognitive flexibility, self-regulation skills, and the motivation to overcome challenges” (p.4).

Internal resources such as insight, initiative, creativity, and humor, as well as, external supports such as family and social connections can foster resilience and act as a buffer to the stresses associated with caregiving (Aldwin, 2012; Boss, 2006). Similarly, an even-temper and a higher level of intelligence act as protectors against the strain (Walsh, 2015). A caregiver’s belief in their ability to acclimate to ever-changing caregiving demands enhance the adjustment to the many required caregiving duties. Resilience can be considered a sense of coherence; a belief that life’s adversities were understandable, meaningful to address, and manageable (Zolli & Healy, 2012).
There is often a misinterpretation of resilience as a characteristic exhibited when people just “bounce back” from adversity (Walsh, 2015). Conversely, resilience is much more complex and typically involves integration of the painful experience through time. The question for caregivers becomes how to cope with the many unknown aspects of AD progression while maintaining their own sense of well-being. Wolin and Wolin (1993), through their study of behavior patterns among adults and adolescents, identified specific factors that increase resilience amongst individuals. The factors included:

1. Well-developed skills of self-regulation and adjustment
2. Ability to temper and regulate strong emotions as they arise
3. Maintain perspective on life’s circumstances. Understanding life on life’s terms
4. Regulate potentially harmful substances or self-medicating behaviors
5. Ability to live in the present
6. Regulate activity levels through engagement in both work and rest
7. Live with both social and intimate connection
8. Ability to own and process unwanted, painful emotions rather than project emotions

The ability to withstand role strain, physical demands, and changes in the context of the relationship is enhanced when the caregiver can modify their expectations along the way. The accumulated loss experienced in caregivers of PWA has been described as akin to the bereavement stages following death. “Risk and resilience are not a characteristic of a child or a family or a school, but are characteristics of a process involving the interactions of a system” (Pinata & Walsh, 1998, p.411). Hence, support from family networks, community connections, cultural traditions, and spiritual resources can foster resilience. Clear, consistent information from medical providers and community respite providers, along with emotional support such as
therapy can build resilience among CG. With consideration of the sheer number of caregivers impacted, emotional impact of the disease, physical consequences, and the growing costs of medical care related to AD, clinical social work interventions are needed to determine best practice methods with caregivers which can better address their needs (Gaugler, Potter, & Pruinell, 2014; Samia, Aboueissa, Halloran & Hepburn, 2014; Teri et al., 2012; Van Mierlo, Meilan, VanHout, & Droes, 2016; Zarit et al., 2013).

**Summary**

The objective of this chapter was to examine the history of Alzheimer’s Disease, identified in 1906, by Alois Alzheimer, who focused his medical career on understanding the neuropathological consequences of memory impairment in the aged. As the disease was better defined by organizations such as the Alzheimer’s Association and the National Institutes of Health, risk factors were identified, although the cure remains obscure. Clinical identification of AD near the onset of the disease process remains an enigma because, in some instances, it can appear as normal progression of memory decline among the aged.

The number of aged impacted by AD is growing rapidly with an estimated 1 in 10 individuals over age 65 diagnosed with dementia of Alzheimer’s type (Alzheimer’s Association, 2017). With AD being the only major disease yet to uncover an effective treatment regimen, medications are believed to offer a slowing of disease progression and, in some cases, mild symptom alleviation.

In 2017 alone, an estimated 15 million people offered unpaid care to their loved ones affected with AD (Alzheimer’s Association, 2017). With increased longevity, care provision for people with Alzheimer’s has become a concern among adult children who are trying to care for an aging parent with AD, maintain gainful employment, and care for their own family. As a
consequence of AD, adult children experience changes in the emotional attachment to their parent. As the framework of their relationship disintegrates, often sadness, loss, and disruption in activities of daily living are experienced by caregivers. The next chapter will review two theoretical frameworks including attachment theory, ambiguous loss theory, and then intertwine of the two theories to explain the emotional context of adult children providing care to their loved one with Alzheimer’s Disease.
CHAPTER 3: Theoretical Framework

The objective of this chapter is to introduce theoretical frameworks that offer an understanding of adult children caring for a parent diagnosed with Alzheimer’s Disease. Both attachment and ambiguous loss theories will be introduced and discussed through the lens of the caregiving relationship. I will start by examining attachment theory, which offers a foundation for understanding behaviors and emotional interactions in the parent and child dyad. This will be followed by an examination of the four types of attachment to include secure, insecure, insecure-ambivalent, and disorganized. The second theory, which will enhance our understanding of the emotional changes in the caregiving system, is the theory of ambiguous loss. The theory of ambiguous loss was initially researched and coined by Dr. Pauline Boss as a way to explain the phenomenon when a loved one is physically absent, but emotionally present which is the case when a loved one goes missing in a war, or a tragedy such as 9/11. The theory of ambiguous loss later expanded to include the type of loss when a loved one is physically present but emotionally absent, as is the case in people with Alzheimer’s Disease. These two theories together offer an understanding of the changes in emotional connection adult-child caregivers experience when their parent has Alzheimer’s Disease.

Attachment Theory

The theories of attachment developed by Bowlby (1969, 1973 & 1980) and Ainsworth (1985) have had significant influence in the field of social work practice. Attachment theory provides a foundational understanding of behavioral patterns from birth through old age. Bowlby (1979) postulated that “attachment behavior is any form of behavior that results in a person attaining or maintaining proximity to some other differentiated individual” (p.129). In the
1940’s, John Bowlby began to examine and formulate his theory of attachment emphasizing the influence early childhood environments had on lifelong attachments (Parkes, Stevenson-Hinde, & Marris, 1993; Thyer, Dulmus, & Sowers, 2012; Wallin, 2016). Bowlby put forth the notion that therapists should study the nature of the client intensely, the properties of the foundational attachments, and the intersectionality of the two (Bretherton, 1992; Parkes, Stevenson-Hinde, & Marris, 1993).

Bowlby (1969) identified that attachment behaviors are activated in specific circumstances including:

1. Situations when a child experiences discomfort in association with hunger, exhaustion, pain, or sickness.
2. When the caregiver or mother is physically absent, departing, or not engaging in proximity behaviors.
3. Threats or other environmental events invoked by adults.

The three distinct phases that children experience in their mother’s absence include: protest, despair, and detachment (Bowlby, 1973). Mary Ainsworth later collaborated with Bowlby as a research partner. In a classic study entitled the *The Strange Situation Room* (1978), Ainsworth examined patterns of behavior in children when their mothers departed the room (Brandell & Ringel 2007; Wallin, 2016) finding that when the child expects the mother to return, the child will reject alternative adults. If the mother does not return, the child enters the despair phase. In early childhood, children develop a sense of self from attachments with early caregivers (Ainsworth, Blehar, Waters, & Wall, 1978). The quality of the relationship attachment is influenced by the parent’s response when the young child is feeling upset by physical illness,
feelings of insecurity, fear, or hunger among others. Attachment styles described by Ainsworth to address the ways in which infants attached to their primary caregiver include secure, insecure-ambivalent, and insecure-avoidant and later disorganized attachment was added (Ainsworth & Blehar, Waters & Wall, 1978; Berzoff, Flanagan, Melano, & Hertz, 2016; Wallin, 2016).

Securely attached infants are able to easily explore their environment when feeling safe and will retreat or seek comfort when concerned (Thyer, Dulmas & Sowers, 2012). Insecure avoidant infants often do not respond to bids of physical or emotional connection, avoid cuddling, and dislike physical connection. Insecure ambivalent caregiver attachment occurs when the caregiver is only occasionally available to the infant, which may inhibit the infant’s safety and ability to explore their external environment. Lastly, the disorganized attachment style, later put forth by Main and Solomon in 1986, describes infants who experience the primary caregiver as concurrently a source of fear and contentment (White & Yellin, 2011). The disorganized attachment can occur when the parent-child dyad lack emotional regulation. Significant research has identified that this type of fragmentation in childhood can lead later to dissociative disorders or borderline personality disorders. For example, if the primary caregiver has an anxiety disorder, depression, or significant financial strain, there is a higher occurrence of disorganized attachment styles because these stressors interfere with attachment behaviors (Solomon & George, 1999). Additionally, if the mother has experienced a significant loss during the child’s early years of life or, alternatively, if the child experiences abuse, neglect or exploitation the child may be at risk for a pattern of disorganized attachment. The child with disorganized attachment style may find interactions with their caregiver to be frightening or hostile, while simultaneously feeling the natural desire to have proximity with the caregiver which creates what is called “fright without solution” (Main & Hesse, 1990, p. 163). Bowlby
posited that attachment behaviors through the life cycle are a basic survival function offering simultaneous care and protection to the infant (Thyer, Dumas & Sowes, 2012; Wallin, 2016; White, 2014).

The internal working understanding of relationship attachments are maintained through ongoing, dynamic relationships with family, friends, and primary attachments. Bowlby and Ainsworth (1978) emphasized that early interactions, attachments, and nonverbal interactions become the template and later served as a model for behaviors with loved ones, colleagues, and friends in adulthood (Berzoff, Flanagan, Melano & Hertz, 2016). In adulthood, similar reactions to loss of an attachment occur when love is lost or safety threatened, leaving the adult with symptoms of loneliness and despair (Bretherton, 1992; Eppel, 2009). Similar to early childhood, most adults try to maintain their sense of self through consistent dyadic family relationships.

The caregiving system, according to the theory of attachment, fosters progression, emotional growth, and alleviates pain, thereby offering what Bowlby entitled “a safe haven” (Mikulincer & Shaver, 2016). The caregiving system has two important functions which include (1) assisting with the concerns and needs of dependent persons when in distress and (2) offer security when a loved one feels threatened. As humans, by our inherent nature, we are programmed to have empathy for others and to provide assistance to one another when needed (Bowlby, 1969, 1982). The attachment bond associated with a primary attachment figure is not interchangeable by another, or fully replaced, therefore what differentiates the relationship with a primary attachment from others is the desire to reconnect through interactions and proximity (Antonucci, 1983; Ainsworth, Blehar, Waters & Wall, 2015).

Although adults commonly have a sense of autonomy and agency in adulthood as a natural result of the growth process, most adults do not terminate attachments with trusted
parental or family figures (Parkes, Stevenson-Hinde & Morris, 1993). In response to death or significant change, most adults typically maintain internal working models (Ainsworth, Blehar, Waters & Wall, 2015) which continue to be an influence in their lives. Mikulincer and Shaver (2016) stated “An adult’s caregiving system is influenced by his or her experience with caregivers early in development” (p.347). Five salient features of adult mourning addressed by Bowlby and Parkes who worked in tandem to develop five phases of grieving in adulthood included:

1. Thoughts directed to the lost individual
2. Numbness
3. Yearning and protest
4. Disorganization and despair
5. Reorganization

(Parkes, Stevenson-Hinde, & Marris, 1993)

**Ambiguous Loss Theory**

When first conceptualized by Pauline Boss in 1973, the Theory of Ambiguous Loss described the experience among family members who had lost their loved one during the Vietnam war. Boss discovered that, although the family member was physically missing, they remained psychologically present in the family system. With continued research into her theory, Boss identified that this was the case among families of the physically missing from similar circumstances to include natural disasters, terrorism, or the disappearance of a loved one (Boss, 2009). Through systematic investigation with families, it was determined that the family’s ability to experience closure and cope with the uncertainty inherent in this type of loss over a prolonged period was burdensome (Boss, 2009). Moreover, during the Vietnam era, family members of
those who were missing periodically received reports of military members who were still found alive, thereby regenerating the feelings of loss that were starting to mend (Boss, 1999).

Boss recognized that the emotions of those left behind were overpowering. Families that learned to adjust to, make meaning of, and understand how to live with the ambiguity of their loved one required adeptness and “acquiring a new set of skills” (Boss, 2009 p. 32). Letting go of concrete absolutes increased the families’ ability to adapt over time and enriched resilience in the family structure. “People experiencing ambiguous loss are filled with conflicting thoughts and feelings. They dread the death of their family member who has been hopelessly ill--or mysteriously missing for a long time--but they also hope for closure and an end to the waiting” (Boss, 2009, p.61).

Considering the fact that there were 150,000 United States service members deployed or in war zones in 2016, many military families of today face ambiguous loss and adjustment while their loved one serves the country. Adjustment and reunification periods can create particular risk for families when the active duty member re-immerses back into the family system and they again need to jostle the reintegration of their familial roles related to boundary ambiguity (Faber, Willerton, Clymer, MacDermid, & Weiss, 2008). For example, the reintegration strain impacts both the spouse and the children when trying to renegotiate household duties, expectations, or disciplinary rules with children.

Boss’s second trial run of the theory was with families who experienced a member diagnosed with dementia and later led her to write her first book about the theory in 1999 entitled *Ambiguous Loss* (Boss, 1999). Ambiguous loss describes grief frequently encountered by PWA and their families. Boss (2011) proposed that ambiguous loss is the most challenging type of grief because it “defies resolution”. She calls it “the goodbye without leaving (Boss, 2011). The
theory of ambiguous loss offers a framework for both those experiencing AD and their caregivers. It helps to make some sense of the progressive losses which lack a solution while simultaneously helping to construct the loss in a way that empowers caregivers to cope with the unknown. Boss distinguished her explanation of loss by defining the difference between physical presence and psychological absence which occur simultaneously, and she stated:

> Ambiguous loss is the stressor which leads to boundary ambiguity where the perceptions of the ambiguous loss are experienced by individual family members, as well as, the family as a whole. Boundary ambiguity is a continuous variable that predicts the outcome, with a high degree being immobilizing both systemically and relationally. The process of struggling with ambiguous loss is also circular and continuous (Boss, 2011, p.15).

The theory of ambiguous loss is based on the premise that loss can be seen as a part of the human struggle. Although, in losses such as those associated with dementia, the family members experience numerous ‘deaths’ of their loved one in a continuous fashion throughout the disease. Related to lack of closure, families of PWA experience simmering feelings of grief and isolation in their grieving process because this type of loss is not recognized in larger society. It has been rightfully called non-death grief because of their loved one’s physical presence. As Alzheimer’s dementia progresses, the level of pre-grieving increases (Blandon & Pepin, 2017).

Similar to Alzheimer’s Disease, ambiguous loss has been studied and applied to individuals and family systems who experience other forms of medical illness. An illustration of the application was among those whom have suffered a mild traumatic brain injury (MTBI). Families facing MTBI described asynchrony while renegotiating roles in the family system
Despite the fact that the individual with MTBI appear physically normal, challenges completing daily activities of living, emotional or behavioral problems, apathy, and lethargy could impinge the individual and family post-concussive (Landau & Hissett, 2008). In a similar fashion, ambiguous loss was applied to those facing End Stage Renal Disease, Chronic Obstructive Pulmonary Disease, and emphysema, among others, to better explain the unpredictable symptom exacerbation and powerlessness families experienced in trying to cope and adjust to the progression of the disease course (Boss & Coudin, 2002). Moreover, chronic illness and illnesses such as AD, in the context of the family system, can create a deluge of role changes, loss, depression, and unpredictability. According to Boss, “Illnesses that are difficult to diagnose and have no cure are rife with ambiguity” (Boss, 2002, p.1352). In the case of chronic illness as mentioned above, Boss postulates that role confusion promulgates inconsistency and often a “freeze” response ensues (Boss, 2002). As is the case with most chronic illnesses, they often have an arduous, unpredictable course, thereby creating emotional and mental strains to even a robust family system. Naming, identifying, and understanding the progression of chronic disease can enhance normalization and coping resources in the family (Boss, 2002).

As with any theory, it is composed of underlying assumptions which specify the groundwork for its construction. The Theory of Ambiguous Loss has the underlying understandings (Boss, 2016):

1. A phenomenon can exist even if it cannot be measured.
2. With ambiguous loss, we assume that truth is not attainable and thus is relative. Instead of the usual epistemological questions, we ask how people manage to live well despite the absence of truth. Many do, and we learn from them.
3. Ambiguous loss is a relational phenomenon; it assumes attachment to the missing person. The theory is thus useful for studying couples and families as well as other close relationships.

4. Cultural beliefs and values influence how individuals, families, and communities tolerate ambiguous loss, as well as how they perceive it. We assume the primacy of perceptions but are aware that they are not all that matters.

5. With ambiguous loss, the source of pathology lies in the loss and not in the type of grief experienced (Boss, 2010; Carnes & Boss, 2012).

6. With ambiguous loss, closure is not possible. Without finality, the loss and grief may continue indefinitely, for years or a lifetime, and even across generations (e.g., slavery, the Holocaust, genocide, war, terrorism, forced migrations).

7. People do not know how to cope with a problem until they know what the problem is that they are facing. Naming the stressor as ambiguous loss, therefore allows the coping process to begin with greater understanding for the individual.

8. If a loss remains unclear and ambiguous, it is still possible to find some kind of meaning in the experience. This requires a new way of thinking, on that is not binary, but dialectic. For example, “She is both gone and maybe not”; “He is both here and also gone”; “My kidnapped husband is probably dead-and maybe not”; “My grandfather who has dementia is still here but also gone”.

resilience in families (Masten, 2007, 2014), but we assume that the tolerance for ambiguity can be influenced by the family’s cultural beliefs and values.

10. Core to the theory of ambiguous loss is the assumption that families can be both physical and psychological entities which foster resilience. A psychological family is a family in one’s mind. It comprises loved ones near or far, related or not related, alive or dead. The psychological family is made up of the people we lean on (physically or symbolically) in times of adversity or celebration. To assess the presence of a psychological family, we ask the following questions: Who is there for you now? Who is there for you in times of sadness? Cross-culturally the answers vary.

The theory of ambiguous loss is based on the premise that loss can be seen as a part of the human struggle. Although, in losses such as those associated with dementia, the family members experience numerous ‘deaths’ of their loved one in a continuous fashion. With lack of closure, families of PWA experience grief associated with AD and feel alone in their grieving process with acknowledgement of loss by those outside of the situation. Some have rightfully called this non-death grief because of their loved one’s physical presence.

Boss’s (2006) release of *Loss, Trauma, and Resilience: Therapeutic Work with Ambiguous Loss* identified specific methods to normalize the feelings of ambiguous loss and foster resilience in the family system. She contends that resilience can be strengthened when caregivers can: (1) find meaning, (b) reconstruct identity, (c) adjust their sense of mastery (d) revise the expectations of the attachment (e) find ways to foster a new sense of hope in their situation, and (f) normalize the feelings of ambivalence (Boss, 2006). Resilience can act as a protective factor for both the PWA and the CG. It is common knowledge that feelings of loss are a normal response to a disruption in an important attachment, such is the case with death or loss. The assumptions of
theory provide a broader picture of how to understand AD and provide clinical interventions (Bowlby, 1969, 1973; Mancini, Robinaugh, Shear & Bonano, 2009; Neimeyer, Prigerson, & Davies, 2002; Shear, 2010).

**Attachment and Ambiguous Loss Theories**

In 1980, John Bowlby wrote *Attachment and Loss: Volume III: Loss, Sadness and Depression* addressing the emotional and physical impact of the loss of a loved one. He wrote: “Loss of a loved person is one of the most intensely painful experiences human beings can suffer” (Bowlby, 1980, p. 7). With this knowledge of attachment, it is easy to comprehend the impact of loss and the subsequent sadness or distress experienced by the adult child when their parent is slowly declining and the ability to maintain emotional proximity is diminished. Loss has been likened to an intense physical wound which requires attention, tending, and heals over time. Feelings of uncertainty arise when one can no longer make sense of the relationship with a primary attachment, such is the case commonly with Alzheimer’s (Marris, 1993).

When a parental figure is cognitively and emotionally impaired, as in Alzheimer’s Disease, role reversal can be considered a normal, healthy response (Minuchin, 1998). Clinically speaking, role reversal in early childhood through young adulthood is considered a malfunction within the system, although adults typically enter into a reciprocal shared relationship with their primary parental figure as time progresses in the life cycle and this would be considered a normal progression along the trajectory (Kalish-Weiss, 1982).

As human beings, we are faced with uncertainty every day, although if unable to make sense of the uncertainty, may experience angst, strain, or worry (Parkes, Stevenson-Hinde, & Marris, 1993). The uncertainty of Alzheimer’s Disease can cause a variety of responses which
challenge the attachment and coping mechanisms of the caregiver who faces unpredictable, ambiguous loss.

**Summary**

This chapter applied the theories of attachment and ambiguous loss with close examination of how they work in tandem to better explain the experience of adult children providing care to their parent with Alzheimer’s Disease. Examining the changes in the parent-child relationship under the lens of attachment theory offers a framework for understanding how these foundational attachments are impacted by AD. While no parent is perfect, most children desire to maintain an emotional connection with their parent, and unfortunately AD interrupts the attachment system. Alzheimer’s Disease leaves behind a shell of the parent they once knew and the relationships they shared.

Examining and defining ambiguous loss creates the scaffolding to better explain the type of loss experienced by adult children caring for their parent with Alzheimer’s Disease. It explains the phenomenon of their parent’s is physically presence, yet emotionally absence in their relationship. This experience creates tension and grief that is often unrecognized in a greater societal context. Gradually learning to live with the unpredictability of AD is important for CG experiencing the loss of their normative family experiences. The combination these two theories provide a robust explanation of the common responses adult children experience in the attachment to their parent, caregiving responsibilities, and their unique experience of loss. It is important to recognize that the parent-child attachment adjustments impact both the person with Alzheimer’s Disease and the adult child who grieve the loss of their life-long understanding of their relationship. The changing patterns in emotional interaction and dissolution of the attachment bond create isolation, anxiety, and moments when social supports are required to
maintain the caregiving course. The objective of the next chapter will be to explain the methodology and design of the study.
CHAPTER 4:

Methodology

The objective of this chapter will be to examine the rationale for this study and then move into an explanation of research design, arguing that qualitative methods were most appropriate for this type of study. Qualitative methods offer the reader the opportunity to hear from the adult caregivers about their lived experience and how the disease has impacted the shared attachment with their parent. A description of the sample of adult caregivers, the methods of data collection, and analysis of data will follow. Folded into the data collection segment, are the questions utilized with research participants to garner a better understanding of their experience caring for their parent.

Research rationale

The purpose of this research is to explain the essence of ambiguous loss and resilience among adult children caregiving for their parent with Alzheimer’s Disease. This qualitative study sought to expand the knowledge base of the experiences of adult children caring for their parent with AD using phenomenological methods to reveal their personal experiences of ambiguity in caregiving, attachment to their parent both prior and during their role as caregiver, and the concept of resilience as a CG.

Qualitative methods were employed through interviews with adult caregivers in order to garner rich descriptions and insights about their experiences. Due to the nuanced nature of this subject, this research topic would be challenging to measure in a quantitative manner. These findings will be critical to developing therapeutic responses to adult children in the midst of caring for the parent with AD and the resources necessary to build resilience for the care trajectory.
**Research Design**

Qualitative research aims to explore the lived experiences, the meanings attached to the experience, and their multiple views of reality (Padgett, 2017; Strauss & Corbin, 1998). One essential element of a qualitative methodology is a degree of immersion by the researcher while collecting data to gather a clearer understanding of their lived experience (Creswell, 2007; Padgett, 2017). Padgett (2017, p.2), offers six essential characteristics in a qualitative study including:

- Insider rather than outsider perspectives
- Person-centered rather than variable centered
- Holistic rather that particularistic
- Contextual rather than de-contextual
- Depth rather than breadth
- Inductive rather than deductive

Phenomenological research examines the common, personal descriptions of the lived world, and reveals the significance participants have attached to their human experience (Finlay, 2011). To garner a textual understanding of the meaning the individual assigns to their particular experience, the researcher serves as an active instrument collecting data, interpreting findings, analyzing transcripts, and summarizing the findings. Phenomenological analysis in qualitative research employs the methodology of reduction and examination of participant statements, review of plausible meanings, and construction of themes (Creswell, 2007; Strauss & Corbin, 2008). In a phenomenological research study, researchers are able to understand both the “experiences of the inward and outward consciousness based on memory, image and meaning”, to offer the reader their actual reported experience with the phenomenon of interest (Creswell,
Therefore, interviews with adult caregivers provided the opportunity to capture a
glimpse of their experiences, and to make sense of their views on loss and resilience using
phenomenological methods. Phenomenology assumes that all judgements are suspended in order
to establish a natural inquiry regarding the study topic (Moustakas, 1994). The researcher
designed the study questions to explore the caregiver’s experiences via detailed elaboration on
their daily experiences, thoughts, and feelings in the role as caregiver for their parent with AD.

Sample selection criteria

This research study employed convenience and snowball sampling through the use of open-
ended interview questions. The sample size, 12 participants, all met the inclusion criteria as
follows:

1. Able to speak English
2. 18 years of age or older
3. Caring or cared for a parent with Alzheimer’s Disease
4. Willing and able to participate in the study

Sample

Participants in this study population ranged in age from 38-63 years of age. Three were
Hispanic, two Native American Navajo and the rest self-identified as Caucasians. Of those that
participated, 6 were caring for their father and 6 were caring for their mother. The disease stage
their parent was experiencing varied from those newly diagnosed to late stages and two of the
participants had a parent who had died within the last six months. Three considered their parent
in the early stages, four considered their parent in the middle stages, three had a parent in later stages, and two had died within the last 6 months.

Nine worked full-time and 3 were not working because they were caregiving full-time for their parent with Alzheimer’s Disease. Although the stage of their parent’s progression in Alzheimer’s Disease varied, their experiences and expression of feelings had a number of similarities across disease stages. Many elderly today may experience physical challenges or frailty as they age, thereby looking to their adult children or extended family for physical, emotional, and occasional financial support. The residence of their parent included those living at home (N=8) with them to residing in assisted living facility (N=2) and those with parent who had died (N=2) and resided both at home and in institutional care facilities.

**Ethical Considerations**

After successful proposal defense, the researcher presented the study to the Institutional Review Boards at the University of Pennsylvania and the San Juan Regional Medical Center to conduct this study with adult caregivers. This qualitative study was conducted as a part of the doctorate in social work program at the University of Pennsylvania School of Social Policy and Practice and received IRB approval prior to initiation of the study (Appendix: A). The Collaborative Institute Training Initiative (CITI) program, an online student research training, was completed by the researcher (Appendix F)

After the researcher received approval from both of these institutional review boards, recruitment commenced. All of the participants volunteered to participate. They were provided with data on the purpose and nature of the study, were made aware that they could withdraw at any point during the study, and their confidentiality was held in utmost confidence. In
accordance with the National Association of Social Work standards, social workers have the duty to protect the confidentiality of data provided, except for under compelling circumstances (NASW, 2017).

**Recruitment Strategy**

This study aimed to recruit between 10-15 adult children using convenience and snowball sampling. Recruitment efforts occurred between August 15 and October 20, 2017 through the national Alzheimer’s Association organization, and social media. Snowball sampling took place as participants referred other adult children whom they knew were caregivers for their parent with Alzheimer’s Disease, and would meet the inclusion criteria. The Alzheimer’s Association is a non-profit organization focusing research efforts to improve delivery of care to patients and families experiencing Alzheimer’s Disease. They conduct a wide variety of medical research, 24 hour hotlines, professional education, and on-line resources for patients and caregivers. The recruitment flyer (see Appendix B) was distributed to the local residents, home health agencies, nursing facilities, and those that expressed interest or provide assistance to families facing Alzheimer’s Disease.

Recruitment lasted for 2 months starting August 15, 2017. The researcher provided information to study participants after their qualitative interview and they passed it on to others who they knew may be interested and eligible. This method proved most effective as many of the adult children had helped one another in the process of caring for their parent with Alzheimer’s Disease and had supported one another in the caregiving journey. Those who were interested as prospective participants contacted the researcher for more information and possible inclusion. All of the participants who made contact expressed interest in participating. If the
participant mentioned another possible participant, the researcher would ask them to provide a flyer to the prospective participant and they could choose to call on their own volition. The researcher did not directly contact the potential participant without request by referral contact. Within 4 weeks of starting the recruitment process, numerous individuals offered to participate and met inclusion criteria. The interviews were conducted over an 8-week period at the location of the participant’s choosing which included places such as their office location, local coffee shop, and one interview conducted at their home.

**Limitations**

Some limitations included the presence of the researcher during the interviews, which could impact or shape participant’s responses or create bias. The location of the study in an isolated, rural-area of the country, thus less generalizable to population at large. More women than men participated in this study which could alter results or could reflect societally that adult daughters more often assume the role of caregiver for their parent. At the time of the interview, each parent was at different phase disease trajectory, thereby creating different understanding of their emotions, loss, and resilience at that time period.

**Consent**

The recruitment flyer and materials explained the purpose of the research along with the researcher’s cellular phone number and email. Interested individuals were invited to contact the researcher. Upon making telephone contact, the researcher described the purpose, identity herself and discussed the role of the researcher, the length of the one-time interview, and stated that the participant is free to withdraw from the study at any point in time. During the telephone pre-screening, the researcher verified that the participant met the inclusion criteria. Individuals were
able to review the consents (Appendix B) and ask questions prior to the interview. There was minimal risk for adult caregivers participating in this research study and none of the participants asked for any additional assistance or expressed distress during our interviews.

*Data storage*

The researcher assigned participants alphanumeric codes as identifiers to protect their privacy. The researcher’s documentation and all related data, including audio recording and transcriptions, were labeled with a corresponding numeric code. A listing containing the assigned codes of the related data and corresponding participants’ identifiable information is maintained in an electronic word document that is password protected, and only the researcher has access. All digital recordings and Microsoft Word documents of the transcriptions are stored on a password protected hard drive and a backup version stored on an external password protected hard drive. Field notes were maintained in a locked file cabinet.

In terms of privacy, the information provided by the participants is strictly confidential. The researcher will not use participant names and maintained all printed records under lock and key for security and privacy purposes. The researcher removed any spoken information that could serve to identify participants including geographic locations and names the participant may mention in the course of the interview. The participants will be described by use of gender or age only to protect their identity when using direct quotations of their caregiving experience. The researcher will be the only individual to have access to the digital recordings and the recorded information will be erased and deleted from the computer files upon conclusion of the research. Pseudonyms were used and inconsequential information changed to provide additional privacy.
Reflexivity Statement

I identify as a social worker who has been working with the aging population of San Juan County New Mexico the past 10 years in an acute care medical setting and prior to that in outpatient settings. I have both an understanding and familiarity with the emotional struggles of the patient, family, and caregivers for those with Alzheimer’s Disease. I employed journaling and memo writing to increase my awareness of personal bias and made sincere efforts to contain any bias, thoughts, or pre-conceptions about findings.

Data Collection

In accordance with a phenomenological approach, information was gathered about their experiences via in-depth interviews. All of the interviews occurred with participants through face-to-face interviews at the location of the participants choosing to include their office space, participant’s homes, and two at a coffee shop. All interviews lasted 60-90 minutes in duration. Prior to each interview and the recording process, the researcher had a brief conversation to again clarify the purpose, establish rapport, sign related consents, complete demographic questionnaire, and discuss confidentiality. All semi-structured interviews were audio recorded to allow the interviewer to focus on the interview instead of note-taking.

Each participant completed a demographic questionnaire (Appendix C), which gathered data regarding their age, the sex of the parent receiving care, ethnicity, gender preference, amount of time they spend caring for parent each week, and employment status. The interview guide (Appendix D) was used as a semi-structured template.

The interview guide, questions, and probes were developed to explore how adult caregivers over the age of 18 perceive caregiving, loss, and resiliency in their experience
caregiving for their parent with AD. The aim is to better understand the essence of ambiguous loss and give voice to the subjective experiences of these caregivers through exploration of their stories about the caregiving. Not giving voice to these stories can add to the ongoing isolation, minimization, stigma, and sense of loss associated among caregivers. To this end, three core qualitative research questions included:

(1). Caregiving for their parent with AD:

- Tell me about your caregiving experience with your parent. Can you describe how you first started to notice that things were changing with your parent? What is your typical day like as a CG? How would you describe the caregiving experience since the symptoms first began? Could you describe your attachment or connection with your parent prior to AD?

(2). Experiences with Loss and changes

- How has your role with your parent changed? How would you describe your experience of loss over the disease trajectory? Can you share these with me? What, if anything, has given you strength or resilience through the process of Alzheimer’s Disease caregiving? How would you describe your strengths in coping with the many demands?

(3). Using supports and advice to other adult children

- Do you use any type of support systems or have contact with others who are in a similar situation as you? What do you do when you experience caregiver burnout? What would you like to share with other adult children whose parent is diagnosed with Alzheimer’s Disease?
Qualitative research methodologies give way to a better understanding of social work practice with benefits leading to enhanced clinical outcomes for our clients. Each study participant received a unique alphanumeric identifier linking them to the audio recording. Printed information was kept in a locked cabinet. Interviews were transcribed by a professional transcription service, REV transcription, who were the only individuals besides the study researcher to hear the audiotaped interviews and received the information with an alphanumeric identifier. The transcribed data was examined for accuracy and personal data was removed to include names, and identifying information, or descriptions.

The pre-interview arrangements included choosing a setting with the participant that was quiet and free from distractions, describing to the participant caregiver the purpose of the study, review of confidentiality guidelines, description of the format of questions, and answering any of their questions prior to the initiation of the audio recorded interview. Participants agreeable to participate and met study criteria were compensated $50.00 for their interview time and willingness to fully participate. Participation included the completion of the demographics questionnaire and in-depth interview. Following the interview, the researcher took notes to record field observations and emerging themes.

Methods of Data analysis

Phenomenological analysis was used in this research and included a description of their experiences as a caregiver, summary of specific themes, and the quoted excerpts of the participants lived experience as caregivers (Padgett, 2017). Phenomenological analysis typically involves an outline of the participants understanding (“textual descriptions”), detailed inspection of their experience (“structural description”), followed by development of themes, summary of
findings, and specified participants excerpts from the interviews (Moustakas, 1994). The nature of open-ended qualitative questions provided this researcher the opportunity to probe for more information about their attachments and experiences with caregiving. Staying close to the interview data while simultaneously conceptualizing the information is necessary in qualitative analysis (Padgett, 2012).

Analyzing began with the assignment of identification numbers for transcripts, notes, and audio recordings. While in the process of qualitative researcher Corbin and Strauss commanded the researcher “Do not control variables, discover them” (Corbin & Strauss, 2008, p. 318). Initially, the researcher analyzed the data by listening to the recorded audio interviews and reading the transcripts to verify that what was transcribed and what was verbalized by the caregivers in the audio recordings were consistent. “The heuristic researcher returns again and again to the data to check the depictions of the experience to determine whether the qualities or constituents that have been derived from the data embrace the necessary and sufficient meanings” (Moustakas, 1994, p. 180). Following the check for accuracy, the researcher initially began by reading and re-reading the transcripts again and jotting down initial impressions. Line by line open coding was conducted to identify words, phrases, and frequency of their described feelings about caregiving. Padgett (2012) argued “coding involves transferring chunks of text into bins”, which serves to separate the data into conceptually related components (p. 174). Coding interviews with the caregivers was a way of breaking participant’s information into meaningful segments. This process was followed by writing down the identified codes on a separate sheet of paper. As the common patterns became evident, recurrent words or phrases were tracked, the potential themes amongst the caregivers interviewed began to emerge naturally over time. Repeated readings of the transcripts, listening to the interviews, and review of the
field notations enhanced the depth. As the information was compiled, three primary segments emerged which were losing connection, negotiation, and reorganizing. The corresponding themes under each segment included recognizing change, reversing roles, emotional loss, following their footsteps, sibling connections, financial negotiation, caring for self, revealing resilience and gaining insight, and developing high quality connections with others. Saturation of themes was met in the course of the study.

Strategies to ensure rigor

Data triangulation included detailed review of in-depth interviews, transcripts, field notes, and self-reflective writing to refine understanding of the participants meaning, as well as, member checking (Moustakas, 1994). The process of member checking serves to clarify the meanings and interpretation of information (Lincoln & Guba, 1985). Moreover, it serves as a protection against any inherent bias that the researcher possesses (Padgett, 2017). After each interview, the researcher wrote notes in a field journal that highlighted thoughts, observations, and possible themes. The field notes helped in reflecting on the information garnered from the transcripts and the impressions during the interview. Throughout the study, the researcher discussed the emerging themes, observations, data collections and analysis with her dissertation chair.

Summary

This chapter explains the qualitative methodology employed with the participants in this study. The complex human experiences and life changes for the caregivers of their parent with AD can be better explained through qualitative research. The purpose of the study was to provide an in-depth look at the experiences of the adult children who provide the day-to-day care for
their parent with Alzheimer’s Disease. Qualitative methods offered the researcher a way to study their situation in context and shed light on their understanding of the CG experience. Employing convenience and snowball sampling methods, twelve participants offered to provide in-depth interviews lasting 60-90 minutes. For privacy, all of the data collected remains confidential and the information detailed in the findings section will describe the participants by their age or gender to protect their anonymity. The next chapter will address the findings of the study.
CHAPTER 5

FINDINGS

The objective of this chapter is to describe the research participants and offer an account of their shared narratives. In-vivo coding was employed to identify emerging themes among study participants and the findings were separated into three segments; losing connection, negotiation, and reorganizing. Each segment will include themes, ideas, and direct quotes from the participants to provide information about their complex interactions with their parent experiencing AD. With thoughtful consideration of their lived experiences as caregivers, the direct quotes were chosen to offer the reader a first-hand account of their stories.

Description of research participants

Twelve participants were recruited via convenience and snowball sampling and all agreed to participate in the study. Data was obtained from one-on-one interviews with the 12 participants. Of these participants, 10 were adult daughters and two were adult sons. Six participants were caring for their mother and six were caring for their father. At the time of the interview, the participant’s parents were at different phases in the diagnosis and disease trajectory. Three considered their parent in the early stages, four participants considered their parent in the middle stage, three later stage, and two whose parent had died in the last six months from advanced Alzheimer’s Disease. Due to the insidious, roller-coaster nature of AD, some of the participants stated that their parent may be between middle and later stages because their functioning fluctuates day-to-day.
Three participants self-identified as Hispanic, two were Native American Navajo, and seven self-identified as Caucasian. Nine were employed full-time and three were unemployed citing that they were unable to work because they were caring for their parent with Alzheimer’s Disease. The participants reported the amount of time expended caring for their parent ranged from 3 to 24 hours per day, 7 days per week depending upon their parent’s stage, needs, and level of outside support. Those respondents who lived with their parent provided increased amounts of care. To protect the confidentiality and anonymity of the participants, their experiences and quotes will be cited using their age or gender preference.

**Losing connection**

The first segment, entitled *losing connection*, encapsulates their description of feelings about the noticeable changes in the relationship with their parent. *Losing connection* was emphasized across participants as a pervading element and supported by the data collection. As the disease progressed, the previous rules of the relationship were extinguished and the family structure experienced entropy. This was recounted in two conceptual themes; *recognizing change and reversing roles*. Participants explained how they were *recognizing changes* at the onset of Alzheimer’s Disease which included physical, emotional, and mental changes out of character for their parent. At times, they questioned their interpretation of the changes and grappled to gain clarity about whether their parent had Alzheimer’s Disease or another diagnosis. The subsequent theme *Reversing roles* marks the rich description by participants of their personal adjustments and role transition with their parent’s deteriorating mental capacity.

**Recognizing Change**

The first theme related among participants, *recognizing change*, was explained as desire to connect with their parent on an emotional level, but gradually starting to realize that the path
of their parent’s memory was significantly changing their shared interactions. They described the realization that the events and behaviors unfolding with their parent were going to alter both of their lives. Evidence shared by participants about these recognized changes ranged from repeated questioning, forgetting names of common objects, and odd behaviors. Participants grappled with whether the changes were a “normal part of the aging process” or actual “memory loss”. As recounted by one 53-year-old participant,

*Her thoughts might be clear, but there’s such a gap in her being able to express what she’s thinking and actually come up with the words to say those things anymore. Because I’m her daughter, I’m able to fill in the gaps. But other people can’t. I think that’s incredibly frustrating for her and for my mom, that’s one of the hard things. She’s very aware of what’s happening, she’s very aware of the changes that are about to happen in her life, very aware.*

A female respondent gives this glimpse of her father’s changes,

*He would steal my second-grade son’s homework and his Hot Wheels car. And my dad did not steal……..his personality was changing and he was becoming more childlike. He started to really relate well to my toddler*

Eye-opening, odd conduct were disconcerting and respondents had questions such as “is this really happening?” or “What are they thinking?”. As chronicled by a female participant,

*It’s, he’s having a hard time distinguishing from people to other people but he wants to go, be doing…be doing whatever he used to be doing. But, he is not remembering a lot of stuff. Like he’s left the house with the stove on and the doors open. He’s left the water on in the kitchen when he was gone.*
The unpredictable and confusing behaviors began to hamper interactions and the respondents described their wish to reconnect with their parent. Each participant described repeated questioning and name recall as a common communication adjustment they initially recognized. These initial communication changes invoked participants questioning if “something was amiss” with their parent’s ability to recall recent conversations. One 52-year-old details her experiences,

*Repeat a story, repeat a question, repeat ... And you just have to get used to that, and you just listen to the same thing over and over. That gets frustrating after a while. You just want to say, "I've heard this five times in the last 30 minutes! I know! I know!" But she can't help it. She doesn't know that she's already said it, so I just try to pretend like it's the first time she told me, or mentioned it, or asked me about it*

Some caregivers recognized changes through “things not being completed” such as paying their bills and fulfilling their normal household duties as described by this daughter,

*Oh my gosh, they're not paying their electric bill. They're not paying their utility bills, and then their utilities are cut off because they ... People that start this Alzheimer's, they just shut down. They really, literally can't take care of themselves and they can't figure out how to write a check. So, things get shut down, the parents are working so hard, they have Alzheimer's and pretend like everything's okay. And it's not okay, and it's exhausting*

Changes, in some instances, were described as imperceptible, gradual patterns. Conversely, other CG felt the change occurred quickly and a 45-year-old son explains it this way, “*It was hard because my dad was always outside, working, doing stuff and we'd be out there helping him, but all of a sudden, he just couldn't understand it, comprehend stuff*”. Another 57-year-old’s first realization of the disease was when their parent was starting to forget how to
get back home, “she would leave, she would just disappear, like you see on TV all the time. Dad would call and say, ‘Can’t find Mom’”.

Moreover, some participants were unsure if their parent was just being difficult with them or experiencing memory issues as recounted by this daughter,

_The more my dad went downhill I started to wonder...does he really know what he is doing? I would think not, but if he did know what he is doing, he is being really, really bad. It is so hard, because it drives me, as the child, crazy_

Some questioned how they going to manage the unpredictable course ahead. Some explained that realization of the changes may have been delayed because they were not living with their parent at the time and suspected that it may have been covered up for quite some time by parent. Once the changes in memory were recognized, a number of the participants stated that they began to understand that AD would subsequently change their connection on numerous levels. Wishing for their old ways of knowing and sense of attachment to their parent were common among respondents. New “workings” in their relationship created a situation where the participant entered unknown and unfamiliar territory.

_Reversing Roles_

Alzheimer’s Disease created role strain and changed the way CG viewed their attachment; shifting from the one who was being protected by their parent to the one actively protecting their parent. The change in roles exacerbated and turbulent for respondents. The role changes signaled “the beginning of a new career of caring for my parent” which was often “not something I signed up for” or “not what I had planned”. Concerns for their parent’s safety and well-being was straining, unpredictable, and ever-changing. Their parent’s unraveling mental
capabilities brought with it the loss of the previous idea that they were going to watch their parent grow old gracefully. Some felt angry and found themselves in fits of rage with nobody to be mad at just “mad at the disease and what is has taken from me”. The role reversal described by participants became wearing over time and concerns for the safety of their parent in activities of daily living resonated amongst respondents.

Initially, after the realization and diagnosis of AD, supporting the autonomy of their parent was identified as a “balancing act” because, while they wanted to encourage self-sufficiency, they did not want to compromise safety. The role reversal was also expressed as uncertainty about the role they should take with regards to their parent’s safety operating a vehicle and money management, in particular. Moreover, some of their parents were harder to convince as reiterated by a 63-year-old female participant,

*It’s like a 10-year-old kid with money and a car. That’s what it feels like because you can’t give him any instruction he’s just going to do whatever he wants to do. We’ve had to just kind of step back and say, “God, we hope you take care of him and those around him because I don’t know what else we can do.” “He's not debilitated, so it's not like he's home and you can take care of him but yet he's not fully functional he's dangerously functional*

They reported that the role reversals became increasingly evident over time as expressed by one female respondent,

*And you, of course, reversed the roles, and I'm having to take my mom's keys away from her as she probably would have had to do when I was 16 and maybe got grounded, she might have had to take my keys. And here I am, taking her keys because I was afraid*
she’d forget that she wasn’t supposed to drive and might try to go somewhere. So here I had to take her keys, and ... The roles are just very, very reversed. And I give her money now. Back in the day, she probably gave me allowance. Now I’m giving her money

These adult children, accustomed to following the directives of their parent, now faced the task of setting boundaries with cooking, driving, money management, household tasks, and personal hygiene. The participants whose parent was in the later stages of AD stated that role reversal in later stages of the disease included physical care, which was “outside the bounds of comfort”, as captured by this adult daughter whose father is in advance stages of AD,

So, now in the relationship, I am more the parent role. Or the parent role. I feed him, you know. He won’t eat unless I either bring him something or sit him down and feed him.

I have to take care of all the bills, have to take care of all the [ ... ] Take him to the doctor.

I have to sit in the doctor, talk to the doctor, and tell the doctor, you know, everything like you do with your child about histories and allergies. I’m completely the sole caregiver, really not the child anymore.

It helped one son understand the role reversal by being prepared for the change after he realized his dad had AD. “Just be aware that it’s going to take away from your life. It’s going to change your whole life because it’s like you’re taking care of a little baby again”.

The initial changes invoked a new way of thinking about the attachment to their parent. Bowlby’s theory of attachment states that the parent is a secure base for the child’s safe welcoming emotionally and physically (Bowlby, 1969). However, with Alzheimer’s Disease, this fortress of safety was changing as they experienced the gradual disintegration of their
communication patterns and emotional connection. As contributed by this 51-year-old female discussing the initial changes with her mother, whom she considers in the early stages of AD,

She's just changing quickly in front of my eyes. I hate that. I'm trying to change in my brain from just remembering that she's starting to not remember, and you can't choose how you die. You can't choose if you [ ...] There's things you can do to be as healthy as possible, but aging is aging, whether it's your brain or your heart or cancer or just atrophy

The adult children elaborated on the daily demands such as preparing their parent’s breakfast, assisting with dressing, personal hygiene, and medication prior to starting their own day or going to work. Participants reiterated that their mother or father’s medical appointments, power of attorney, and day-to-day care needs was a significant undertaking and felt “heavy”. As cited by this 43-year-old whose father was placed in institutional care relates,

The relationship changed. I felt like I was his mother. I totally felt like his mother when he lived with me. He was just one of my kids. When I went on a three-day vacation with my husband, I would worry about him the whole time. He was like a child because he had diapers, needed to be fed, and his health was tricky

The role adjustments changed the amount of time dedicated to their marriage and other family obligations. Three respondents did not have a positive connection before AD diagnosis with their parent. One variable identified by respondents without a positive prior attachment was that, despite the role reversal, their faith and belief system motivated their care for their parent. One female respondent states,
Not because I think he can't, but because I love him, and I just want to help. I just want to. That's what God called us to do is to be servants and to care for our parents. Like I said, he wasn't exactly really nice ... in many ways he was a very mean father, but he did the best he could with what he could, and it's not my place to judge anyway.

Another 58-year-old related that their parent was “a stinker” and difficult to get along with, however she felt her faith helped her “cope with the role changes” as expressed in her sentiments,

Well my faith is huge, that’s the number one thing that keeps me going. Sometimes when I’m not ... or when my faith isn’t function at full force, I kind of pull back away, and I can see that

The mind-boggling role changes were uniquely experienced among the caregivers interviewed, reflective of their parent’s stage in disease process, and their previous attachment to their parent.

**Negotiation**

Alzheimer’s Disease creates a specific type of loss: one involving the extinguishing psychological attachment and then the eventual physical death of their mother or father. The participants developed a strategic process for deliberating a variety of issues that arose. This arbitration included identifying how to collaborate with their siblings to offer the care required. Finally, fiscal matter entered into the equation of how to provide the care and fear that the expense of the care may exceed the resources.
Emotional Loss

Emotions started to shift and were expressed as an on-going feeling of loss with “no closure”. These losses, described by some respondents, were a series of farewells with an unpredictable course. A 38-year-old relates that she feels like “one of the many nameless faces” her mother sees daily at the nursing home as she recounted,

*It is sad, exhausting, lonely. With every change, it is another grieving process. Except for denial. You know, the denial goes away after the first year. But the anger, bargaining, all that stuff. It happened to me when she forgot how to tie her shoes. It happened again to me today when she was trying to talk to me and was unable to come up with the words. It was just torture. It is really hard to sit down and try to entertain her when there is hardly any ‘there, there’. She knows me as somebody who was at one time important in her life. She does not know me as her daughter and you think ‘wow’, my mom does not know me as I am and that is so bizarre. It is really sad*

The respondents wanted to connect with their parent on an emotional level and the absence created a gap filled with wishes that their parent “would come back” as explained by one daughter,

*I think that what people don’t want to say, or maybe people do say, it’s just this person is no longer there. But yet, they are. So, in my mind my mom is not [....] Or, my relationship, she isn’t really my mom anymore. It is like a shell of a person cause’ there is no real connection, there’s no real conversation*

The prolonged loss was described by another female respondent as a “*loss of their shared memories*”
Every time I go to see her, I leave feeling sad. Every time I see her I want to talk about something that is from my childhood or have some kind of connection, and there’s just that that there. You are constantly feeling like that grief is just getting prolonged all the time, 'cause there’s this person that really is not your parent anymore. I didn’t understand the level of grief I would feel, and how there, as I mentioned earlier, there just seems to be no end to the grief.

Some changed their views about who their parent was in an effort to ease the pain of loss as a 50-year-old explains “It’s not seeing her the same as she always was. She’s not my mom. She’s not my friend. It’s different.” The understanding that the transformation of the relationship was due to the disease speaking versus their parent who had once loved them was significant reconceptualization as stated by this 46-year-old,

So, you grieve the person who they used to be because now they are this whole different person. You have like this child now in front of you who is fun sometimes, but also a lot of naughty. And, it is a grief for the loss of your parent. It is like they died already and they are this new, different kind of person. But, there is no funeral”

The ambiguity of the loss combined with sadness continue with the gradual dissolution of the emotional attachment. The average lifespan for PWA is an estimated 8-10 years and the grieving takes a toll (Alzheimer’s Association, 2017). The changes in societal social supports and increased sense of isolation combined with the fact that rugged individualism remains consistent in the United States, made grieving feel like a long, lonely journey for many of the participants.
Sibling Connections

The relational connection and process of support amongst siblings was discussed in all of the interviews, however the narrative was varied. Even amongst the sibling relationships which were positive, participants struggled with how to communicate on a topic that they had never faced together previously; that of how to care for their now vulnerable parent. Forced into the role of caregiver had created enough strain that four of the participants had ceased contact altogether with their siblings and they questioned if the wedge between them was repairable. Geographic distance and limitations, in some of the circumstances, forced caregivers into their unforeseen role of caring for their parent because they simply lived closest “But, caregiving has really changed. My brothers moved away. People are spreading out and the care is changing” as stated by a son caring for his father. Some respondents gathered with their siblings to decide who would take over the care and others just “fell into the role” as the main caregiver.

That was the hard part and then I finally realized, I kind of was upset with my siblings because they didn't come in and help. I mean, they see what we go through or it's like they don't want to see it, more like they don't want to see what's going on. I kind of realized that, kind of tell myself, "If they're not there in the beginning, they'll never be there." I just came to terms with that. I just kind of put all that aside and I don't think about that no more

Conversely, some sibling dyads found that although they may have different ways of interacting with their parent, they came to consensus and discovered ways to make decisions together as reiterated by one adult daughter, “I knew my sister and I would be the [...] We're it. We are going to have to make the decisions for her.” For numerous siblings who lived in the same area, the teamwork was easier.
Obviously, we’re a team in this now. We really work together well on things. We share the duties of what has to be done as far as taking her to the grocery store and doing some things around the house right now that have needed to be done […] so we’ve really tried to divvy those things out. And we text a lot and say, “Hey, I’m going over there today”

In contrast, during the later stages the decision regarding caregiving, in one sibling group, fell to the adult child who could manage the physical care as related by a 47-year-old,

*Then when you stand him up, we always got to be around him, holding on to him or something. Walking him, we have to be behind him and holding him up and stuff. It takes physical work. I think only my brother and I can do that. My sisters, well, he’s kind of a little too heavy for them*

Other sibling dyads with a parent in the later stages found that shared decision making eased coming to terms with their parent’s needs as this 50-year-old conveyed,

*But my sister and I both realized several months ago that it was time to go to that next step. But we want to keep her in her home as long as possible, so that’s why we did find somebody who was interested in moving in and caring for her. Luckily, we are lucky in that my mom has no physical medical issues.*

The relationships between siblings was varied and could be reflective of past attachments, but was emotionally significant for each of them in the ways the relationship was helpful or unhelpful. This points to a possible area of further research considering the long-term care trajectory for PWA and how siblings can help or hinder one another during the care.
Financial Strains

Alzheimer’s medical care, bills, and related household costs were a prominent concern for respondents. The question for many became how to pay their parents bills, while maintaining their own employment. Some explained it as feeling “outside the bounds” of manageable. Respondents described that the coverage provided by federal insurance was meager and failed to live up to the actual needs of their mother or father. While some had their college degrees, others worked jobs that made it questionable if paying for a private caregiver was hardly worth it or possible. One daughter explains,

And I had to come in and just ... Oh, it's terrible. I have to take care of his insurance, and his Medicare, and his retirement, and his, I mean, everything. So not just my own household, but my father's, too. And right, wrong, or indifferent, you just have to do it. Of course, financially because you're going to have to have somebody there all of the time, at least two people I'd say switching off, then more if you can be switching out. Start preparing financially because it's going to take a toll financially. Start getting things ready

A 50-year-old participant remarked that the financial negotiation with their parent brought up anger, despite their desire to be of help and concern for their parent.

I don't want to take anything away from him, but I've had to strip everything away from him at the same time. Take away his money, take away his credit cards, take away his cars, take away everything because he couldn't handle it”.

The long disease process creates additional care needs with the passing of time and increased monetary help as explained by one daughter. “But it just breaks my heart knowing that he
worked so hard for this life and his retirement and he did enjoy it for a while, but then the disease [...]”.

The respondents faced a variety of financial concerns, which some described as their parents making “too much money” for Medicaid or the need to “spend down assets” to obtain the care required. Three of the adult children opted to leave the workforce citing the difficulty obtaining time off work, cost of care, and the unpredictable situations they faced as explained by one daughter,

“I think if I could work part-time, it would be a good balance for me, but there’s times I get called in the middle of the night, I’ve got to go to the hospital. I’ve got to go. I spent all night in the hospital. And then there’s all the after care. You’re taking him to the private care doctor. I mean, it goes on and on and on and on and on. It does.”

For those respondents in the earlier stages of the disease process, the financial concern became the impending cost for institutional care as this daughter describes,

“I think there will come a time when we realize, okay, she can’t be at home anymore. I don’t know what that looks like, ’cause that’s expensive. I don’t know what that looks like in the future. I do think it’s a shame that to find care is just such a huge financial burden. For some families there is, of course, Medicaid and everything, but it’s hard. You don’t know what it looks like financially. A lot of times, you end up selling the house, and ... My mom always wanted my sister and I to inherit the house

As the narratives demonstrated, the circumstances of caring for a parent with Alzheimer’s Disease required financial negotiation and management, along with anticipation of cost involved
in future care with disease progression. Many of said they hoped to just get by with the resources their parent has accumulated to pay for care.

**Reorganizing**

The third segment, *Reorganizing*, details resilience and adaptation among participants to the long-term challenges of caregiving. One unexpected finding delineates the process of emotional adjustment, and the resulting emergence of resilience as their parent’s disease progressed. The caregiving burden changed from that of noticing and coping with the emotional disconnection at the beginning of the disease trajectory to managing the day to day changes in their parent “one step at a time” near the middle stages. Most participants explored and referred to how they started to look at the disease differently, developed methods for self-care, and found ways to mine personal resilience for the road ahead. Some respondents related discovering “untapped strengths” and found they coped better than ever expected in the face of their parent’s unpredictable decline. They developed their own methods for reorganizing their life around their role as caregiver. In describing their adjustment, one adult daughter related “it gets easier, not better” with disease progression.

**Caring for Self**

The participants universally conveyed the significance of self-care. To be able to continue the caregiving journey, they worked on finding ways to recover, adjust, and then return to the caregiving tasks. Caregivers expressed the realization that need for self-care took on greater importance as the caregiving duties increased. One participant describes,

*I think the first thing, and I didn’t do this very well, and it's very true, is you have to take care of yourself. It's very hard to do, but when we get tired and worn out, hungry, all of that, you can't care for someone. Alzheimer's is a very unpredictable disease. It's a*
physical demand. I physically have to lift him sometimes. You have to take care of
yourself.

Finding relief and rest required on-going self-awareness among participants. Self-care, as a
positive coping technique, was identified by this 38-year-old participant,

*It is adequate sleep, it is takin’ time out for myself. If I want to binge on Netflix show for
an afternoon I will do that. Yoga is a big help. Not relaxation yoga, but power yoga. You
are getting aggression out and grounding yourself. If I am feeling really bad for more
than a few days, I will go to the doctor*

An adult daughter relates that she tries to step back and recall what her mother would
recommend if her mental faculties were intact and she repeats these to herself sharing “*My mom
would say take a break. Live your own life. Live your life. I know my mom would want me to*”.

**Revealing resilience and gaining insight**

Participants identified strengths that they did not know they possessed prior to their
parent’s disease onset. Finding, identifying, and recalling the strengths seemed easier in the
middle stages of AD among respondents. Some indicated that they gained deeper introspection
about themselves. For example, one daughter describes,

*Oh, yeah. It’s made me so emotionally strong. It’s hard, but it’s made me so much
stronger. Capable. And I guess it’s giving me self-esteem. It’s told me that you are
capable, you can handle this. In other situations, it’s just kind of ... It’s allowed me to go
into other situations and know that I could handle it and be strong*

One daughter commented on how becoming her father’s caregiver changed her
perspective about how to motivate herself,
I just changed the way I looked at it. And now, if there is something I do not want to do that I have to do, I reward myself. I think about the positive instead of the things I do not want do. You do become a stronger person because of this...

Some participants explained that their resilience and stamina came as “a sense of duty, love, respect, and faith”. One 45-year-old related that the sense of duty has created resilience, patience, and compassion for others

This has really taught me a lot of patience and that's what I needed. I think it's like really, before I started, it was all about me. Me, me, what am I going to do? Then this has really taught me. Looking back at it, I'm like, "This is just patience." It took me out of that person that wants stuff like this and it's like, "You just got to wait and be patient and put yourself aside and focus on something else." It's like a service, like I joined a service, like a duty or something

Resilience provided valuable insight as one son describes,

You can't look at everything else that's going around outside of you. You just have to focus in on this and do this one job. Just have some compassion. I think that's what this thing has taught me is compassion. It's like, you really put yourself in his shoes to see how he's seeing it and how he's feeling and stuff

One 57-year-old respondent said his strength came from viewing it as an honorable duty akin to serving in the military,

I mean I view it as like an honorable duty or something because I see what's going on. You see it around town and stuff. It's funny because I always think that nobody prepares for this, but it's going to happen to maybe 90 to 95 percent of the people. Eventually,
they're going to be taking care of a parent or a loved one. "I'm thinking you need to prepare for this. It's going to happen. It's coming. You can't get around it"

The respondents whose parent had passed said that they would not trade the experience because of what it taught them about their own strength in times of darkness.

*Developing high-quality connections with others*

One of the resonating narratives among caregivers was that social support took on “greater significance”, increased their resilience, and their ability to reframe their situation. Connecting with others decreased loneliness. These connections took many different forms from online supports, help from faith-based groups that offered concrete help, and quality in-person connections with family members. The younger adult children identified the use of technology to find the support they needed outside of their rural community through creation of their own online support groups. A daughter describes how she connected with others,

*Well, I have reached out to this online forum on Alzheimer’s Disease websites between other adult children whose parent was diagnosed at an early age to try to chat with other adult children. And so, I started this Facebook group with a few other the other younger women. So, we have grown a lot since then and now there are like two hundred women. I set it up because initially I felt so alone. You know, it is just so lonely...*

Finding someone who can support and listen offers welcome relief as stated by this son whose mother had passed away recently,

*That is one of the best things I could ever recommend. Because not everybody has loved ones and family, and stuff like that, they need somebody that they can sit and just talk*
about the weather or what’s going on today, or just whatever. Don't even have to talk about Alzheimer’s. They talk about that enough!

Recalling that they were not alone and shared camaraderie decreases isolation as cited by a 58-year-old caregiver,

Connecting with others, learning, finding a partner for support, siblings. Because not only are you when you're dealing with the Alzheimer's- you're actually dealing with the person who has it. I think you get your strength from your family. I think you really need to put that in perspective when you're down in the dumps because so is your family.

So is my brother. Everybody's feeling this and you kind of got to hold each other up

As related by a female participant about how sharing with others and her own experience has increased her sense of empathy

I guess like with any trauma or traumatic situation, you build empathy for other people who have gone through the same thing or are going through the same thing. I think we all, over the years, heard "sandwich generation", but you don't really get what that means until you're the one in the middle of the sandwich.

Social support, as a resource, can aid caregivers in normalizing and coping with their situation.

**Easier, not better**

The journey is challenging with unpredictable twists, but those in the later stages unanimously thought emotional distress decreased with time. A daughter reiterates,

Well, it is difficult. It gets easier, not better. That has been my motto throughout the whole thing. She was diagnosed in 2014 and back then she was actually more dependent
on me for mostly things like socialization, making sure she was having a good time, being stimulated, and she would be very upset when I would leave her, almost like a child, I would say.

One adult daughter relates that the information overload at the beginning made it challenging.

Or it could be because I knew nothing about Alzheimer’s before my mom was diagnosed. And then once she was diagnosed and I was going throughout the process of settling and taking care of her, selling her house, not one single professional knew exactly what to do. You know, it was just a rigmarole of going through the process of finding an elder care social worker. And then by the time it was done, I was like an expert in how to understand social security disability.

The reports from participants about the feeling of loss dissipating seemed to alleviate emotional strain. Some of the respondents viewed the later stages as an opportunity for them to build a connection that was not there previously. “The care is changing. It was really, for me, a second chance at developing a relationship with my dad. I had to form something that wasn’t there in the past with my dad”.

Summary

Chapter 5 has offered the descriptions of the themes and narratives among adult children caring for their parent with AD in this research. It demonstrated their variety of experiences based on the parent’s stage in the disease, sense of emotional loss, influences of attachment prior to AD, and how use social connection. Most of the children were surprised as the disease progressed that they had a variety of increased demands to negotiate to include finances and assets.
Participants detailed the unrelenting emotional loss AD has caused and the desire to share old memories together with their parent, but that the opportunity to talk about these had vanished. The daily changes and losses were uncertain and ambiguous. The participants described the many nonsensical, meaningless actions of their parent when entering later stages of AD, however all of the adult children maintained the idea of their parent as a “significant figure” in their lives despite their parent’s loss of self. Each of the adult children, in some sense, strived to share the experience of Alzheimer’s Disease with their parent, all the while bearing witness to the daily struggles of disease progression. Some of the adult children treasured their parents laugh or moments when their parent had some lucidity. Making sense and meaning of their role changes increased a sense of self-efficacy and resilience.

Negotiating the changes in their communication patterns with their siblings was mixed for the participants. Some participants were able to work together to forge new ways of relating and coordinating the necessary care for their parent, whereas in others the stress of their parent’s disease had caused a wedge in their relationship. Due to the fact that AD is unpredictable, the adult children questioned when or if they would have the necessary finances to cover in-home lay caregiving expenses. Moreover, some had adjusted their occupations or needed to work with their employer for more flexible scheduling.

As the adult children in the caregiving role redefined their role in their parents life, they made changes in the way they managed themselves and their connections with others. Some increased self-care strategies and others used social supports. Coping with the loss eases later during the disease trajectory as eloquently captured by one female respondent who said “it gets easier, not better”.
CHAPTER 6

Discussion and Practice Considerations

“When we are no longer able to change a situation, we are challenged to change ourselves.”
--Victor F. Frankel, Man’s Search for Meaning.

The purpose of this study was two-fold; (1). To explore the experience of ambiguous loss among adult children caring for their parent with Alzheimer’s Disease and (2). Examine resilience in the face of the caregiving journey for their parent. The significant findings that emerged in this study support the hypothesis. The initial realization that their parent was losing their mentation brought forth a variety of questions to include;

- What will Alzheimer’s Disease mean to me and how will it change my life?
- How will my relationship with my parent change?
- Will I be able to endure this journey?
- Will I be able to afford the care my mom or dad need to keep them safe?
- How will I deal with my parent’s behaviors and health?

Considering that there are 5.4 million individuals diagnosed with AD and the baby boomer population is burgeoning, the duties of caregiving often fall to their adult children. Over the course of many decades spanning the 1970’s to present, scientists continue to investigate and examine patterns of neurofibrillary tangles and plaques, transmitter deficits, and amyloid in abnormal locations of the brain which can attribute to Alzheimer’s Disease (AD), although progress to locate a definitive cure has not yet been isolated or identified. Long hours caring for their parent with little, if any, compensation, offer a glimpse of this hero’s journey.

In conducting this qualitative study, the thematic findings that emerged among participants included losing connection, negotiation, and reorganizing. The uniqueness of the
parent-child attachment versus other caregiving attachments requires a different clinical approach. The majority of research on caregiving involved spousal caregiving, therefore a lack of data on this topic peaked this researcher interest and desire to delve more deeply into how the adult children come to make sense or reconcile with the physical presence and emotional absence of their parent. Ambiguous loss theory provides a way framework for understanding the grief adult children face while caring for their parent. In the words of Pauline Boss, who established the term ambiguous loss, “Because of the incongruence between absence and presence, ambiguous loss is the most stressful kind of loss” (Boss, 2011, p. 15). The type of loss experienced by adult children caring for their parent with AD is much different than the type of grief from a natural or unexpected death. The loss of a parent to AD involves unrecognized grief caused by the gradually diminishing quality of interaction with their parent.

The findings of this study revealed difficulties related to the loss of emotional connection with their parent and resulting changes in their lifestyles, time management, boundaries with their parent, and coping. Although organizations such as the Alzheimer’s Association and the National Institutes on Aging have worked ceaselessly to identify treatments and biomarkers, AD has no known cure and the journey of the disease is long for families. Care for PWA, often absorbed by their adult children, involved feelings of a loss of connection with their parent an experienced in a myriad of ways during the entire disease process. This was followed by the theme negotiation of care, sibling relationships, and financial negotiation. Lastly, adult children began the process to reorganize their understanding of their “new” role in their parent’s lives relating that it gets easier, not better.
Losing connection

The loss of emotional connection with their parent at the beginning of disease created tension in their attachment to their parent, changes in communication, and feelings of loneliness. The participants in this study addressed specific concerns. At the beginning of the disease process, the adult children interviewed questioned if the changes in their parent could be the onset of memory loss. In the initial stages of the disease, their parent’s behavioral changes were cited as frequent forgetfulness of common information, repeating of words and confusion.
Although each parent had different changes, all of the adult children came to understand that something was amiss and their parent’s ability to manage. This was met with normal emotions such as denial and worry. When the behavioral changes started the adult children questioned how they will help their parent navigate these changes. Some adult children simultaneously worried about how they will maintain their lifestyles and their own livelihood when facing new responsibilities for their parent who is vulnerable. During the study, some of the adult children were living with their parent while caregiving, some had hired private caregiving help in the home for their mother or father while they worked, and some had their parent in institutional care prior to their parent’s death. Regardless of where their parent was living, they all discussed noticeable losses in their communication, emotional connection, and ability to count on their parent for support as they had in the past. For those that did not experience positive past attachment with their parent, they cited faith and a sense of duty as motivators for decision to care for their parent.

The strain shortly after the realization that they parent had AD, was described by CG as one of the most challenging parts. Determining how to set boundaries for their parent’s safety with activities such as driving, financial management, household cooking, and other activities of
daily living was difficult for both of them. The role changes persisted and most found a way to work with the changes as time moved forward.

**Negotiation**

Emotional loss for the participants was related as unrelenting. This research shows that the loss resonated differently among respondents, depending on the stage of their parent’s AD and the attachment prior to the disease. As would be expected, their reactions to the loss were not uniform in nature because of the historical factors of the relationship. For example, those participants who did not consider their pre-AD attachment with their parent as strong, verbalized that it was not the emotional loss but rather the instrumental care needs which caused strain. In this study, the loss of emotional attachment was more prominent in the beginning and participants related that it eased with the adjustment during the middle and later stages. Feelings of sadness at the outset are more intense and described by a participant as a “roller coaster of emotions”.

All of the adult children in this study had at least one sibling and their experiences with their sibling covered the entire spectrum of connections. While five of the adult children felt that they were effectively working with their sibling on strategies to help their parent, the remainder had a variety of concerns. Some expressed anger that they were the ones left providing the majority of care and two of the adult children had ceased contact with their sibling because their sibling was unwilling or unable to help. Although their attachments and responses were different, the sense of connection and the desire to share the care burden during disease progression was paramount. With their parent no longer present emotionally, those with a positive sibling connection viewed the relationship as a way to teamwork for their parent’s care needs, and as someone to offer support.
Financial worries were at the forefront of concerns for adult children caring for their parent. The question becomes, for some, how they can manage their jobs, obtain the care needed for their parent, and provide the best support to their parent over quite a long period of time. Add to this situation, the knowledge that the average social security payment will not cover private in-home care expenses, some tried to determine how to manage assets and spend down savings to qualify for state Medicaid benefits. With lack of federal programs to offer respite to caregivers under the auspices of Medicare, the onus falls on families creating strains for the PWA and their children. A few of the respondents mentioned that they had promised their parent they would not place them into institutional care and were concerned that the cost of in-home private care would be prohibitive.

Reorganizing

The theme reorganizing represents the participant’s resourcefulness in the face the uncertainty surrounding Alzheimer’s Disease. They each cultivated resilience through a combination of methods which will be discussed and include caring for self, revealing their strengths, and developing quality connections. As their parent became less able to exercise their own autonomy, they described the duty as protection for their “parent who was vulnerable”. Some recounted how their parent was an “excellent” mother or father and that now was their turn to give back what was given to them.

With the lack of time because of job duties and family responsibilities, some CG found that self-care was pushed to the side, especially at the beginning of their parents disease process. Conversely, they said that this was one of the most important factors in creating their strength to endure. The respondents who had a parent in later disease stages, each described their self-care regimens which included yoga, time with friends, exercising, or allowing themselves to travel.
Out of the change and chaos, they all discussed surprising strengths they learned and acquired. The decision to face the reality that things were not going to go their way or the way they had hoped, created an opportunity to look at how they could adjust themselves to make the best of the unfortunate circumstance. Some discussed the realization that they could endure more than they thought possible, some discovered that they had patience they had never realized previously, and some mentioned that they now can do the things they thought they could not do before with greater sense of self-reliance. Some respondents were surprised at their ability to adapt with the loss of their emotional attachment.

The connections with other adult children or CG was helpful. They three younger adult children cited computer technology to engage in discussions forums, acquire educational information, and strategies to solve obstacles in care. Regardless of the differences in the 12 participant’s connections, it normalized their experiences of loss and change by sharing with other adult children in the same boat. Moreover, the connections with other adult children offered them ideas and resources for the instrumental care needs such as paid caregivers, nursing facility, and insurance options. I found that participants, regardless of their parent’s stage in AD, found talking with other caregivers and educational resources as helpful.

Participants whose parent was in the middle and later stages had faced, with some sense of honesty, the changed roles and that their tasks involved the “proper provision of needs” to their parent. While they did not deny that the tasks were challenging, they were described by the participants as different. More specifically, they were less emotionally distraught and more focused on what their mother or father needed physically. Respondents seemed to shift their focus to self-control and related internal adjustments they could make to accept the consistently changing dynamics with their parent.
Limitations

There are limitations of this qualitative study that should be considered when examining the results. Of these caregivers who offered to participate, just two were sons and the remainder were daughters caring for their parent. While noticeable differences in themes were not noted, an equal portion of sons and daughters may offer a greater balance in gender perspectives. Moreover, this research was conducted in a remote, rural area of the country, therefore this factor should be considered when examining the evidence as some of the resources available to caregivers may vary with population, cultural influences, and demographics. Future studies could address the effects of the parent’s gender on their perception of care and garner balance between the sons and daughters in the CG role, and additionally closely examine the influences of cultural implications on adult caregivers.

Clinical Implications

As uncovered through qualitative interviews and covered in the data analysis section, findings seem to indicate that developing a clinical model of support for caregivers at micro and macro levels offers the best benefit to their well-being and resilience. Social work practitioners may want to consider the following implications.

1. Provide additional social support near time of initial diagnosis to offer adult children knowledge of the disease process, identification of coping mechanisms, and opportunity to share information from other caregivers of PWA. Guidance and personalized support can act as a buffer against the strain of role adjustments and loss.

2. Community based support groups for adult children of PWA can directly help with their concerns while simultaneously providing a venue for caregivers to be vetted in relationships with other adult children from the beginning.
3. Establishing an assessment tool for use after their parent’s diagnosis, targeted at adult children in the caregiving role to determine their level of support, peer support from other caregivers, financial considerations, and caregiver burnout. The timeliness of the social work interventions and treatment appear paramount to facilitate better caregiving transitions over the continuum.

4. Personalized clinical interventions for the adult child, who are often maintaining their jobs and working full-time, may need to include increased use of computer technology by clinical social worker to ease access to services for those CG juggling many demands. Additionally, web-based supports could connect their parent’s medical provider via e-mail and other routes can ease worry and strain.

5. Social workers will better serve their clients through knowledge acquisition of elder resources at local and national levels. For example, knowledge of respite services for PWA can help families anticipate how to seek respite when the need arises to avoid burnout and burden. Addressing issues similar to this in clinical treatment prior to the adult child’s strain or caregiving burden can act as a protective and preventive mechanism prior to crisis.

6. Targeted social work interventions which help reframe their experiences and strategies to self-identify resilience to offer hope or ways to increase adaptive responses. For example, these could include aspects from the data analysis section such increased self-care or increased high quality connection to social supports.

7. Participants expressed the concern about financial expenses associated with their parent’s care, which points to the need for a federal safety net or program to help people facing AD and their family caregivers. Alzheimer’s Disease has an uncertain course, but clearly involves increased dependency as time progresses. Many of the caregivers were concerned
that if they were unable to maintain their job or their parent could not pay for care, it could plunge the family into additional stress or conflict. With the knowledge that the disease rates are predicted to increase, federal legislation to assist families with programs such as Medicare expansion for AD are paramount. Increased community support programs from non-profit and faith-based organizations that offer paid respite services targeted to AD could be particularly helpful, however they cannot shoulder all the burden and efforts need to be placed at federal policy levels. At present, the funding for respite care is non-existent, although if caregivers are at home 24/7 with their parent, being able to rely on respite seems like a humane strategy at both personal and societal levels.

8. Continue to increase aging and geriatric curriculum concentrations at Council of Social Work (CSWE) accredited schools. At present, according to CSWE there are 812 accredited schools, however a mere 57 schools report offering gerontology as a concentration. Curriculum could include increased practicum experiences with Alzheimer’s Disease patients and their families to better serve this burgeoning population of seniors and their caregivers who will benefit from clinical social work interventions. Considering the Alzheimer’s Association (2017) states that there is a new diagnosis of AD every 66 seconds, social workers are uniquely positioned in medical facilities and clinics to address the emotional aspects of the changing relationship between CG and adult child, caregiver strain, or psychoeducation programs to name a few.

**Future research recommendations**

With the knowledge that adult sons and daughters constitute a significant portion of CG and these numbers are expected to rise, research and development of social work interventions targeted to address the unique relationship of adult children who are CG for their parent with AD
is indicated. Research on clinical interventions could include information on social connections, expansion of computers supports, caregiver fatigue, and how social workers can implement programs for hands-on training for CG could be considered.

This qualitative research sample of respondents included two Native American Navajo participants who explained that they were helping their father due to their ability to provide physical care and this was associated with role expectations and boundaries within their cultural practices. Further research to examine differences, role expectations, and experiences of ambiguous loss among adult child caregivers of African American, Native American, Hispanic, and other cultural dissents could enhance social work service delivery.

Additionally, a common concern mentioned by most of the adult children in this study was a fear that they would experience Alzheimer’s Disease themselves as they age. With this as a common concern, expansion of medical research into genetic components is indicated and likewise social workers could research the emotional impact of genetic testing for Alzheimer’s Disease on adult children. Lastly, research is indicated to improve best social work service delivery practices for patients and families discharging from acute care medical facilities. Since most of the PWA will have a hospital stay during the disease trajectory, research could assist in determining optimal transitions of care back into the community through effective case management and supportive resource provision.

**Conclusion**

This research study investigated ambiguous loss and resiliency among adult children caring for their parent with Alzheimer’s Disease. The results confirmed that adult children experience grief and grapple with how to make sense of the emotional loss in their shared
relationship. As the caregivers adjust to the ramifications of the disease process, they described decreased anxiety and increased identification of self-support measures which eased caregiving strain. The participants addressed a desire to maintain the attachment with their parent their parent who was experiencing changes in mental faculties, despite the parent’s ability to communicate or connect. The nature of the parent-child relationship is different than that of a relationship with a spouse, therefore the clinical interventions need to be reflective of this fact. More specifically, a spouse may expect to take on the caregiving role for their partner, whereas the adult-child may understand they need to assist, although not for the intensity and eight to ten-year disease trajectory associated with Alzheimer’s Disease.

The adult children in this study changed their lifestyles, adjusted their relationships with their siblings, and worked to create safe, fiscally viable care plan for their parent. The access to support resources, such as support groups, is more limited in rural areas. The consideration of enhanced digital support through mainstream media could be helpful to adult children in rural locations. This research study points to the fact that adult-children caring for their parent would need resources and clinical intervention tailored to the unique type of loss associated with AD. This could include augmented support after initial diagnosis, increased education about external care resources, personalized treatment plans to cope with sense of loss, and further examination of methods to increase caregiver resiliency.

The fact is, because we have a brain we are at risk of developing Alzheimer’s Disease. This disease impacts many families. The question then becomes, how can we squelch the idea that our elders are a burden and increase the support to the PWA and their adult children in a larger societal context. As social workers or healthcare providers, we can look ahead and ponder how to better organize the care, address the sense of loss, offer affordable care options to adult
children who want to remain in the workforce, and increase policy to better address the inequities in care to our elderly.
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Appendix A: IRB Approval


08-Aug-2017

The above referenced protocol and was reviewed and approved using the expedited procedure set forth in 45 CFR 46.110, category 6,7, on 07-Aug-2017. This study will be due for continuing review on or before 06-Aug-2018.

Approval by the IRB does not necessarily constitute authorization to initiate the conduct of a human subject research study. Principal investigators are responsible for assuring final approval from other applicable school, department, center or institute review committee(s) or boards has been obtained. If any of these committees require changes to the IRB-approved protocol and informed consent/assent document(s), the changes must be submitted to and approved by the IRB prior to beginning the research study.

If this protocol involves cancer research with human subjects, biospecimens, or data, you may not begin the research until you have obtained approval or proof of exemption from the Cancer Center’s Clinical Trials Review and Monitoring Committee.

The documents submitted in the application noted below were approved:

- HS-ERA Application, Confirmation code: cefaigfd, Submitted: 08/07/2017

When enrolling subjects at a site covered by the University of Pennsylvania's IRB, a copy of the IRB approved informed consent form with the IRB approved from/to stamp must be used unless a waiver of written documentation of consent has been granted.

If you have any questions about the information in this letter, please contact the IRB administrative staff. Contact information is available at our website: http://www.upenn.edu/IRB/directory.

Thank you for your cooperation.

Sincerely,

IRB Administrator
Appendix B: Consent

Protocol Title: Ambiguous Loss in adult children providing care to their parent with Alzheimer’s Disease

Principal Investigator:

Emergency Contact:

Maria L. Balintona  4221 Cristo Rey Avenue Farmington, NM 87401  
505-793-2173

DSW Dissertation chair: Dr. Ram Cnaan 215-898-5523

APPENDIX B: UNIVERSITY OF PENNSYLVANIA

RESEARCH INFORMED CONSENT FORM

IRB Approval from 08-07-2017 to 08-06-2018

Why am I being asked to volunteer?

You are being asked to take part in a study on Ambiguous Loss among adult children in the caregiving role for their parent with Alzheimer’s Disease. You are being asked because you may be taking care of your parent with Alzheimer’s Disease.

Participation is voluntary. If you decide to participate or not participate there will be no loss of your benefits to which you are otherwise entitled.

This study is being conducted for a dissertation in social work.

Participation in this study involves a one-time 60-minute interview.
This is a voluntary study; you are free to refuse to answer any questions during the interview, to withdraw at any time, or discontinue participation.

You will receive a copy of this consent form and should ask any questions.

You will be asked to sign this form if consent is given.

If you do not understand what you are reading, do not sign it. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this paper and a copy will be given to you. You may ask to have this form read to you.

You are being invited to participate in a research study. Your participation is voluntary which means you can choose whether or not you want to participate. If you choose not to participate, there will be no loss of benefits to which you are otherwise entitled. Before you can make your decision, you will need to know what the study is about, the possible risks and benefits of being in this study, and what you will have to do in this study. The researcher is going to talk to you about the research study, and they will give you this consent form to read. You may also decide to discuss it with your family, friends, or others. If you decide to participate, you will be asked to sign this form.

What is the purpose of this research study?

The purpose of this study is to learn more about the experience of adult children providing care to their parent with Alzheimer’s Disease and the impact of ambiguous loss in the course of care.

This study is being conducted for a dissertation in social work. This interview will be a part of research conducted for a doctoral dissertation.

IRB Approval from 08-07-2017 to 08-06-2018

To gain a better understanding of what can help or hinder caregivers assisting their loved one with Alzheimer’s Disease a series of questions will be asked. The findings will be not report on individual responses, but rather on the similarity of the experiences of numerous adult caregivers.
The knowledge gained from this research study may help other caregivers.

How long will I be in the study? How many other people will be in the study?

You will be asked to engage in one 60-minute session.

The study will be completed over six months; however, your time involvement will be a one-time session.

There will be 12 people interviewed for the purposes of this study.

What am I being asked to do? You are being asked to participate in one 60 minutes’ session with a clinical social worker to examine the experience of ambiguous loss among adult children caring for their parent with Alzheimer’s Disease.

I will make an audiotaped recording of the interview and write notes while in session with you.

I will be asking you questions about your experience as a caregiver for your parent with Alzheimer’s Disease, how you have experienced change as the disease progresses, and your understanding of the emotional loss.

The interview will take place at the location of your choosing such as a quiet place or your location preference.

What are the possible risks or discomfort? There will be minimal risks involved in participating in this study. Risks of this study would be discomfort with expression of feelings. You will also be giving up 60 minutes of your personal time to participate in the study, therefore this may impinge upon your personal responsibilities.

If at any time you are uncomfortable, please let me know. You do not have to answer any questions that make you feel uncomfortable. I can also provide you names and numbers or agencies that can help.

What are the possible benefits of the study? There will be no benefit to you, however as a result of your participation you could enhance your understanding of ambiguous loss and resiliency among caregivers which
may benefit you indirectly. In future care, this may benefit other people who are caring for loved ones with Alzheimer’s Disease.

IRB Approval from 08-07-2017 to 08-06-2018

What other choices do I have if I do not participate? *You have the right not to participate in this study.*

**Will I be paid for being in this study?**

*You will be compensated $50.00 for completion of the interview session.*

**Will I have to pay for anything?**

*There is no cost associated with your participation, other than your time.*  
**What happens if I am injured from being in the study?**  
*If you should experience any injury or emotional distress, please contact the investigator at 505-793-2173*

**When is the study over? Can I leave the study before it ends?**

*The study will be over within six months of the start date.*

*If for some reason the researcher has an unforeseen issue, it may cause the research to be discontinued.*

*You can elect to leave the study at any time.*

This study is expected to end after all participants have completed the interview and all information has been collected. This study may also be stopped at any time by the researcher without your consent because:

The researcher feels it is necessary for your health or safety. Such an action would not require your consent, but you will be informed if such a decision is made and the reason for this decision.
If you decide to participate, you are free to leave the study at any time.

**Who can see or use my information? How will my personal information be protected?**

Every effort will be made to keep information obtained during this study confidential. The records will be kept confidential and any information collected through this research project that IRB Approval from 08-07-2017 to 08-06-2018 personally identifies you will not be released or disclosed without your separate consent, except as specifically required by law. Research records will be stored securely and only the researcher will have access to the records. Information you share and anything with your name on it, such as signed consent forms, will be stored in a locked file cabinet, in a different location than the audio recording and written transcripts and destroyed at completion of the study. The interview will be audio recorded, however the names and any identifying information will not be used while recording to keep names and any identifying information private. The digital recording will be destroyed after transcribed. Every precaution will be taken to secure your confidentiality.

**Who can I call with questions, complaints or if I’m concerned about my rights as a research subject?**

If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with the study investigator, Maria Balintona at mbalin@sp2.upenn.edu or 505-793-2173 as listed on page one of this form. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs
with any question, concerns or complaints at the University of Pennsylvania by calling (215) 898-2614.

When you sign this form, you are agreeing to take part in this research study. This means that you have read the consent form, your questions have been answered, and you have decided to volunteer. Your signature also means that you are permitting the University of Pennsylvania to use your personal information collected about you for research purposes within our institution. You are also allowing the University of Pennsylvania to disclose that personal information to outside organizations or people involved with the operations of this study.

A copy of this consent form will be given to you.

By signing this consent, I am agreeing that I am over 18 years of age and am agreeing to the terms of the informed consent and study requirements.

IRB Approval from 08-07-2017 to 08-06-2018

____________________________________ Name of Participant
(Please Print) Signature of Participant Date

IRB Approval from 08-07-2017 to 08-06-2018
Maria L. Balintona, R.N.
San Juan Regional Medical Center
801 West Maple Street
Farmington, New Mexico 87401

RE: Dissertation Research Plan – Ambiguous Loss and Resiliency in Adult Children Caregiving for Their Parent with Alzheimer’s Disease

Dear Ms. Balintona:

This is to inform you that on August 15, 2017, Dr. Carletta Thompson, Chair of the Institutional Review Board (IRB) of San Juan Regional Medical Center, in compliance with the Federal Wide Assurance as negotiated with the Office of Human Research Protection (OHRP) conducted EXPEDITED Review and APPROVAL of the above referenced project, data collection instrument and informed consent document.

- It was noted that the University of Pennsylvania IRB has also approved this project (via expedited review- dated Aug 8, 2017) and that their approved consent document will be utilized.

- It was also noted that NO recruitment will occur at our institution – San Juan Regional Medical Center.

- Approved the project for a one year period, noting that data collection is now being planned to begin in August 2017 and shall be complete within a year.

As per our Policies and Procedures based on Federal guidelines, you are required as Principal Investigator to:

1. Submit all correspondence regarding the protocol to the IRB.

2. Submit any protocol/consent form revisions to the IRB for approval prior to implementation. Changes necessary to eliminate apparent immediate hazards to subjects in an approved protocol may be implemented prior to IRB approval.

3. Report ALL serious adverse events/deaths according to the IRB guidelines.

4. Your periodic review is due by August 1, 2018.

5. Submit a final report to our IRB within 30 days of the study’s completion.

Sincerely,

Carletta Thompson, M.D.
Chair, Institutional Review Board

CT/bp

Our Mission: To personalize health care and create enthusiasm and vitality in healing.
## Demographic Tables

### Demographics: Face-Sheet Data

Name ________________________________

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<table>
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</table>
Appendix C: Semi-structured Interview Questions

This study will explore the lived experiences of loss and resiliency among adult children caring for their parent with Alzheimer’s Disease.

Interview questions

This specific study and questions aim to explore the experience of how adult caregivers over the age of 18 perceive caregiving, loss, and resiliency when caring for their parent with Alzheimer’s Disease. How do they experience caregiving? How has their role changed and their experience of loss along the disease trajectory? How would they describe their resiliency in coping with the many demands?

Caregiving for AD parent

- Can you tell me about being a caregiver for your parent with AD?
- Can you describe your involvement with care and what a typical day is like for you now?
- Can you tell me about any progression in care needs and your role?
- How has your family managed caregiving roles?
- If you were talking with someone about caregiving for your parent with AD, how would you describe the care and what would you want them to know?
  *Probe*: has caregiving caused any changes in other relationships?
  a. Tell me more about your experience you mentioned…
  b. Can you clarify your role, experience or provide an example?

Coping with caregiving and resilience

- What has been the challenging part of caring for a parent with AD?
- Tell me about times of strength or resilience on your part while caregiving?
- In what ways has caregiving for your parent changed you and your view of yourself?
- How has your attachment with your parent changed?
  *Probe:*
  a. If you could change something in regards to the caregiving experience, what would it be?
  b. Can you explain ______ in greater detail?
  c. How have you responded to your feelings?

Future

- If there anything else about caregiving for your parent that you would like to share or that I have not yet asked?
- What would you like to tell other adult children in the midst of caring for their parent with AD?
Appendix D: Invitation to participate

Your Participation is Requested in a Study to explore Ambiguous Loss and Resiliency among Adult Children Providing Care to their Parent with Alzheimer’s Disease

Who: Adult children who are providing care to their parent with Alzheimer’s, are over age 18, have been providing care for greater than 6 months and are willing to participate in this study.

When: August 2017 through January 2017

What: This study is looking to improve understanding of ambiguous loss among adult children providing care to their parent who has Alzheimer’s Disease.

Where: The study will take place at the location of your choice following the pre-screening interview.

Why? To find ways to help other adult children better understand their own responses and enhance care delivery. With the increasing number of people experiencing Alzheimer’s Disease, it is helpful to gather a better understanding of this experience.

You will be compensated $50.00 for completion of your interview. These compensations will be provided if you complete the study interview.

If you are interested in learning more about this opportunity or you would like to participate, please contact Maria L. Balintona, MSW, LCSW at 505-793-2173.
### Appendix E: Code Tables

<table>
<thead>
<tr>
<th>Theme</th>
<th>Codes</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Losing Connection</strong></td>
<td><strong>Recognizing Change</strong></td>
<td>Participants explained the initial realization that their parent had concerning behaviors that signaled change in mental capacity. Ex: “Repeat a story, repeat a question, repeat ... And you just have to get used to that, and you just listen to the same thing over and over” OR “but all of a sudden, he just couldn’t understand it, comprehend stuff”</td>
</tr>
<tr>
<td><strong>Reversing Roles</strong></td>
<td><strong>Recognizing Change</strong></td>
<td>Participants expressed skepticism about their parent’s ability to remain safe, their driving, and decision making. Realization that they will be taking over as caregiver. Ex: “‘So now in the relationship, I am more the parent role. Or the parent role. I feed him’” OR “And I’m having to take my mom’s keys away from her as she probably would have had to do when I was 16”</td>
</tr>
<tr>
<td><strong>Negotiation</strong></td>
<td><strong>Emotional Loss</strong></td>
<td></td>
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<td>---------------------------------</td>
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<td></td>
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<tr>
<td><strong>Sibling Connections</strong></td>
<td>Experiences relating with siblings were varied, however addressed among participants as a central issue</td>
<td></td>
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<tr>
<td></td>
<td>“Obviously, we're a team in this now. We really work together well on things”.</td>
<td></td>
</tr>
<tr>
<td><strong>Financial Negotiation</strong></td>
<td>Participants explained how the financial aspects of care and paying for the care their parent need was utmost on their minds. <strong>Start preparing financially because it's going to take a toll financially. Start getting things ready.</strong></td>
<td></td>
</tr>
<tr>
<td>Reorganizing</td>
<td>Caring for yourself</td>
<td>Respondents stated that self-care became an increasing important component to sustain care for their parent and created strength. Ex: “I think the first thing, and I didn't do this very well, and it's very true, is you have to take care of yourself.”</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>It gets easier, not better</td>
<td>Taking care of their parent was described as more emotionally difficult in the beginning because of boundary changes, adjustments in communication, and emotional attachment.</td>
<td></td>
</tr>
<tr>
<td>Connecting with others</td>
<td>Use of medical providers, counseling, home health for parent, assisted living, nursing home, and on-line support groups were described as important resources. Ex: “Connecting with others, learning, finding a partner for support, siblings”. OR “That is one of the best things I could ever recommend”</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX F: CITI Report

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)
COMPLETION REPORT - PART 2 OF 2
COURSEWORK TRANSCRIPT**

** NOTE: Scores on the Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores in the time all requirements for the course were met.

- Name: Marla Ballatore (ID: 5775209)
- Email: mbain@ps2.upenn.edu
- Institution Affiliation: University of Pennsylvania (ID: 849)
- Institution Unit: School of Social Work and Policy
- Phone: 555-753-2173

- Curriculum Group: Human Research
- Course Learner Group: Social/Behavioral Research Course
- Stage: Stage 1 - Basic Course
- Description: Choose this group to satisfy CITI training requirements for investigators and staff involved primarily in Social/Behavioral research with human subjects.

- Report ID: 207728264
- Report Date: 01-Oct-2016
- Current Score*: 97

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES

<table>
<thead>
<tr>
<th>Module</th>
<th>Most Recent</th>
<th>Score</th>
</tr>
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<tbody>
<tr>
<td>Students in Research (ID: 1321)</td>
<td>20-Sep-2016</td>
<td>55 (100%)</td>
</tr>
<tr>
<td>History and Ethical Principles - SSE (ID: 480)</td>
<td>50-Sep-2016</td>
<td>55 (100%)</td>
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<tr>
<td>Defining Research with Human Subjects - SSE (ID: 491)</td>
<td>30-Sep-2016</td>
<td>55 (100%)</td>
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<tr>
<td>Belief Report and CITI Course Introduction (ID: 1127)</td>
<td>19-Sep-2016</td>
<td>55 (100%)</td>
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<tr>
<td>The Federal Regulations - SSE (ID: 500)</td>
<td>30-Sep-2016</td>
<td>55 (100%)</td>
</tr>
<tr>
<td>Assessing Risk - SSE (ID: 500)</td>
<td>30-Sep-2016</td>
<td>55 (100%)</td>
</tr>
<tr>
<td>Informed Consent - SSE (ID: 554)</td>
<td>30-Sep-2016</td>
<td>55 (100%)</td>
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<tr>
<td>Privacy and Confidentiality - SSE (ID: 505)</td>
<td>30-Sep-2016</td>
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<tr>
<td>Research with Children - SSE (ID: 507)</td>
<td>30-Sep-2016</td>
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<tr>
<td>Research in Public Elementary and Secondary Schools - SSE (ID: 508)</td>
<td>30-Sep-2016</td>
<td>55 (100%)</td>
</tr>
<tr>
<td>International Research - SSE (ID: 606)</td>
<td>01-Oct-2016</td>
<td>55 (100%)</td>
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<tr>
<td>Internet-Based Research - SSE (ID: 610)</td>
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<tr>
<td>Research and HIPAA Privacy Protections (ID: 14)</td>
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<tr>
<td>Vulnerable Subjects - Research Involving Workers/Employees (ID: 483)</td>
<td>01-Oct-2016</td>
<td>55 (100%)</td>
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<td>Conflicts of Interest in Research Involving Human Subjects (ID: 484)</td>
<td>01-Oct-2016</td>
<td>35 (90%)</td>
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<tr>
<td>University of Pennsylvania (ID: 1097)</td>
<td>19-Sep-2016</td>
<td>No Quiz</td>
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For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing Institution identified above or have been a paid independent learner.

Verify at: https://www.citiprogram.org/verify/727176a17-7f6b-44f4-8000-9990015a9009

Collaborative Institutional Training Initiative (CITI Program)
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Phone: 888-529-5929
Web: https://www.citiprogram.org