THE CAREGIVING EXPERIENCES OF ADULT CHILDREN WHO WERE PRIMARY CAREGIVERS TO A PARENT WITH DEMENTIA: A PHENOMENOLOGICAL STUDY

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A PHENOMENOLOGICAL STUDY: THE CAREGIVING EXPERIENCES OF ADULT CHILDREN WHO WERE PRIMARY CAREGIVERS TO A PARENT WITH DEMENTIA (293 pp.)

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The purpose of this descriptive phenomenological study was to explore the experiences of adult children who were primary caregivers to a parent diagnosed with dementia. Descriptive phenomenology was chosen as the research method to describe and illuminate the lived experiences of dementia caregiving. Eight co-researchers were recruited from Northeast Ohio through online and on-site advertisements. The following research question guided this study: What were the lived experiences of adult children who were primary caregivers to a parent with dementia? Two face-to-face, semi-structured interviews were utilized to collect data. During these interviews, the co-researchers were asked questions regarding their experiences as adult children who were caregivers to a parent with dementia.

Data analysis was conducted using Colaizzi's (1978) descriptive phenomenology method. Additionally, NVivo, a qualitative data analysis computer program, was used to organize the data. Five themes emerged from the data analysis consisting of prominent caregiving roles in the co-researchers' primary caregiving careers: (a) advocate/protector, (b) liaison, (c) decision-maker, (d) direct care provider for ADLs, and (e) mourner/griever.

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CHAPTER I

INTRODUCTION TO THE STUDY AND REVIEW OF THE LITERATURE

Throughout history, humanity has asked and answered questions on how to care for their ailing elderly. Scientists estimate that caregiving for the aged has been part of the human experience since the Middle Pleistocene period approximately 500,000 years ago (Bonmati et al., 2010). The earliest example of caregiving may be of an elderly Homo heidelbergensis male, a species of a human before the Neanderthal. The man, whom the archeologists nicknamed "Elvis," had a bone disorder that would have made ambulation and carrying objects difficult. Bonmati et al. (2010) speculated that "Elvis" could not have survived into old age without having others hunt and gather his food. The ancestors of modern man may have been the first caregivers, but perhaps no time in history has elderly caregiving been more prevalent or demanding than the present.

Before the 20th century, most individuals did not survive to old age, and time caring for a loved one was usually short, with death coming quickly due to a communicable disease or acute medical issue (LoboPrabhu, Molanari, & Lomax, 2006). The development of antibiotics, immunizations, and medications to postpone or minimize the deleterious effects of chronic conditions (e.g., hypertension, hyperlipidemia, and diabetes) combined with public health initiatives such as safe drinking water, sanitation, and wellness programs have increased life expectancy (Villeponteau, 2014). In 1900, the life expectancies of men and women in the United States were approximately 46 and 48 years, respectively, whereas their 2013 counterparts had a life expectancy of 76 years and

82 years, respectively (Oxlade, 2014). The majority of individuals in industrialized nations will survive to be 65 years or older, and with advancing age comes the increased possibility of age-related disease and disability. Furthermore, due to medical advances, individuals are living longer after the onset of illness, resulting in a substantial increase in the length of the caregiving career (LoboPrabhu et al., 2006). One of the most challenging and demanding caregiving experiences may be supporting a loved one with the primarily age-associated disease of dementia.

Every 65 seconds, an individual is diagnosed with dementia in the United States (Alzheimer's Association, 2019). The World Health Organization estimates that 50 million people worldwide have dementia, with 10 million new cases expected yearly (World Health Organization, 2019). A crucial source of support and care for these individuals is family caregivers. Per the Alzheimer's Association (2019), unpaid caregivers in 2018, which included family and friends, provided 18.5 billion hours of informal (unpaid) care to people with dementia per year, which translates into approximately $234 billion worth of services. To put the economic value of informal caregiving into perspective, this is little less than 11 times the yearly revenue of the fast-food giant McDonalds in 2019 (21 billion; McDonald's Corporation, 2019). The Facts and Findings Report of the Alzheimer's Association (2019), reported that over half of those with the most responsibility in caregiving for an individual diagnosed with dementia are their children. Although there is a vast amount of research on dementia caregiving, a lack of research exists addressing the caregiver's journey from inception to completion.

Research Question

The guiding research question of the current study was: What are the lived experiences of adult children who are primary caregivers to a parent with dementia?

Purpose and Rationale

The purpose of this qualitative study was to learn about the experiences of adult children who were primary caregivers to a parent diagnosed with dementia and the meaning they ascribe to those experiences in a post-caring time. Millions of adult children undertake the arduous role of caregiver for a parent with dementia; however, their experiences throughout the caring process are neglected in the literature. The preponderance of published studies has examined being a caregiver concurrent with the caregiving experience. This research focuses on exploring the recalled experiences of a caregiver when their primary caregiving tasks have concluded (e.g., the death of the care recipient or the role of primary caregiver has been assumed by another).

The purpose of focusing on post-caregiving was to capture the caregiver's experiences after a period of possible self-reflection and to uncover persistent meanings and themes ascribed to these experiences over time. By understanding the past lived experiences and the meaning that adult children attribute to caring for a parent with dementia, orientation programs to caregiving and supportive counseling programs for caregivers may be developed, both active and post-caregiving.

Researchers in the disciplines of gerontology, medicine, nursing, social work, and sociology have conducted the majority of studies investigating caregiving. I searched for studies published in the counseling journals of *Adultspan Journal (*1999-present) and the *Journal of Counseling & Development* (1984-present) using the keywords of dementia, Alzheimer's disease, caregiving, and caregivers in the EBSCO database. The *Adultspan Journal* had three articles addressing the needs of dementia caregivers, whereas the *Journal of Counseling & Development* had one article related to the keywords.

The lack of caregiving studies in these two counseling journals was unexpected considering research conducted by other disciplines has found counseling to be an effective intervention for decreasing the stress of caregiving (Elvish, Cawley, & Keady, 2013; Elvish, Lever, Johnstone, Cawley, & Keady, 2012; Luchetti et al., 2009; Sorensen, Pinquart, & Duberstein, 2002). Also, caregiver counseling has been a factor in delaying nursing home placement and assisting caregivers during the transition of a loved one into nursing home care (Gaugler, Reese, & Mittleman, 2013; Gaugler, Roth, Haley, & Mittleman, 2008).

The current study will add to the literature on the experiences of adult children caring for a parent with dementia. It may also assist clinicians in treatment planning for caregivers throughout the continuum of their caregiving careers. Moreover, understanding the adult child's experiences may encourage additional interest and research into elderly caregiving from a counseling perspective.

Review of the Literature

A review of the literature offers an expansive and general overview of the relevant theories and scholarly knowledge on the topics of dementia and adult children caring for a parent with dementia. The literature review begins with the history of dementia followed by the types of dementia or neurocognitive impairments as defined by the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association 2013). Because Alzheimer's disease, dementia with Lewy bodies, and vascular dementia combined comprise up to 80% of dementia cases, a more thorough overview of these subtypes was undertaken, including symptomology and characteristics of disease progression (Rowland, Pedley, & Merritt, 2016). The literature review continues with exploration and critique of the literature on adult children who are caregivers to a parent with dementia, including theoretical frameworks used in caregiver studies and prominent themes presented in the dementia caregiver research.

The History of Dementia

Dementia, with the Latin root word of *men,* meaning mind, and *de*, meaning without, has a literal translation of "without mind." Scholars have debated the first use of the term dementia. Some researchers credit Philippe Pinel (1745-1826), the father of psychiatry, with coining the term dementia in 1797; however, others report it was Aulus Celsus (AD 14-37), a Roman physician, in the first century AD (Hughes, Louw, & Sabat, 2006). Boller and Forbes (1998) contended dementia or the French equivalent, *demence*, was first used in 1381. Perhaps a possible explanation for the multiple dates of origin may be attributed to the evolution of the term dementia.

Before the nineteenth century, dementia was a generic term for insanity with reversible symptoms of cognitive impairment and psychosis unrelated to aging (Berrios, 1996). During the nineteenth century, Esquirol, a student of Pinel's, developed a taxonomy of mental disorders that clarified the meaning and subtypes of dementia (Berchtold & Cotman, 1998). Esquirol's classification system and the advances in recognizing the pathology in the brain, particularly cerebral atrophy, led to the medical use of dementia (Qizilbash et al., 2008). It is unknown when or who coined the term dementia; nevertheless, philosophers identified the connection between advanced age and memory loss in antiquity.

Greco-Roman period. The percentage of adults in Ancient Rome or Greece who survived to old age is unknown; however, reaching old age may not have been an extreme rarity due to the attention it received by philosophers and physicians. Pythagoras, Aristotle, Plato, Hippocrates, and Cicero identified, described, and hypothesized about cognitive and behavioral changes in the elderly (Feldman, 2007). Aristotle and the majority of his contemporaries acknowledged the cognitive decline in the geriatric population but did not seek its etiology because they assumed dotage (a second childhood) was an unavoidable consequence of aging (Berchtold & Cotman, 1998). Cicero, the Roman philosopher and statesman, disagreed that dementia was a by-product of old age and asserted that aging, combined with a weak will, was responsible for cognitive impairment in the geriatric population (Berchtold & Cotman, 1998).

Furthermore, Cicero suggested that individuals prevent or delay "senile debility" by actively engaging in intellectual activities (Berchtold & Cotman, 1998, p. 174).

Current research has substantiated Cicero's claims of postponing dementia through cognitive activity (Wilson, Segawa, Boyle, & Bennett, 2012). However, Aristotle's belief that dementia always accompanied aging would inform scientists and scholars on their conceptualization of dementia in his time and for the next thousand years (Feldman, 2007).

Middle ages. During the Middle Ages, no known advancements contributed to the knowledge or understanding of dementia. The Roman Catholic Church, the ultimate authority in Europe, postulated that any mental illness, including dementia, was a punishment for sin, and scientific inquiry was heresy (Berchtold & Cotman, 1998). Furthermore, the Bubonic Plague may also be partially responsible for the dearth of writings on dementia (Boller & Forbes, 1998). The death toll, although inexact, ranges from regions losing a third of their population, to some areas losing up to 60% of their citizens (Kelly, 2006). With people dying before reaching 65 years of age, age-related dementia most likely garnered little interest.

Seventeenth, 18th, and 19th centuries. The 17th and 18th centuries brought a resurgence of scientific inquiry into mental disorders, including dementia. Scholars rejected Aristotle's theory that the heart was the seat of cognition and identified abnormalities in the brain as the source of behavioral and cognitive dysregulation (Berchold & Cotman, 1998). During the 1600s, the brain was examined post-mortem for pathological changes in those with mental illness (Feldman, 2007). The results of dissection were limited to the appearance of the brain, such as color, blood vessels, weight, size, and texture; however, scientists had turned their attention to exploring the etiology of dementia rather than merely describing its clinical symptoms (Berrios, 1996). Thomas Willis (1621-1675), a British physician, astutely observed that some individuals develop dementia by aging, whereas others develop dementia through a head injury, alcohol and drug abuse, prolonged epilepsy, congenital factors, and disease (Feldman, 2007; Qizilbash et al., 2008).

The 19th century ushered in changes in the conceptualizing of mental illness, including dementia. Jean-Etienne-Dominique Esquirol, a French psychiatrist, gave an accurate description of the progression of modern-day dementia (Bourgeois & Hickey, 2011). Also, Esquirol divided mental illness into two types: amentia and dementia. Esquirol articulated the difference between amentia and dementia as: "A man in a state of dementia is deprived of advantages which he formerly enjoyed; he was a rich man who has become poor. The idiot, on the contrary, has always been in a state of want and misery" (cited in Qizilbash et al., 2008, p. 211). In 1864, Sir Samuel Wilks, a British physician, advanced the knowledge of dementia pathology by identifying and defining atrophy or shrinkage of the brain (Feldman, 2007). Alois Alzheimer and Otto Binswanger in the 1890s attributed ischemic strokes and focal lesions as causes for atrophy due to the lack of blood supply to the brain (Berchtold & Cotman, 1998). This discovery led to what was known as senile dementia and presently diagnosed as Major or Minor Neurocognitive Disorder Due to Vascular Disease in the *DSM-5.* (APA, 2013).

20th century. The 20th century saw advances in identifying the etiologies of dementia. With technological improvements in the microscope and brain tissue staining procedures, scientists would see neuronal changes in the brain for the first time (Bloch, Green, & Holmes, 2014). Neuropathologists could identify specific forms of dementia, such as neurosyphilis, Alzheimer's, Lewy Body, Pick's, Frontotemporal, and Prion disease based on brain pathology (Birren et al., 1992). Moreover, they could identify how the different types of neuronal abnormalities affected specific areas of the brain.

In 1906, Alois Alzheimer described neurofibrillary tangles and widespread plaque in the brain tissue of a deceased female, Auguste Deter, who had experienced symptoms of dementia at age 51 (Ramirez-Bermudez, 2012). Alzheimer believed he had discovered a new disease due to the early age of onset and Mrs. Deter's rapid decompensation, which suggested criteria for differential diagnosis based on the patient's age at the onset of dementia (Maurer & Maurer, 2003). Older adults were diagnosed with senile dementia, whereas those with dementia in middle age had Alzheimer's disease (AD) or presenile dementia.

Later in the 20th century, additional research found that tau proteins were responsible for the neurofibrillary tangles documented by Alzheimer (Ali, 2015). An overabundance of tau and phosphates causes the tau to break free of the neurons and form tangles (Ali, 2015). These tangles result in the cell being unable to communicate, and without tau maintaining the cell's integrity, the cell collapses (Ali, 2015). The brain plaques in AD is another protein identified as beta-amyloid. Beta-amyloid is broken down and eliminated in a healthy brain; however, in AD, beta-amyloid accumulates and forms plaque that interferes with neuron functioning (Turkington & Mitchell, 2010). Presenile and senile dementia share the same brain pathology, and in 1977, researchers consolidated the diagnoses into Alzheimer's disease (Boller & Forbes, 1998).

Six years after Alzheimer's initial research on plaques and neurofibrillary tangles, Friedrich Lewy observed abnormal nerve cells in the midbrain region of Parkinson's patients (Hof & Mobbs, 2010). The aberrant cells or Lewy bodies are clumps of alpha-synuclein proteins that, in the mid-brain, create Parkinsonian symptoms; however, when Lewy bodies diffuse and invade the cerebral cortex and other parts of the brain, cognition and behavior are affected (Hof & Mobbs, 2010). Researchers discovered the correlation between dementia and Lewy bodies approximately 40 years later (Okazaki, Lipkin, Aronson, & Stanley, 1961).

Okazaki et al., (1961) identified Lewy bodies in the cerebral cortex during the autopsy of two patients diagnosed with Parkinson's and cognitive impairment. The researchers claimed that the diffusion of Lewy bodies was uncommon, and further studies were not conducted until the late 1970s (Okazaki et al., 1961). Additional research, aided by advances in brain tissue staining, contradicted the rarity of the disease (Keltner & Steele, 2019). During the first International Workshop on Lewy Body Dementia in 1995, participants developed criteria for the diagnosis of dementia with Lewy bodies (McNamara, 2011).

The *DSM-5* and Classification of Dementia

The American Psychiatric Association identified the criteria for the diagnosis of dementia in the second edition of the *DSM* (*DSM-II*; APA, 1968). Senile and pre-senile were subtypes under the category of psychoses associated with organic brain syndromes. Senile dementia was primarily diagnosed in those with advanced age-related dementia (onset over 65). At the same time, "characteristically younger age groups" with Alzheimer's or Pick's disease had a diagnosis of pre-senile dementia (APA, 1968, p. 24). Although the classification and terminology used to describe dementia has evolved within the diagnoses, the use of dementia has been a part of the DSM nomenclature for approximately 45 years.

In the *DSM-5* (APA, 2013), the American Psychiatric Association removed the word dementia and replaced it with a more neutral and less stigmatizing classification of major neurocognitive disorder (APA, 2013). The *DSM-5* Task Force also asserted that dementia has a long association with age-related degenerative dementias whereas "neurocognitive disorders have been more widely accepted for younger adults who may be experiencing cognitive and behavior changes" (APA, 2013, p. 591). Thus, major/mild neurocognitive disorders (NCDs) may not have advanced age-related connotations or bias as dementia. The APA decided to end the use of dementia; however, it remains throughout the *DSM-5* for continuity (APA, 2013, p. 591). Furthermore, the APA supports its usage in "settings where physicians and patients are accustomed to the term" (APA, 2013, p. 591). The APA's decision to retire the word dementia is not globally accepted. The Alzheimer's Association, National Institute on Aging, Centers for Medicaid and Medicare Services, and the Lewy Body Dementia Association have not adopted the neurocognitive disorders (NCD) classification and continue their use of dementia ("Alzheimer's Association," 2019; "National Institute on Aging," 2019; "Center for Medicaid and Medicare Services," 2019; "Lewy Body Dementia Association," 2019). The term dementia will be used in this research to refer to NCDs.

In addition to these changes, clinicians must determine if a client meets criteria for the probable or possible subtypes of the diagnoses of dementia (e.g., Major Neurocognitive Disorder due to probable Alzheimer's disease or Mild Neurocognitive Disorder due to possible Alzheimer's disease; APA, 2013). The probable and possible subtype diagnoses also account for any genetic testing the client may have completed, family history, and results from standardized or quantifiable assessment (APA, 2013).

The APA has emphasized the etiology of dementia since the third edition of the *DSM* (*DSM-III*; APA, 1980). However, in the DSM-5, a specifier was added that addresses the impact of dementia on the client's ability to complete daily activities. The mild, moderate, and severe specifiers reflect the level of caregiving required by the care recipient to complete the instrumental activities of daily living (IADLs) and activities of daily living (ADLs) due to the NCD. Lawton and Brody (1969) described IADLs as those essential tasks required to live in the community. Typical IADL tasks are money management, taking medication as prescribed, using the telephone, shopping, preparing meals, laundry, and traveling (Lawton and Brody, 1969). The BADLs are self-care activities such as eating, dressing, bathing, ambulation, and toileting (Schell & Gillen, 2019). BADLs and ADLs are used interchangeably in the scholarly literature. For continuity, the term ADLs will be used in this chapter and subsequent chapters to reference self-care activities, such as eating, dressing, and toileting.

Subtypes of Major/Minor Neurocognitive Disorders/Dementia

The *DSM-5* has identified the following 13 subtypes of NCDs: Alzheimer's, disease, Lewy body disease, vascular disease, frontotemporal lobar degeneration, traumatic brain injury, substance/medication use, HIV infection, Prion disease, Parkinson's disease, Huntington's, another medical condition, multiple etiologies, and unspecified. Each subtype, except NCD, unspecified, has its etiology and symptoms. Although various factors affect the caregiver's journey, the different characteristics of each diagnosis offer a glimpse into the tasks and challenges of being a caregiver.

Late-onset Alzheimer's disease. Late-onset AD is the most prevalent form of dementia and is considered part of the beta- amyloidopathy and tauopathies disorders (Rowland et al., 2016). According to the Alzheimer's Association (2019), an estimated 5.8 million people in the United States have late-onset AD (65 and older). The significant risk factors for late-onset AD are advanced age with the prevalence of AD doubling every five years past the age of 65 and first-degree family member with AD (e.g., mother, father, siblings; Kennedy 2012). Currently, there is no cure for late or early-onset AD. The average life expectancy of an individual with AD is approximately six to eight years; however, the age of onset, gender (typically, males progress more quickly), and level of impairment at diagnosis are contributing factors in longevity (Portenoy & Bruera, 2000).

Researchers continue to search for the cause(s) of late-onset AD (LOAD); however, a deterministic gene, a gene that results in the disease, or a genetic mutation has not been identified (Jeong, 2008). Several risk genes, genes that increase the probability of developing AD, have been found with the most common being apolipoprotein E-e4 (APOE-e4; Feldman, 2007). APOE occurs in four forms (e.g., APOE-e1, APOE-e2, APOE-e3, and APOE-e4), and individuals receive one APOE gene from each parent (Turkington & Harris, 2009). Research indicates that people with one APOE-e4 gene have three times the risk of developing AD with symptoms possibly developing five years earlier than those who do not carry the gene. Moreover, those with two APOE-e4 have 12 times the risk and may experience symptoms up to 10 years sooner than those without the gene (Agronin, 2007; Dening & Thomas, 2013). Although APOE-e4 may increase the likelihood of AD, particularly for women inheriting the gene(s), it does not ensure an individual will get AD (Feldman, 2007).

Early-onset Alzheimer's disease. In 2017, The Alzheimer's Association estimates that approximately 200,000 people in the United States had early-onset (EOAD) or younger-onset AD. AD is categorized as early-onset when people experience symptoms before 65 years of age. It can occur in the 30s and 40s; however, the majority of people experience symptoms in middle age (Gogia & Rastogi, 2008). Individuals with EOAD frequently experience different personal complications than those with

LOAD. Stricken at a younger age, they may still be employed, raising a family, and may be a caregiver to a parent or grandparent. Also, misdiagnosis may occur in EOAD due to the perception that AD is an illness of advanced age.

EOAD is rare and represents 5-10% of all Alzheimer's cases (Anderson, Murphy, & Troyer, 2012). EOAD is classified as sporadic or familial (Feldman, 2007). Currently, there are no identified genetic links for sporadic AD; however, researchers have identified genetic mutations in the amyloid precursor protein (APP), presenilin 1 (PS1), and presenilin 2 (PS2) that cause familial AD (Rowland et al., 2016). Since these are deterministic genes that are autosomal dominant, a person who inherits one of these mutated genes will inevitably develop EOAD (Anderson et al., 2012). Each of these genes has shown EOAD causation, and together represent nearly half of all EOAD (Turkington & Mitchell, 2010). Although researchers have discovered these possible genetic markers for late and EOAD, there is low specificity and sensitivity in genetic testing for the APOE-4 gene in LOAD, and identifying APP and PS1 mutations in EOAD does not offer improved treatment outcomes (Rimoin, Pyeritz, & Korf, 2013).

Stages of Alzheimer's disease. Researchers have been able to develop staging models that illustrate the progression of Alzheimer's disease. Although there is a distinctive pattern of decline in AD, no two individuals advance through the stages in the same way or within the same timeframe. Some people may skip a stage, whereas others may linger in a phase for years. Staging models are predominantly divided into three to seven stages with healthcare professionals using assessment instruments to assist in diagnosing and distinguishing between levels of severity.

The Mini-Mental State Exam (MMSE) is one of the most extensively used screening tools for AD and its stages containing items assessing orientation, word recall, attention, calculating, language, and visuospatial ability (Folstein, Folstein, & McHugh 1975). The MMSE has a total possible score of 30 with the following cut-off scores suggesting levels of cognitive functioning: normal cognition = 27-30, mild cognitive impairment = 21-26, moderate cognitive impairment = 11-20, and severe cognitive impairment = 0-10 (Tombaugh & McIntyre, 1992).

Despite the widespread adoption of the MMSE, it is not without its shortcomings. Research studies have found it to have a floor effect in progressed AD and a ceiling effect in mild cognitive impairments (Mitchell, 2009). Moreover, the MMSE measures deficits in cognitive functioning and does not address the behavioral or physiological changes that occur throughout the disease process.

The Functional Assessment Staging Test (FAST) is a seven-stage model that describes the cognitive, behavioral, and physical changes of AD as it progresses (Reisberg, 1987). The FAST offers insight into the support a caregiver may need to provide as AD advances into severe dementia. The first stage is healthy aging, and the person shows no deficits (Zaretsky, Flanagan, & Moroz, 2010). In the second phase, possible mild cognitive impairment, an individual may complain of misplacing items or problems in recalling names from the past (Zaretsky et al., 2010). Daily tasks are done without any assistance but may take longer to complete. Normal aging is considered the cause of any deficits during this time, and a diagnostic assessment may detect problems with memory. (Ali, 2015).

The third stage, mild cognitive impairment, parallels changes that occur due to AD affecting the temporal lobe (Ali, 2015). As the temporal lobe is responsible for language, memory, auditory processing, and spatial navigation, persons with AD begin experiencing difficulties in those domains (Garrett & Hough, 2018). Family and friends start to observe a decline in the individual, and a diagnostic interview may detect cognitive deficits (Ali, 2015).

In this third stage, the following resulting deficits may occur, difficulty remembering new names or finding the right word, losing things, reduced reading comprehension, difficulty in writing fluency, and deterioration of organizing and planning skills (Zaretsky et al., 2010). The care recipient can complete tasks without the direct intervention of the caregiver; however, this may be a time when caregivers begin to offer support by providing prompts and reminders. A caregiver may call to remind the parent to take their medication, set up a calendar of important dates and appointments, and make a reminder list of household tasks. Persons experiencing symptoms of AD at this level recognize their decline and may try to conceal it (Ali, 2015).

The fourth stage, mild AD, shows changes in the frontal lobe associated with attention, short-term memory, planning, and motivation (Ali, 2015; Garrett & Hough, 2018). At this point, the person is oriented to place and time, recognize family and friends, and can complete the necessary activities of daily living (Zaretsky et al., 2010).

The person with AD may experience the following deficits: forgetting recent events, impaired ability to recollect experiences, and problems in managing instrumental activities of daily living (Zaretsky et al., 2010). The need for assistance from the caregiver increases. Caregivers may be preparing meals, completing necessary housework (e.g., washing clothes and cleaning), shopping, managing finances, providing transportation, making appointments, and managing medications. The care recipient may deny the extent of their cognitive losses and challenge the necessity of caregiving (Ali, 2015).

In the fifth stage, moderate Alzheimer's disease, the person needs daily support and supervision. They will most likely remember the names of their spouse and children but are unable to recall their address, phone number, grandchildren's names, and may, at times, experience disorientation to time and place (Portenoy & Bruera, 2000). Individuals with moderate AD may neglect their ADLs (e.g., bathing, dressing, and eating; Portenoy & Bruera, 2000). A caregiver most likely will assist a parent with wearing proper clothing for the season and dressing appropriately (e.g., socks before shoes and underclothes before outer garments). Also, caregivers could offer parent prompts and encouragement to complete their ADLs.

During the sixth stage, moderately severe AD, people need more assistance to complete the activities of daily living. They will need help in dressing, bathing, and toileting (Portenoy & Bruero, 2000). As this stage progresses, an individual may have times of incontinence (Zaretsky et al., 2010). They may have difficulty remembering a spouse's name and experience disturbances in their sleep patterns (Turkington & Mitchell, 2010). Sundowning, a condition consisting of reoccurring confusion, restlessness, and agitation in the late afternoon and evening, could develop (Aminoff, 2014). Personality and emotional changes may increase agitation, anxiety, inappropriate sexual behavior, and obsessive behavior (e.g., hand-wringing or small cleaning tasks; Turkington & Mitchell, 2010). Doraiswamy, Gwyther, and Adler (2009) reported that more than 40% of individuals with Alzheimer's disease experience psychosis throughout their illness; however, psychosis is more likely in the moderately severe AD stage. Persons with AD can show paranoid behavior, react to their hallucinations, and voice delusions of persecution. Safety may be an issue should care recipients act in response to their disordered thinking. They may become aggressive or combative during care. Also, for some care recipients, wandering becomes a life-threatening behavior. Wandering away from home and becoming lost is not exclusive to AD and is a challenge faced by caregivers for other dementias. Approximately 60% of persons with AD will wander, and caregivers have the task of safely securing the care recipient's home environment (Santulli, 2011).

In the seventh and final stage, severe AD, individuals are unable to relate to their surroundings. The care recipient's speech diminishes until only a few words are spoken (Portenoy & Bruera, 2000). As the AD progresses, the person will lose their ability to speak, control their movements, and will require assistance with all ADLs, including eating, bathing, dressing, and toileting (Zaretsky et al., 2010). They will be incontinent of bowel and bladder and eventually, unable to ambulate, sit up without support, hold up their head, and have difficulty swallowing (Portenoy & Bruera, 2000). The care recipient requires extensive 24-hour care, which may exceed what can be provided at home, resulting in nursing home placement.

Dementia with Lewy bodies. Dementia with Lewy Bodies is the second most prevalent type of dementia (Weiner & Lipton, 2009). Approximately20% of all dementia cases in the world are dementia with Lewy bodies (DLB), and approximately 1.3 million individuals in the United States have DLB (Ravdin & Katzen, 2012; Gurd, Kischka, & Marshall, 2012). Lewy body dementias are synucleinopathy disorders and consist of the diagnoses of dementia with Lewy body and Parkinson's disease dementia (Rowland et al., 2016). The *DSM-5* differentiates between DLB and Parkinson's disease dementia (PDD) based on the timing of the impaired cognitive or motor symptoms (APA, 2013). In DLB, the observed cognitive changes are within a year of the onset of parkinsonian symptoms; however, in Parkinson's disease dementia, movement symptoms may be present for several years before any neurocognitive changes occur (Weiner & Lipton, 2009). If Parkinson's disease "clearly precedes the onset of the neurocognitive disorder," then a diagnosis of major or mild neurocognitive disorder due to Parkinson's disease is warranted (APA, 2013, p. 620). Presently, there is no cure for DLB or PDD. Although the rate of progression differs for each person, the average life expectancy after onset is approximately six to nine years (Yachnis & Rivera-Zengotita, 2012).

Advanced age is the most significant risk factor for dementia with Lewy bodies

(Potocny, 2010). Boot et al. (2013) identified several other risk factors such as anxiety, depression, stroke, family history of Parkinson's, and carrying the APOE-4 gene. Also, REM sleep behavioral disorder, which results in a person physically acting out their dreams, is not only a symptom of DLB but a possible predictor. Research shows that at least 50% of individuals with REM sleep behavioral disorder will develop DLB (Whitworth & Whitworth, 2010). Unlike Alzheimer's disease that affects more women than men, the occurrence of DLB is slightly higher in men (Whitworth & Whitworth, 2010).

Dementia with Lewy bodies was recognized approximately 20 years ago as a neurodegenerative disease, and research into its possible genetic factors has lagged behind AD. Although there is no known deterministic gene for DLB, researchers have suggested that a mutation in the β-synuclein and GBA gene (glucosidase, beta, acid) may increase a person's susceptibility to developing DLB and Parkinson's with dementia (Rowland et al., 2016). Duplication or triplication of the β-synuclein gene was discovered in rare early-onset familial dementia with Lewy Bodies (Pfeiffer, Wszolek, & Ebadi, 2012). The risk gene in AD, APOE-e4, has also been found to increase the possibility of dementia with Lewy bodies (Boot et al., 2013). Brain autopsies have revealed the co-morbid pathology of plaques and neurofibrillary tangles of Alzheimer's disease with Lewy bodies in some patients resulting in the medical community coining the term Lewy body variant of Alzheimer's (Qizilbash et al., 2008).

Characteristics of dementia with Lewy bodies. The progression of Lewy body dementia cannot be staged linearly as in Alzheimer's disease due to the fluctuation of diverse symptoms. In the early stages, symptoms such as inattention or inability to concentrate may change from hour-to-hour, morning to night, or day-to-day (Qizilbash et al., 2008). The varying symptoms and the shared characteristics of Alzheimer's and Parkinson's disease result in the frequent misdiagnosis of DLB. Although symptoms overlap in DLB with AD and Parkinson's disease, Aarsland, Cummings, Weintraub, and Chaudhuri (2013) identified the following unique core characteristics of DLB: well-formed hallucinations, fluctuating cognition with changes in alertness and attention, and sudden Parkinsonian symptoms (e.g., tremor, slow movements, muscle stiffness, and impaired speech).

Psychosis in dementia with Lewy bodies. It is estimated that approximately 85% of people with DLB experience well-defined visual hallucinations (Mace & Rabins, 2017). Unlike AD, when hallucinations may occur in the moderately severe stage, visual hallucinations may be the first symptom of DLB (Mace & Rabins, 2017). Mosiman et al. (2004) conducted a qualitative study of 56 patients (35 Parkinson's disease dementia and 21 DLB) to identify the characteristics of persistent, complex hallucinations. The most frequent complex hallucinations identified were: unknown people or soldiers, friends or family members, babies or children, body parts, animals, or machines (e.g., cars, buses, and planes). The study participants reported consistent hallucinations, and many found their hallucinations unpleasant (PDD 49%, DLB 45%).

Vivid, visual hallucinations may occur throughout DLB due to Lewy bodies in the temporal lobe (Harding, Broe & Halliday, 2002). In addition to visual hallucinations, some individuals may experience auditory hallucinations and delusions. A common delusion is a belief that there are strangers in the home or that a deceased loved one is visiting and frequently cited auditory hallucinations include knocking, footsteps, and banging (Huang & Halliday, 2013).

The treatment of psychosis in DLB is challenging. Although an individual with Alzheimer's disease may have his or her psychosis managed with neuroleptics, people with DLB may experience neuroleptic sensitivity that may increase confusion, exacerbate parkinsonian symptoms, and cause acute sedation (Owens, 2014). Furthermore, the neuroleptic malignant syndrome may occur and if left untreated, is fatal. Research indicated that up to 50% of Lewy body dementia patients have a neuroleptic sensitivity (Yachnis & Rivera-Zengotita, 2012). Atypical antipsychotics (e.g., Risperdal, Zyprexa, and Seroquel) and cholinesterase inhibitors (Aricept, Exelon, and Razadyne) have shown some efficacy in treating hallucinations, sleep disturbances and fluctuating cognition (Neff & Walling, 2006).

Cognition in dementia with Lewy bodies. Individuals with DLB experience unpredictable fluctuations in concentration, attention, and alertness. They have episodes of "zoning out" and staring off into space (Qizilbash et al., 2008). Furthermore, a person with DLB will most likely experience hypersomnolence during the day and appear tired and drowsy despite having a restful night's sleep (Weiner & Lipton, 2009). In the initial stages of DLB, executive functioning is affected, which results in poor decision-making, impaired problem-solving, and difficulty with abstract thinking (Perry, McKeith, & Perry, 1996). Memory problems arise as DLB progresses and appear to be with memory retrieval rather than encoding, as in the case of AD (Noe et al., 2004). Thus, a caregiver cueing on tasks or assisting care recipients with problem-solving may find these to be effective strategies for managing early memory deficits.

Parkinsonism in dementia with Lewy bodies. In dementia with Lewy bodies, Parkinsonian symptoms usually develop as the disease progresses. Bradykinesia (slow movements), shuffling gait, and stooped posture are physical features of DLB (Weiner & Lipton, 2009). Also, blunted facial expressions, and a low or weak voice are prominent characteristics (Rowland et al., 2016). Resting tremors that occur in Parkinson's disease dementia are rarely present in DLB; however, balance is more problematic with DLB (Perry et al., 1996). The Parkinsonian symptoms and visuospatial/visual perception impairments experienced by persons with DLB put them at high risk for frequent falls and possible injury (Weiner & Lipton, 2009).

Progression of dementia with Lewy bodies. The spontaneous Parkinsonian and fluctuating cognition symptoms increase in intensity and duration as DLB progresses. Although memory loss may not occur in the earlier stages, memory impairment will occur as the Lewy bodies create more atrophy in the cerebral cortex (Schneider & Bhatia, 2012). Dementia with Lewy bodies may not have a linear progression as in the case of Alzheimer's disease; however, the end stages of physical and cognitive decompensation are comparable. The individual with advanced DLB will lose their ability to ambulate, be incontinent and uncommunicative, and may have difficulty in swallowing (Growdon & Rossor, 2007). They will be unable to complete basic activities of daily living and require 24-hour care.

Vascular dementia. Researchers disagree over the prevalence of vascular dementia (VaD). While some researchers classify VaD as the second most common dementia, others contend that the number of VaD cases are decreasing due to improved medical care, enhanced diagnostic capabilities, and healthier lifestyles (Paul, 2007; First & Tasman, 2013). Studies estimate that approximately 10-20% of all dementia cases are due to VaD (Caplan, 2014).

Paul (2007) defined VaD as "a loss of cognitive functions to a degree that interferes with activities of daily living, resulting from ischemic and hemorrhagic cerebrovascular disease or from cardiovascular or circulatory disturbances that injure brain regions that are important for memory, cognition and behavior" (p. 7). The risk factors for developing VaD are the same as those for increasing the risk of cerebrovascular and cardiovascular disease, including advanced age, history of stroke, smoking, atrial fibrillation, hypertension, diabetes, and hyperlipidemia (Paul, 2007). Vascular dementia may occur at any age in older adults but occurs less frequently after the age of 75 and affects more men than women (Markides, 2007; Turkington & Harris, 2009). The life expectancy for people with VaD is approximately six to eight years (Gelb, 2016).

Vascular dementia may occur due to a massive, single brain stroke, multiple "mini-strokes" or transient ischemic attacks (TIAs), or small blood vessel disease that decreases blood flow to the brain (National Institutes of Health, 2017a). The clinical symptoms of VaD vary based on the location, timing (a single stroke or part of a series of strokes), and the size of the stroke (Gelb, 2010). VaD, unlike Alzheimer's disease, does not follow a predictable course. The onset of VaD may be swift and progressive, but more commonly has a stepwise course (Turkington & Harris, 2009). In the stepwise progression, a stroke occurs, which results in cognitive decline; however, the loss of functioning plateaus and the individual experiences no additional deficits until the next stroke (Sbordone & Saul, 2000).

Multi-infarct dementia (MID) is the most common subtype of VaD after mixed dementia (VaD and AD). It is a result of a series of transient ischemic attacks (Coetzer & Balchin, 2014). TIAs cause tissue death or infarcts in different regions of the brain and may disproportionally affect one side of the brain (Coetzer & Belchin, 2014). Whereas Alzheimer's disease has global symptoms that produce multiple deficits and affects both sides of the body, MID may have focal symptoms that impair one side of the body and produces deficits based on the locations and distributions of the infarct formations (Coetzer & Balchin, 2014). Mild memory deficits and impairments in executive functioning may be the first symptoms of MID along with possible frustration and depression as the person recognizes their cognitive decline (Turkington & Harris, 2009). As MID worsens, judgment is impaired, and mood changes are prevalent (Gogia & Rastogi, 2008). Apathy, agitation, and laughing or inappropriate crying is common

(Gogia & Rastogi, 2008; Turkington & Harris, 2009). Cognitively, people with MID experience recent memory loss, are unable to follow instructions, and may have paranoia and delusions (Coetzer & Balchin, 2014). Also, nocturnal confusion, somatic complaints, and emotional lability are more prevalent in MID than in other dementias (Stein & Wilkinson, 2007).

Subcortical vascular dementia (SVD) results from extensive small vessel damage located under the cerebral cortex in the basal ganglia, thalamus, brainstem, and the white matter of the brain (Kalaria & Erkinjuntti, 2006; Noggle, Dean, & Horton, 2012). Research estimates that SVD accounts for approximately 50% of all VaD cases (Kalaria & Erkinjuntti, 2006). The most common risk factors for SVD are hypertension, diabetes, high cholesterol, sleep apnea, and smoking (Noggle et al., 2012). SVD is mostly steadily progressive with impairments in the cognitive, behavioral, and motor functioning domains (Gauthier & Rosa-Neto, 2011). Physically, the care recipient may have slow movements, issues with balance, swallowing difficulties, and incontinence (Gauthier & Rosa-Neto, 2011). Speech may be slow and slurred (Ayd, 2000). The individual may experience depression, apathy, emotional lability, and personality changes (Moretti, 2006). In the cognitive domain, poor executive functioning, mental process slowing, visuospatial problems, and difficulty in retrieving information are typical (Gabbard, 2014).

Frontotemporal lobar degeneration dementia. Frontotemporal lobar degeneration dementia (FTLD) is a classification for a group of neurocognitive disorders in which the frontal and temporal lobes atrophy due to the accumulation of tau or TDP-43 proteins (National Institutes of Health, 2017). FTLD syndromes develop between the ages of 40 and 60 and represent 5-15% of all dementia cases (Goldstein & Naglieri, 2014). FTLD is the second most prevalent form of early-onset dementia behind Alzheimer's disease (Miller, 2009). Currently, there is no cure or way to hinder its progression. The median life expectancy for all FTLD subtypes is 5 to 10 years (National Institutes of Health, 2017).

There are primarily two subtypes, progressive behavior/personality decline, and progressive language decline, in frontotemporal lobar degeneration (National Institutes of Health, 2017). Behavioral variant frontotemporal dementia (bvFTD) is the most common of all frontotemporal neurocognitive disorders and begins with changes in personality and behavior (National Institutes of Health, 2017). People with bvFTD are frequently disinhibited, lack social skills, experience no sympathy or empathy, and have poor executive functioning (Mendez et al., 2013). Also, compulsive binge eating is common, particularly starches, which may result in additional health problems (National Institutes of Health, 2017). As bvFTD advances, the care recipient may develop language problems, decreased motor skills, and personality, and mood changes may intensify. A caregiver may notice compulsive and repetitive behaviors such as hoarding, cleaning, clapping, and echolalia (Yudofsky & Hales, 2008).

Primary progressive aphasia (PPA) is another subtype of frontotemporal lobar degeneration and begins with impairments in language, including speaking, writing, reading, and comprehension of speech (Nair & Sabbagh, 2014). Behavioral and personality changes comparable to those with bvFTD may appear in the later phases with increasing changes in the frontal and temporal lobes (Nair & Sabbagh, 2014). Memory and executive functioning deficits are not present with the onset of PPA but will most likely occur with disease progression (National Institutes of Health, 2017).

Traumatic brain injury dementia. The *DSM-5* subtype of traumatic brain injury (TBI) dementia is related to symptomology after the loss of consciousness (APA, 2013). Cognitive changes in TBI dementia include impairments in attention, concentration, executive functioning, and language (Gentile & Gillig, 2012). The degree of cognitive, mood, and behavior disturbances are dependent on the location and extent of brain injury (Kelsey, Nemeroff, & Newport, 2006). Mood disorders are common after a TBI. Major depression affects approximately 25% of people who experience traumatic brain injury (Marion, 1999). Furthermore, apathy, mania, and anxiety disorders may also occur (Silver, McAllister, & Yudofsky, 2011).

Perhaps one of the most challenging aspects of caregiving for TBI dementia is behavioral dysregulation. Impulsivity, aggressiveness, poor judgment, and social inappropriateness can create explosive reactions to perceived environmental threats or demands (Marion, 1999). Psychosis may exacerbate the care recipient's emotional lability (Silver et al., 2011).

Substance/medication-induced dementia. Individuals may develop dementia due to drug abuse, prescription medication, and exposure to toxins. The symptoms of substance/medication-induced dementia may be temporary or progressive. If an individual has continuous sobriety, discontinues the problematic prescription medication, or avoids additional exposure to toxins (e.g., arsenic, mercury, and excessive manganese), dementia symptoms may abate (Rabins, Lyketsos, & Steele, 2016). Substance and medication-induced dementias are not progressive; however, persistent drug use or prolonged exposure to toxins may result in neuronal damage in the brain and irreversible dementia (Rabins et al., 2016).

Alcohol-related dementia (ARD) is the most common form of substance-induced dementia. It occurs due to years of alcoholism combined with deficiencies in thiamine and niacin (Moore, 2008). Nace and Isbell (1991) estimated that 9% of people who chronically abuse alcohol develop dementia. Whereas damage is diffuse throughout the brain, the frontal lobe and cerebellum are most at risk (Koob & Le Moal, 2005). ARD is similar to other dementias with impairments in cognition, language, and motor skills; however, behavioral and mood changes frequently occur before any other symptomology (First & Tasman, 2013). People with ARD may refuse care or become aggressive during care due to irritability, agitation, and psychosis (Moore, 2008).

HIV-associated dementia. The human immunodeficiency virus (HIV) causes HIV-associated dementia (HAD) or AIDS dementia. The Centers for Disease Control and Prevention estimated that over 1.1 million people in the United States have HIV infection, and approximately 14% do not know they are infected (HIV Basics, 2019). HIV-associated dementia is a subcortical dementia that affects the regions of the brain below the cortex, impairing cognition, behavior, and psychomotor functions (Hales, Yudofsky, & Gabbard, 2008). For people with HIV, risk factors that increase their possibility of developing HAD are the older age of onset HIV, low body weight, and low hemoglobin (Rabins et al., 2016). A low CD4 count, a type of white blood cell, will exacerbate problems with cognition (Rabins et al., 2016). The frequency of HAD has diminished with the use of antiviral therapies that manage the HIV infection (Rabins et al., 2016).

Dementia due to prion disease. Prion diseases (PDs) is a grouping of rare, progressive neurocognitive disorders that occur in humans and animals. The human prion diseases are Creutzfeldt-Jakob, Gerstmann-Straussler-Schneiker, Fatal Familial Insomnia, and Kuru (Soto, 2012). Creutzfeldt-Jakob is the most common and occurs in one in one million people (Cutler, 2014). Prion diseases are sporadic (arising from unknown causes), inherited or acquired (i.e., through contaminated equipment for a medical procedure or exposure to contaminated food; Goldstein & McNeil, 2013). All PDs begin with a prion protein that misfolds (Soto, 2005). The misfolded prion induces other healthy prions to misfold, resulting in an accumulation of abnormal proteins that damage the brain (Soto, 2005). Although each classification may have different features, shared symptoms in the domains of behavioral, language, memory/cognition, motor skills, and visual/perception have been identified (Cutler, 2014). Each PD subtype has a rapid decline, with the average life expectancy after onset being less than two years (Brillman & Kahan, 2005).

Dementia due to Huntington's disease. Huntington's disease (HD) is a hereditary, autosomal dominant progressive disease that results in early-onset dementia (Esiri, Lee, & Trojanoski, 2004). The rare genetic disorder occurs in approximately 6 out of every 100,000 individuals with onset occurring primarily between the ages of 25-50 (Quarrell, 2008). Although the hallmark feature of HD is the random, uncontrollable muscle movements known as chorea, researchers have identified personality changes such as agitation, paranoia, apathy, and depression as possible precursors to impairments in cognition and chorea (Quarrell, 2008).

Huntington's disease dementia is a subcortical dementia with impairments in mood, movement, and cognition (Lezak, 2004). As the damage from the mutated huntingtin proteins progresses, a care recipient will have difficulty with executive functioning, learning new information, and recall (Quarrel, 2008). Although memories are most likely intact, the brain's search mechanism to find the memories is impaired (Friedman, 2013). Moreover, deficits will occur in motor memories. Motor memories, such as buttoning a shirt, tying a shoe, and driving are lost ("Huntington’s Outreach Project for Education,” 2019).

Dementia due to other general medical condition. Medical causes of dementia may involve degenerative disorders of the central nervous system, nutritional disorders, infection-related disorders, endocrine and metabolic disorders, and other conditions such as depression, brain tumor, multiple sclerosis, and normal pressure hydrocephalus (Gabbard, 2014). The progressive dementias are irreversible, but some dementias due to a general medical condition can be effectively treated and show improvement or reversal of symptoms (Hales et al., 2008).

The nutritional disorders which are most likely caused by a deficiency in the B vitamins (i.e., B12, niacin, folate, and thiamine) cause memory loss and ataxia (lack of coordination; Turkington & Harris, 2009). People with B12, niacin, and folate deficiencies recover when their nutritional imbalances are corrected while approximately 25% with thiamine deficiencies recover completely (Turkington & Harris, 2009). If treatment commences before brain damage occurs, dementia caused by endocrine and metabolic disorders, infections (e.g., neurosyphilis or encephalitis), brain tumor, and normal pressure hydrocephalus are reversible (Yudofsky & Hales, 2008). Although some dementias due to a medical condition may be reversible, others are not (e.g., multiple sclerosis and amyotrophic lateral sclerosis; Gathier & Rosa-Neto, 2011).

Dementia caused by multiple etiologies. Historically, researchers have searched for the singular cause of dementia; however, autopsy studies have shown that some individuals may have brain changes corresponding to more than one type of dementia (Jellinger, 2007). The neurofibrillary tangles and plaques associated with AD may coincide with Lewy bodies and vascular degeneration (Langa, Foster, & Larson, 2004). Researchers initially coined the term “mixed dementia” to denote the co-existing disease processes of VaD and AD; however, the definition has expanded to include any other type of dementia combined with AD (Heerema, 2019). The prevalence rate of mixed dementia is unknown; however, studies have shown that the majority of people over the age of 80 diagnosed with dementia are more likely to have a mixed dementia, a combination of AD and VaD (Jellinger, 2007). Multiple etiologies of dementia may occur within other subtypes of the neurocognitive disorders (e.g., substance-induced and traumatic brain injury dementias, and HIV-associated and substance-induced dementias). Researchers have yet to determine how the different dementia pathologies may impact one another and if the course, severity, and rate of decline is different for those with mixed dementia than those with a single subtype of dementia (Zekry, Hauw, & Gold, 2002).

Caregiving

The etymology of care is from the Old English and Gothic word *carian* or *kara,* meaning “mental suffering, mourning, sorrow, or “bed of sickness” (Smith, Turkel & Wolf, 2012). Care, in its earliest usage in the 10th century, included having a concerned mind or a “burdened state of mind” (Smith et al., 2012, p. 272). Gaut (1983) asserted that the use of the term “care” in research differs from its use in popular culture. Through a semantic and philosophical analysis of the scholarly research, Gaut (1983) discovered Gaut (1983) observed that there is not one definitive meaning of care; instead, there are three underlying meanings of care: (a) responsible to or providing for another, (b) attention and concern for another, and (c) regard or attachment. Perhaps no reference has informed the concept of care in literature and psychology more than the fable-myth entitled “Care” discovered in a second-century collection of myths (Werler & Wulf, 2006).

> As 'Care' once crossed a stream, she saw some clay: she picked up a piece thoughtfully and began to shape it. While she considered in herself what she had created, Jupiter came up to her. Care asked him to provide spirit to the clay form. This he was pleased to do for her. But when she wished to give her name to her creation, Jupiter would not allow it and said that his name ought to be given to it. While 'Care' and Jupiter argued over the name, the Earth came up and wanted the creation to be named after her since she had, after all, given it a part of her body. The three claimants asked Saturn to settle the matter. And Saturn gave them an apparently just decision as follows: 'You, Jupiter, because you have provided the spirit, should receive the spirit when the creature dies; you, Earth, because you provided the body, should receive the body. But because 'Care' first shaped this creature, so should it be that she possesses it as long as it lives (Werler & Wulf, 2006, p. 34).

The etymology of the word give is from the Old English *giefan* and *gefan*, the Dutch *geven*, and the German *geben* ("Online Etymology Dictionary," 2016). The Old English *giefan* means to "deliver to another, bestow, commit, devote, and entrust." The German *geben* translates into "to take or hold" ("Online Etymology Dictionary," 2016). The compound word of caregiving is the "action of delivering help or assistance to those who are suffering" (Hermanns & Mastel-Smith, 2012, p. 1).

Caregiver. The first use of the term caregiver was in the book, *The Meaning of Mental Illness to Caregivers and Mental Health Agents: A Study of Four Different*

Occupational Groups (Mackey, 1966). In the literature, there are informal or formal caregivers. Feinberg and Pilisuk (1999) defined an informal caregiver as:

> One who provides care without pay and whose relationship to the care recipient is due to personal ties (rather than to the service system): family, friends, or neighbors, who may be primary or secondary caregivers, provide full time or part-time help and live with the person being cared for or separately" (p. 3).

In the scholarly literature, the term informal caregivers frequently refer to a family member who provides care. In contrast, formal caregivers are those "individuals who provide their professional services for a fee" (Hutchison & Sleeper, 2010, p. 17).

The categories of informal caregivers are primary, secondary, or long-distance care providers. Briggs (2014) defined primary caregivers as those who "devote the most hours to care, provide the widest range of services, and take on the weight of responsibility in the delivery of care. They are in charge. If decisions are to be made, they will wrestle with them. If problems arise, they will be responsible for finding solutions. If quality care is lacking, they are accountable" (p. 29). Secondary caregivers "provide assistance and support to the primary caregiver by providing psychoemotional, instrumental, and financial support" (Rowles & Teaster, 2015, p. 90). Secondary caregivers may also assist the care recipient; however, it is not to the degree or intensity as a primary caregiver. The definition of a long-distance caregiver is an "individual who lives a minimum of 1 hour of travel or more or 100 miles or more from the care recipient" (Gillen, 2015, p. 310). Perhaps, Parker, Church, and Toseland (2006) provided the most comprehensive, two-part definition of a long-distance caregiver as: "(1) Anyone who provides informal care to an individual experiencing mental, physical, emotional or financial impairment that limits independence and requires care; and (2) who experiences caregiving complications because of geographic distances from the recipients as determined by distance, travel time, travel costs, personal mobility issues, limited transportation, and other factors that affect the caregiver's access to the care recipient" (p. 391).

Caregiving status. Although the etymology of the word caregiver and the types of caregivers have been well-defined, there is not a standardized definition for caregiver/caregiving in research. Some studies identify caregivers as any individual who assists another with IADLs/ADLs while others quantify the meaning of caregiving to mean those who provide the majority of care (Newman & Cauley, 2012). Researchers may also define caregivers based on their relationship with the care recipient and a particular chronic illness (e.g., sons who are caregivers to a father with dementia). Furthermore, some researchers do not attempt to define their conceptualization of caregiving and offer little explanation of what type (e.g., primary, secondary, or long distance) or the level of care a research participant provides to the care recipient.

The definition of caregiving is not operationalized; however, certain conceptual aspects of caregiving may be of interest to researchers in specific disciplines. Sociology research into caregiving has primarily focused on unpaid caregivers with an emphasis on the influence of culture on their caregiving beliefs, caregiver and care recipient demographics, the caregiving role, and caregiver burden (Bruhn & Reback, 2014, Ferrante, 2007, Hermanns & Mastel-Smith, 2012). Swanson et al. (1997) conducted a concept analysis to understand the shared meaning of caregiving among the nursing profession. The findings showed the concept of caregiving as having four components: tasks, transitions, roles, and process. Lastly, in the discipline of psychology, researchers have focused on caregiving outcomes with an emphasis on the effects of the caregiving experience on the caregiver, identifying mediators of caregiving stressors and coping strategies, and exploring the rewards of caregiving (Hermanns & Mastel-Smith, 2012). The lack of a widely-accepted definition and conceptualization of caregiving makes it challenging to compare findings across multiple disciplines (Hermanns & Mastel-Smith, 2012).

Theoretical Models in Caregiving

Researchers have used multiple models and theories to inform their caregiving research and to explain what occurs throughout a caregiver's career. These theoretical research lenses fall into two categories: stress/coping models and caregiver/care recipient relational theories. Stress and coping models such as Lazarus and Cohen's Transactional Model of Stress and Coping and Pearlin's Stress Process Model identify and explain the factors that contribute to the possible physical, emotional, social, and financial outcomes of caregiving (Lazarus & Cohen, 1977; Pearlin, Mullan, Semple & Skaff, 1990). The caregiver and care recipient relational theories explore the evolving and fluid roles between the caregiver and the care recipient and how these transitions affect the caregiving experience. Social exchange theory (Thibault & Kelley, 1959), identity theory (Stryker, 2002), and role-identity theory (McCall & Simmons, 1978) are examples of relational theories extensively used in the conceptual framework of caregiving researchers. These theories and others have guided the research on adult children caregivers; however, the social exchange theory (SET) and the stress process model (SPM) are discussed due to their prevalence in the caregiving research.

Social exchange theory. The social exchange theory (SET) is an economical approach to understanding social behavior. Essentially, social behavior is an outcome of an exchange process whereby the purpose of the exchange is to maximize benefits and minimize cost (Hutchison, 2014). Because an exchange occurs in every interaction, SET focuses on what people may receive from their interactions and what they are contributing to the relationship (Delaney, 2016). Within a relationship, one individual's behavior affects the costs and rewards of the other. These exchanges are not limited to financial gains; non-materialistic rewards in the form of love, acceptance, approval, esteem, safety, and loyalty also shape social behavior. The costs may include feelings of conflict, sadness, embarrassment, or anxiety (Raschick & Ingersoll-Dayton, 2004). Molm and Cook (1995) proposed the following four assumptions of SET: individuals are dependent on others for the things that they value, people behave in ways that increase resources and avoid the loss of resources, people engage in ongoing, mutually unpredictable exchanges with specific individuals over time, and all outcomes obey a principle of satiation or diminishing marginal utility. The value of additional resources decreases once a resource or a result is achieved.

The caregiving journey provides an example of the principle of diminishing marginal utility. In the mild stages of dementia, the care recipient may require a minimum amount of assistance with IADLs, and this level of care most likely will have little impact on the caregiver's other roles and responsibilities. At this point, a few more tasks most likely will not affect the caregiver's perception of burden. However, as the care recipient's needs increase and the caregiver questions their ability to manage the demands of caregiving, additional caregiving tasks may impact the caregiver's other roles resulting in the "cost" of caregiving or perceived burden.

SET theorists, Thibault, and Kelley (1959), asserted that people evaluate their relationships to determine if they are maximizing their benefits or rewards. The adult child may have certain beliefs about the rewards of being a caregiver to a parent with dementia, such as praise, support, or companionship. If the caregiver's expectations are met, they may positively evaluate their caregiver role; however, if their relationship expectations are unmet, they may experience a negative evaluation of the relationship. Furthermore, the care recipient may require more assistance than the caregiver anticipated or judges as necessary, which may upset the caregiver's assessment of what is equitable and fair in the relationship (Call, Finch, Huck & Kane, 1999).

According to SET, the norm of reciprocity governs social exchanges. Parents and children frequently have interactions when there is no exchange of rewards for nurturance (Bell, 2009). Family members do not expect an immediate quid pro quo exchange but operate under life-course reciprocity in which exchanges equal out over time (Silverstein et al., 2002). Throughout time, family members assist one another, reciprocate past care, and expect future assistance so that they do not have to maintain quid pro exchanges (Antonucci, 1990). Adult children provide caregiving to the parent with dementia in return for past parental assistance. Family relationships grounded in life-course reciprocity may accept one-way reward exchanges over time; however, the expectation of "repayment" and the return to balance continues throughout the relationship. If a breach in the life-course reciprocity norm occurs, the connection between the family members may become strained and stressful. For adult children who are caregivers to a parent with dementia, the care recipient's abilities to offer exchanges as "repayment" are limited or non-existent, which may result in a worrisome or oppressive relationship. Furthermore, the care recipient may become frustrated when they can no longer offer reciprocation to their caregiver as his or her dementia progresses.

The stress process model. The Stress Process Model (SPM) is widely used as a conceptual framework for researchers to identify and explore factors that influence caregiver stress (Pearlin et al., 1990). The purpose of the SPM is to explain how specific predictors may affect the variable outcomes of Alzheimer's dementia caregiving, and it is the first model based on stress and coping for dementia caregiving. The researcher's goals in developing the SPM was to identify specific caregiving stressors and to gain an understanding of the origins and the interrelatedness of these stress factors (Pearlin et al., 1990). The SPM is a product of the authors' knowledge of the stress process, previous research findings, and interviews of 555 caregivers (spousal caregivers *n* = 326 and children caregivers *n* = 229) who were primary caregivers for an individual with dementia. The caregivers were recruited from a group of individuals who contacted the Alzheimer's Association in the San Francisco Bay Area and Los Angeles County. The participants were self-described primary caregivers of a spouse or parent (or parent-in-law) with dementia. The authors did not provide information regarding the interview process. The heuristic model identifies the following four domains as components of caregiver stress: the background and context of stress, the stressors, the mediators of the stress, and the outcomes of the stress (see Figure 1).

The background and context of the stress process model. Pearlin et al. (1990) The background asserted that interwoven throughout every aspect of caregiving and the stress process are the characteristics of the caregiver. These characteristics, age, gender, ethnicity, educational level, occupation, and economic statuses, impact the access a caregiver has to personal and community resources to ameliorate stressors. Moreover, the background of a caregiver also affects the types and intensities of the stressors. For example, a primary caregiver with higher economic status may experience less stress because he/she can employ a nurse to provide around the clock care for a parent with dementia. In contrast, a caregiver in a lower economic class may have to shoulder the majority of the caregiving responsibilities.

The caregiving history is a predictor of caregiver stress within the background and contexts domain. The contextual elements of the caregiving history consisted of the

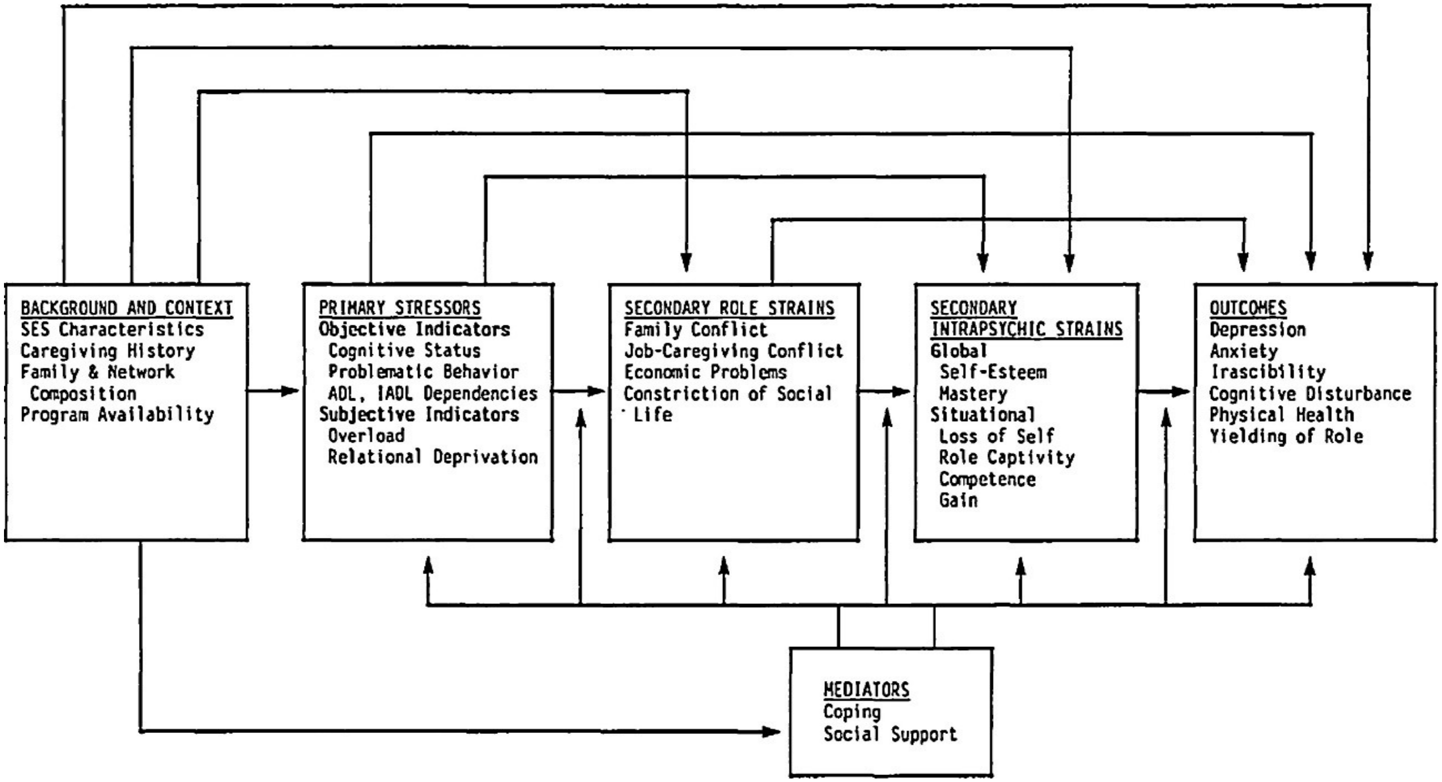

Figure 1. The Stress Process Model. Reprinted with permission. Pearlin, L.I., Mullan, J.T., Semple, S.J. & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*.. 30(5), 583-594 relationship of the caregiver to the care recipient (e.g., spouse, partner, son, and daughter), the quality of the relationship between the caregiver and the care recipient before the onset of dementia (e.g., compatibility, functional/dysfunctional), and the level of care needed by the person with dementia. The cognitive and physical deficits of the care recipient determine the extent of the caregiving demands and, subsequently, impact stress and caregiver burden. Lastly, the length of time spent in the caregiver role is a "marker of the chronicity of the stressors that the caregiver experiences" (Pearlin et al., 1990, p. 586).

The family and network component of the SPM consists of family networks that are possible stressors or available resources for the caregiver. The number of family members assisting in caregiving, family conflict regarding care, additional role demands of the caregiver (e.g., parent, spouse, partner, daughter, son) may influence caregiving burden. Additionally, the living arrangements of the care recipient (e.g., alone, with a spouse, with adult child) is a predictor of stress in adult children who were primary caregivers to a parent with dementia. The final component of the background and context domain is the availability and use of resources and community-based programs. Pearlin et al. (1990) did not identify social supports as a contextual element in caregiving. Still, they hypothesized that it was the totality of the caregiver's relationships or the caregiver's network that offered context to the caregiving experience. The researchers reasoned that a caregiver could not have social supports without a network; however, an individual may have a network without social support. Factors in assessing the caregiver’s network include: the strength of the caregiver’s ties, the composition of the network, and the frequency and quality of the relationships (Pearlin et al., 1990, p. 586.)

Community-based programs are another resource that may be available for caregivers and the care recipients. Pearlin et al. (1990) maintained that although there are community services available, location, hours of the services, transportation, and cost may limit access to the services (p. 586). Caregivers who utilize community-based programs may experience a decrease in isolation and an increase in much-needed assistance that may relieve some of their caregiving challenges.

Stressors. Pearlin et al. (1990) defined stressors as “conditions, experiences, and activities that are problematic for people, that is, that threaten them, thwart their efforts, fatigue them, and defeat their dreams” (p. 586). The authors divided caregiving stressors into two categories: primary and secondary stressors. Primary stressors are directly related to providing care and meeting the needs of the care recipient; whereas, secondary stressors arise from the challenges created by the primary stressors. For example, a caregiver watches over her agitated mother with dementia to prevent her from leaving home. The caregiver’s vigilance lasts throughout the night, and the exhausted caregiver is once again late for work. Due to her repeated tardiness, her employer terminates her employment. The primary stressor in this vignette is the problematic behavior of the care recipient. The secondary stressors are the job-caregiving conflict and the financial consequences of her termination, which are attributable to her primary stressor-caregiving for her agitated mother.

Primary stressors. Pearlin et al. (1990) identified several objective indicators related to the care recipient's health and functioning and the caregiver's subjective experience of caregiving that may contribute to primary stressors. The care recipient's cognitive status (memory deficits, verbal fluency deficiencies, and agnosia) determines the range of challenges the caregiver experiences and, subsequently, caregiver burden. The cognitive status of the individuals with dementia also affects their behavior, or the second indicator of a primary stressor (Pearlin et al., 1990). Problematic behaviors require the caregiver to be vigilant and to find ways to work with their loved ones to ensure the care recipient's safety and the safety of others. Moreover, the problematic behaviors are reminders of the loss of the loved one due to the disease process. The third indicator consists of the amount of assistance required by the care recipient to complete their ADLs and IADLs and the care recipient's acceptance of the caregiver's efforts. Pearlin et al. (1990) asserted that it is not only the extent of the caregiving responsibilities that may create the most stress but the resistance to care that the caregiver encounters from the care recipient.

The cognitive status, behavior issues, and the daily care requirements of the individual with dementia are objective indicators of primary stressors. Pearlin et al. (1990) identified overload (burnout) and relational deprivation as subjective indicators of primary stressors. Overload captures the feelings of exhaustion, being overwhelmed, and the frustration of caregiving. Relational deprivation encompasses the loss of intimate exchanges and activities that the caregiver and the care recipient shared before the progression of dementia. An example of relational deprivation is when a daughter can no longer see her best friend or confidante in her disoriented mother or a partner who can no longer solicit advice from his loved one with aphasia.

Secondary stressors. The primary stressors, directly connected to the caregiving role, may generate secondary stressors. As seen in Figure 1, Pearlin et al. (1990) categorized secondary stressors into role strains and intrapsychic strains. The use of the term secondary is not to imply that these stressors are less intense or impactful than primary stressors but to show that secondary stressors are "an outgrowth of the ongoing caregiving situation" (p. 588).

Role strains. Pearlin et al. (1990) identified the sources of secondary stressors in the domains of family, employment, financial, and social. The family secondary stressors were themes discerned through the interviews completed by the researchers and consisted of conflicts between family members on the severity of the care recipient's level of functioning, the time and quality of attention provided to the care recipient by other family members, and acknowledging the family member's contributions in their role as caregiver. For those employed caregivers, role strains may occur between juggling the demands of their jobs and their responsibilities as a caregiver. In association with employment role strains, financial strains may also occur. Caregivers may have to decrease the number of hours they work outside of the home or leave the workforce to take on the role of primary caregiver. These changes result in a reduction of the household income, while expenditures for the treatment of the care recipient may be increasing (Pearlin et al., 1990).

The last secondary role strain involves the social and recreational domain. As the care recipient's dependency increases, caregivers have less time to pursue their social and leisure activities. (Pearlin et al., 1990). The caregiver is more isolated and may miss previous activities, and prior levels of emotional support received from friends and family.

*Intrapsychic strains***.** Pearlin et al. (1990) contended that intrapsychic strains occur when the primary stressors of caregiving begin to abrade a person's self-concept. According to the SPM, erosion can occur due to intrapsychic strains in the following five domains: mastery, self-esteem, competence as a caregiver, feelings of gain in caregiving, and one's sense of self. The researchers identified role captivity when a person takes on a role unwilling, and a loss of sense of self as two primary intrapsychic themes which emerged during the exploratory interviews (Pearlin et al., 1990). More than role captivity, the loss of self has been found to affect the psychological outcomes of caregiving (Skaff & Pearlin, 1992). The loss of self, the loss of identity that occurs as a result of immersion in the caregiver role, was found to be more prevalent among females, spouses, and younger females who had limited social contact and lacked social roles beyond their caregiving (Skaff & Pearlin, 1992).

Mediating conditions. Dementia caregivers encounter similar stressors; however, their reactions to these stressors widely vary. Researchers attribute some of this variability to mediators. Pearlin et al. (1990) asserted that mediators serve as buffers to lessen the intensity of the stressors and may limit the occurrences of secondary stressors. Two mediators frequently identified in stress research are coping and social support. Pearlin et al. (1990) identified three possible functions of coping: managing a stressful situation, managing the meaning of the stressful situation, and managing the symptoms of stress (p. 590). Social supports are divided into instrumental and expressive categories and serve the same function as coping. Instrumental social supports are those individuals who are available to the primary caregiver to offer support and care to the care recipient. Expressive social supports refer to the provision of emotional support, such as providing encouragement or being a confidant to a caregiver.

Outcomes. Pearlin et al. (1990) maintained that caregiving might affect the psychological and physical well-being of the caregiver. Findings from previous caregiving research showed that persistent, emotional distress led to deleterious physical outcomes. Also, the emotional results of caregiving may include depression, anxiety, irascibility, and cognitive disturbance. It is these emotional and physical outcomes that may contribute to the caregiver yielding caregiving responsibilities to another or placing the care recipient into a care facility. The SPM was developed to explain the outcomes of caregiving, including caregiver burden.

Caregiver Burden

Although some caregivers may experience positive outcomes from caregiving, research findings show that many experience adverse outcomes. Scholars have labeled these negative outcomes or perceptions of caregiving as caregiver burden. The definition of caregiver burden varies. Kim, Chang, Rose, and Kim (2011) defined it as a "multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual" (p. 846). Gaugler, Kane, and Langlois (2000) defined the caregiver burden as the physical, emotional, social, and economic consequences of providing care. Other researchers defined it by the number of hours spent assisting with IADLs, whereas different definitions are inclusive of time spent completing IADL and BADL (Family Caregiver Alliance, 2009).

Although caregiver burden has multiple definitions, research supports that burden is objective or subjective. Montgomery, Gonyea, and Hooyman (1985) conducted a study of 80 informal caregivers of older adults who received assistance from a chore service, which assisted the chronically ill in the community. The majority of participants were adult children (*n* = 60), including daughters (44%), sons (27%), and daughters-in-law (5%). The remaining sample was composed of "eight siblings, four nieces and nephews, one wife and seven "other" relatives" (p. 20).

Structured interviews were conducted in each participant's home and consisted of questions on demographic data and caregiving behaviors, burden, and any possible plans for placement in a care facility. Participants responded to a nine-item objective burden inventory that explored which of their caregiving activities affected specific areas of their lives (i.e., privacy and time for themselves). Cronbach's alpha was used to test the internal consistency of the measure. The measure proved to have strong reliability (Cronbach's alpha = .85). The subjective burden was assessed using a 13 item, 5 point inventory to measure the attitudes and feelings of the caregiver. The inventory had strong reliability (Cronbach's alpha =.85). Alpha values above .80 are indicators of strong internal consistency (Weiner & Craighead, 2010). The types of caregiving tasks were derived from a factor analysis from the respondent's interviews and consisted of assistance with IADLs and ADLs (Montgomery, Gonyea, & Hooyma, 1985).

The data were analyzed using the Pearson product-moment correlation. Objective and subjective caregiving were found to have a linear relationship (r = .34) with a shared variance of 12% (Montgomery et al., 1985). The findings showed that factors that contributed to the objective burden are different from those that contribute to the subjective burden. The correlates of objective burden include the caregiver's tasks and support provided by secondary caregivers; however, the characteristics of the caregiver and the care recipient did not correlate with the objective burden. The characteristics of the caregiver (e.g., age and income) correlated with the subjective burden. Also, the caregiver's age and income contributed to 17% of the subjective burden variance. The findings from Montgomery et al. (1985) suggested that it not be the number of caregiving hours but specific tasks that contributed to the objective caregiver burden. Nursing care, bathing, dressing, walking, transportation, and completing errands were significant predictors of burden.

Studies on caregiver burden for adult children have primarily focused on comparing their burden with that of spousal caregivers, and findings have been inconsistent. Some research findings report that adult children experience more significant caregiver burden (Andren & Elmstahl, 2007; Chappell, Dujela, & Smith, 2014; Molyneux et al., 2008; Reed et al., 2014), whereas others find that spousal caregivers experience more caregiving burden (Hong & Kim, 2008; Serrano-Aguilar, 2006). Conversely, other studies show no significant differences in caregiver burden between adult children and spouse caregivers (Kang 2006, Turro-Garriga et al., 2008).

Conde-Sala et al. (2010) posited that the variability in findings might be due in part to when the research occurs in the care recipient's disease process. Marwit and Meuser (2002) used the Clinical Dementia Rating Scale (CDR) to determine any correlation between caregiver burden and the stages of the care recipient's dementia. The CDR is a five-point scale used to assess cognitive and daily functioning abilities in individuals with dementia. The CDR has the following cut-off scores suggesting stages of dementia: normal cognition = 0, very mild dementia = 0.5, mild dementia = 1, moderate dementia = 2 and severe dementia = 3 (Gauthier, 2006). The Marwit and Meuser study (2002) found that in adult children, caregiver burden is low during very mild and mild dementia (Clinical Dementia Rating Scale (CDR = 0.5-1), very intense in moderate dementia (CDR = 2), and moderately intense in severe dementia (CDR 3; Marwit & Meuser, 2002, p. 1263).

Spousal caregiver burden is positively correlated with dementia progression, the peak of caregiver stress occurring at the care recipient's placement into a care facility (Marwit & Meuser, 2002, Schulz et al., 2004). Also, partial variability may be attributed to spouses living with the gradual changes that occur with AD and making small adjustments, whereas the adult-child caregiver may experience a sudden disruption in their lives while juggling additional roles (e.g., mother and employee; Conde-Sala et al., 2010). Furthermore, adult children who are compelled to take on the role of a caregiver through a sense of obligation, guilt, or social pressure are more likely to experience caregiver burden than perhaps, an intrinsically motivated spouse.

Pinquart and Sorenson (2011) conducted a meta-analysis of 168 empirical studies on the differences between spouses, adult children, and children-in-law who were caregivers to a parent with dementia and/or physical impairment. The researchers conducted a literature search using PSYINFO, MEDLINE, AGELINE, Current Contents, and PSYNDEX databases. Also, additional research was identified through abstracts of gerontological conferences. Studies before September 2010 were evaluated to determine if they met the following inclusionary criteria: comparison of spouses with adult children or children-in-law, comparison of adult children and child-in-law caregivers, size of group differences were expressed in standard deviations or the statistic used could be converted into standard deviations, and studies were in English or German, or in a language that translation was available (Pinquart & Sorenson, 2011, p. 4). The researchers excluded an estimated 24% of the studies identified through the literature review because the spouse caregivers, child caregivers, or child-in-law caregivers were compared with other caregivers, not within the inclusionary criteria.

The selected articles addressed caregiving in a minimum of one of the following domains: psychological distress and well-being, caregiver social and health resources, and caregiving stressors. Seventy-four studies focused on dementia caregiving, 19 studies on caregiving for older adults due to a physical impairment, and 75 studies included a combination of dementia caregivers and caregivers for adults with a physical impairment (Pinquart & Sorenson, 2011, p. 8). In total, the analyzed data represented research findings from 28,980 caregiving spouses, 30,739 adult children, and 4,627 children-in-law. Data analysis consisted of random-effects models and iterative maximum likelihood estimations.

The results of Pinquart and Sorenson's (2011) meta-analysis showed no significant differences between spouses and adult children in caregiver burden, that is, the overall level of distress due to caregiving. However, adult children reported more emotional stress, social strain, and job strain. The social strain was defined as "problems with maintaining other social contacts because of caregiving demands" (Pinquart & Sorenson, 2011, p. 9). Adult children reported more job strain than children-in-law. Spouses had more depressive symptoms than adult children, and adult children had more depressive symptoms (d =.24) than children-in-law (d = .24). Adult children perceived more significant uplifts, positive aspects of caregiving, than children-in-law. The study findings did not support that children-in-law provide less care than adult children. The researchers found few significant differences regarding the social resources utilized by each group. Spouses had less informal support than adult children (d = -.17) but were not significantly different in their use of formal supports or their perceptions of their relationship with the care recipient. Adult children reported a more positive relationship with the care recipient than did the children-in-law.

The Pinquart and Sorenson (2011) meta-analysis had several methodological strengths. The researchers provided the terms used for the search, identified language limitations, and attempted to collect data that may have been unpublished due to non-significant findings (Russo, 2003). The data abstraction process included a thorough listing of analyzed studies, inclusion and exclusion standards, and the use of consensus when the researchers disagreed (Russo, 2003). Pinquart and Sorenson (2011) identified the lack of children-in-law studies as a limitation for the study as well as a focus on the mean variables between the group of caregivers. By using the mean statistic, the effect of variables on other variables (e.g., job strain on depressive symptoms) could not be determined.

Caregiver burden: depression and grief. Caregiver burden has been the focus of researchers for approximately 30 years, and the outcomes of caregiving burden are vast. Physical illness, depression, anxiety, stress, emotional well-being, poor social outcomes, and grief have been predominant themes in the caregiver burden literature. For this literature review, the topic of depression is examined because of the attention it has garnered in the caregiving research. Additionally, due to its unique characteristics in the dementia caregiving journey, grief is reviewed.

Depression. In their seminal study, Dura, Stukenberg, and Kiecolt-Glaser (1991) examined how being a caregiver to a parent with dementia contributed to anxiety and depression. The study was different from previous research because the participants were only adult children, an examination of the participant's mental health history (before and during the study) was completed, the experimental group was paired with a control group, and participants were recruited from multiple sources. For the experimental group, the researchers recruited 78 participants (female = 66, male = 12) from dementia centers in local hospitals, neurologist's referrals, the Alzheimer's and Related Disease Association, respite programs, and caregiver support programs (Dura et al., 1991). The control group, which sociodemographically matched the participants, was recruited through newspaper advertisements and church groups. Any potential control group member was excluded from the study who identified active caregiving activities.

Dura et al. (1991) completed structured interviews, the Hamilton Depression Rating Scale, the Beck Depression Inventory, the Blessed Dementia Scale, the Memory and Behavior Problem Checklist, and the Global Deterioration Scale. The majority of care recipients met the criteria for severe dementia. The types of dementia represented were as follows: Alzheimer's (n = 63), Multi-infarct (n = 3), Parkinson's (n = 6), Huntington's disease (n = 3), and unspecified (n = 3).

Prior to caregiving, 30% of the caregivers reported a history of depression before caregiving in comparison to 19% of the control group, a nonsignificant difference (Dura, Stuckenberg & Kiecolt-Glaser, 1991). Most of the participants who identified a history of depression classified it as major depression. No participant in the control group was experiencing a depressive episode during the study, whereas 18% of the caregivers were diagnosed with depression. During the caregiving period, 26% of the caregivers reported significantly more depression than the control group (4%). Of the individuals with a history of depression, 37% had a reoccurrence during caregiving, whereas 22% of the caregivers (12 out of 55) experienced their first episode of depression during caregiving. Although caregivers with a history of depression may seem more likely to decompensate due to the stressors of caregiving, these findings were not statistically significant (Dura et al., 1991). The diagnosis of depression did not vary by gender, with 25% of the men and 24% of the women reporting a depressive episode during caregiving. Also, the care recipient cohabitating with the caregiver was not related to the prevalence of depression (Dura et al., 1991). The researchers assessed for other psychological disorders with 10% of the caregiving participants experiencing anxiety disorders (generalized anxiety, panic, or phobia)

Grief. Giunta (2002) defined grief as “a normal process of natural emotions and feelings which are uniquely experienced after any loss of any relationship” (p. 63). Mace and Rabins (2017) asserted that caregiving grief does not relent as it may with other losses, but is pervasive throughout the disease process. Furthermore, caregiver grief may be further complicated by the stigma associated with dementia and the lack of social support for grieving a loved one before their death (Large & Slinger, 2015; Walker, Pomeroy, McNeil & Franklin, 1994). Several studies have linked the development of grief in dementia caregivers to cognitive, emotional, or physical changes in the caregiver and/or the care recipient (Lindgren, Connelly & Gaspar, 1999; Noyes et al., 2010; Walker & Pomeroy, 1994). Although grief may not be as prevalent as depression research in caregiving, Walker and Pomeroy (1997) asserted that grief is misdiagnosed as depression when it may be anticipatory grief.

Walker and Pomeroy (1997) interviewed 100 participants (women, *n* = 83, men, *n* = 17), who were informal caregivers that provided a minimum of 20 hours of weekly care to a person diagnosed with dementia. The participants provided ADL assistance to the care recipient in the community. Thirty-one percent of the caregivers were spouses, 53% adult children, and 16% of the participants were categorized as "other relationship." The researchers administered the Grief Experience Inventory and the Beck Depression Inventory. Correlational analysis showed that grief accounted for 63% of the variance in the Beck Depression Inventory, which suggested that what appears to be depression may be more accurately described as grief and/or anticipatory grief.

Anticipatory grief. The concept of anticipatory grief was introduced by Lindemann (1944) to explain the pattern of grief experienced by World War II wives. Lindemann (1944) hypothesized that some military wives had grieved the impending loss of their spouses because they did not believe their husbands would survive. When the soldiers returned, those wives who had completed the grieving process did not wish to remain married because they were no longer emotionally committed (Bryant & Peck, 2009).

The definition of anticipatory grief is "the emotional reactions which occur before an expected loss" (Stephenson, 2014, p. 158). Holley and Mast (2009) conducted a study to explore the impact of anticipatory grief on caregiver burden in dementia caregivers.

The researchers recruited 80 informal caregivers of individuals with dementia and assessed their grief experiences while controlling for background and contextual variables, depression, and caregiver burden. The participants were recruited from advertisements, support groups, nursing homes, and referrals from physicians (Holley & Mast, p. 389). The respondents who agreed to participate in the study received a study packet which included The Revised Memory and Behavior Problems Checklist, Geriatric Depression Scale, Marwit-Meuser Caregiver Grief Inventory (MM-CGI), Anticipatory Grief Scale (AGS), Zarit Burden Inventory Short Form (ZBI-SF), and the Montgomery Burden Inventory. Participants could independently complete the measures or complete the assessments as an interview. Forty-seven participants completed the questionnaires as an interview, whereas 33 participants completed the study packet independently.

Data analysis was conducted on the 80 sets (spouse, $n = 21$, child, $n = 49$, other, $n = 10$) of data using bivariate correlations to explore the relationship between the levels of AG related to the progression of the dementia, the relationships between AG (MM-CGI and AGS) and caregiver burden (ZBF-SF and Montgomery Burden Scale). Anticipatory grief was highly correlated with caregiver burden across the measures ($r = .71$ for MM-CGI, $r = .68$ for AGS; Montgomery Burden Scale ($r = .73$ for MM-CGI) and $r =.72$ for AGS). The results indicated that anticipatory grief is a key aspect of caregiving burden.

*Ambiguous loss***.** Scholars have identified that one of the most challenging aspects of dementia caregiving is the gradual physical and psychological deterioration of a loved one (Boltz & Gavin, 2015, Jacyna & Casper, 2017, Lipton & Marshall, 2012). These challenges increase with the progression of the illness; however, dementia caregivers also experience a sense of growing confusion over the loss of a loved one who is still physically present. Furthermore, the caregiver's roles and identity within the family become unclear and uncertain. Am I still the daughter of the man that I have to dress? Am I still a son to a mother who does not remember me? Boss (1999) identified this type of "goodbye without leaving" as an ambiguous loss (p. 4).

Ambiguous loss is defined as "a loss situation that remains incomplete, confusing, or uncertain for family members (Dupuis, 2002, p. 94). Boss (1999) asserted that there are two types of ambiguous loss. The first category, ambiguous absence, may occur when an individual is physically absent but remains psychologically and emotionally present. An example of this type of ambiguous loss is the unknown whereabouts of Malaysian Airline Flight MH370 and its 227 passengers and 12 crew members (Cawthorne, 2014). Family and friends of the missing passengers and crew do not have a defined loss or proof of death. The second type, ambiguous loss, occurs when a person is physically present but psychologically and emotionally absent (Agnew, 2014). This sort of ambiguous loss may occur with dementia, stroke, addictions, traumatic brain injury, AIDS, or other chronic illnesses that may impede memory and/or alter the care recipient's personality. Regardless of the type, the ambiguous loss is an unusual, incomprehensible loss characterized as unclear, confusing, and externally caused. (Boss, 2009, p. 138).

Dupuis (2002) researched the experiences of ambiguous loss with adult children who were caregivers to a parent residing in a long-term care facility. The participants, 38 daughters and 23 sons, were the primary contacts on the resident's admission form who were in different stages in his/her caregiving career to a parent with a diagnosis of dementia. The caregiving tasks completed by the adult children were not specified. The researcher utilized a grounded theory approach with in-depth, audiotaped live interviews, and an initial interview guide. The interview guide was updated throughout the interview process to explore emerging themes. The average interview ran for approximately 90 minutes.

The Dupuis (2002) research employed a modified constant comparative method with line-by-line analysis resulting in emerging patterns across the groups of caregivers at different phases of their caregiving experiences. Shared patterns among the groups were identified as well as negative cases. Substantive codes were derived from these shared patterns, and theoretical coding was conducted to determine relationships, and the researcher constructed possible phases of ambiguous loss. The findings of the study supported the concept of ambiguous loss and suggested that family members may progress through a minimum of three phases, which included anticipating loss, living through the progressive psychological loss, and acknowledging loss (p. 100).

In the *anticipating loss* phase, the family member is in the earlier stages of caregiving (1-9 months), and the care recipient is "still very much psychologically present and remains a part of the family unit" (Dupuis, 2002, p. 101). Caregivers are concerned about the future and identify how difficult it will be to watch his/her parent progress through dementia. The uncertain future and questions surrounding their ability to cope with their parent's inevitable decline are the primary themes identified in the anticipatory loss phase.

The *progressive loss* phase occurred in the mid-phases (10 months-2 years) of caregiving and involved watching the parent's physical and cognitive status decline. The characteristics associated with the progressive loss phase are emotional pain in observing his/her parent "die mentally," a sense of helplessness in assisting a parent to maintain a quality of life, trying to include the care recipient in family functions, and maintaining the image of the parent before they had symptoms of dementia for as long as possible (Dupuis, 2002, p. 103). Also, research participants expressed that visiting with the care recipient in the facility became more challenging as the disease progressed and became increasingly painful to watch.

In the third identified phase, *acknowledging loss*, the caregivers recognized the psychological loss of their parent. The acknowledging loss stage occurred after two years or more of caregiving (Dupuis, 2002). Several participants no longer identified the care recipient as their mother or father but referred to them as "she or he" throughout the interviews, and some caregivers talked about their parents as though they were deceased (Dupuis, 2002, p. 105). Both sons and daughters expressed uncertainty over their roles in the care recipient's life and questioned whether visiting their parent in the long-term care facility was meaningful or useful. The adult children in this study used acceptance or avoidance to cope with their acknowledged loss. Those caregivers who were able to accept and reframe the ambiguous loss coped with their changing roles better than those who utilized avoidance.

The Dupuis (2002) study had several research methodology strengths. The researcher utilized member checks to enhance the accuracy of the interview transcriptions as well as the researcher's interpretation of themes derived from the interviews. Lincoln and Guba (1985) considered the member check, "whereby data, analytic categories, interpretations, and conclusions are tested with members of those stakeholding groups from whom the individual data was originally collected, is the most crucial technique for establishing credibility" (p. 314). Negative case analysis was conducted to revise the researcher's hypotheses in identifying and constructing phases of ambiguous loss. Yanow and Schwartz-Shea (2015) asserted that this process prevents the researcher from "settling too quickly on a pattern, answer, or interpretation; the researcher consciously searches for any evidence –that is, the "negative or negating case" that will force the reexamination of initial impressions, pet theories, or favored explanations." (p. 139). Also, extensive examples of quotations from the caregivers were provided to strengthen credibility and capture the compelling narrative of the caregiving experience.

Despite the strengths of the Dupuis (2002) study, limitations were identified. The author used a cross-sectional study at different times of the caregiving career when the care recipient was in a long-term care facility. The study did not follow each participant through the trajectory of the caregiving experience. Thus, the findings cannot suggest cause and effect. The research offered a snapshot of the caregiving experience in a moment in time (early [1-9 months], middle [10 months-2 years], and late stages [over 2 years]); however, inferences cannot be made that caregivers sequentially progress through the identified phases of ambiguous loss without a quantitative longitudinal study. Furthermore, the author did not provide the number of interviews conducted or additional methods used to evaluate the trustworthiness of her qualitative research (e.g., peer review, triangulation, reflexive journaling).

Although Boss' (1999) and Dupuis (2002) research has frequently been cited in grief research, there is a paucity of additional research exploring ambiguous loss with adult children who are caregivers to a parent with dementia. In a study on grief, Sanders and Corley (2003) posed the following open-ended question that captured the essence of ambiguous loss, "Do you believe that you are grieving the loss of your loved one even though he/she is still alive? Please explain." The question was part of an anonymous quantitative survey on grief. The sample for the study was obtained from the Alzheimer's Association in the Northeast region of the United States, with 253 caregivers responding to the open-ended question (Sanders & Corley, 2003, p. 41). Forty-one percent of the respondents were providing care to a spouse (*n* = 100), 46% (*n* = 112) were adult children caring for a parent, and 13% (*n* = 31) by another relative or friend (Sanders & Corley, 2003, p. 41). Sixteen percent (*n* = 11) of the male respondents characterized the stage of the care recipient's AD as mild, 39.7% (*n* = 27) were providing care to a loved one in the moderate stage of AD, and 44.1% (*n* = 30) were in the severe stage

(Sanders & Corley, 2003, p. 41). For the female caregivers, 14.5% (*n* = 25) were caring for a loved one in the mild stage of AD, 54.7% (*n* = 94) were caregivers to an individual in the moderate stage of AD, and 30.8% (*n* = 53) provided care to a loved one in the severe stage of AD.

The researchers utilized open coding to divide the data into grieving/non-grieving responses and to develop themes and thematic titles (Sanders & Corley, 2003). Of the 71 male respondents, 48 indicated that they were grieving the loss of a loved one, and 23 stated that they were not grieving (p. 42). Of the 164 female respondents, 123 reported they were grieving while 41 were not. In total, 68% (*n* = 173) of the participants indicated that they were grieving over a loved one. The researchers noted that there was some missing data in each of the cross-tabulations. The findings of grief were consistent with several results of the Dupuis (2002) study. Central themes of grief expressed by the participants included ambiguity over their relationship with the care recipient due to the person's cognitive changes, feelings of ambiguity over not knowing what was going to happen next in the disease process, a loss of previous roles, and a loss of connection to the care recipient (Sanders & Corley, 2003). The themes of relationship loss were identified in the later stages of the disease.

Sanders and Corley's (2003) research expanded on the Dupuis (2002) study by exploring the non-grieving responses of the participants. Through the data analysis, the authors determined the rationale for these responses revolve around the main themes of caregiver relief, religiosity/spirituality, and past relationship conflict (Sander & Corley, 2003, p. 42). As a whole, adult children expressed more feelings of caregiver relief due to focusing on the abilities their parent still possessed and/or because they had glimpses of the “person” in their loved one. Also, caregivers reported that their strong faith in God or a higher power was a source of comfort and proved to be a buffer against ambiguous loss or grief. Lastly, participants attributed their lack of grieving due to the poor relationship they had with the care recipient before the onset of dementia. Caregivers reported that they did not choose the caregiving role but that no one else was available, or others refused to do caregiving. Although the participants did not report feelings of ambiguous loss, they shared feelings of the loss of personal freedom and anger over being a caregiver.

Sanders and Corley's (2003) research had several weaknesses in its methodology. The authors reported using experts in the field to review the findings, which may enhance dependability and confirmability; however, no other strategy was identified to establish trustworthiness. Furthermore, the data were gleaned from one open-ended question on a survey. Thus, the accuracy of the generated themes was not verified with the participants, and the data collection method may not have captured the breadth or depth of the caregiver’s experience with ambiguous loss.

Positive Aspects of Caregiving

In comparison to the amount of research dedicated to exploring caregiving burden, there is a scarcity of studies addressing the positive aspects of caregiving (PAC). With the focus and findings of research on caregiving burden, Sanders (2005) asserted that there is an erroneous underlying assumption that caregivers experience few PAC. Morever, Netto, Jenny and Philip (2009) contended that burden continues to dominate the focus of caregiving research because scholars view the caregiving experience as one-directional, whereby "the care recipient is assumed to be the source of stress or burden on the caregiver, who is thus expected to experience adverse outcomes" (p. 246). Kahana and Young (1990) explained how PAC occur through a caregiver-centered bidirectional model. The caregiver offers care and assistance and in return may receive the companionship of the care recipient, an opportunity to express their altruistic nature and fulfill a need to be a nurturer, and experience a sense of competency and usefulness in caring for a dependent care recipient (Kahana & Young, 1990, pp. 79-80).

A qualitative study by Sanders (2005) examined the caregiving burden (strain) and gain of 85 spouses and adult children who were caregivers to an individual with dementia. Caregivers responded in writing to a series of open-ended questions as part of a survey within a quantitative study. The purpose of the open-ended questions was to gather responses about the caregivers' caregiving experience, positive and negative changes that occurred throughout their caregiving careers, and their emotional reactions to caregiving (Sanders, 2005, p. 62). The study was concurrent with the caregiving experience. The participants' responses averaged 3 sentences with the longest response being 16 sentences, and the shortest consisted of short phrases.

The sample size of the study was composed of 69% females (*n* = 59) and 31% males (*n* = 26) with the mean age of 60 (Sanders, 2005). The participants' ages ranged from 28-89. Fifty-four percent (*n* = 46) were Caucasian, 31% (*n* = 26) African American, 11% (*n* = 9) Hispanic, and 5% (*n* = 4) were Asian. Thirty-three percent (*n* = 40) of the sample were daughters, 15% wives, 14% were husbands (*n* = 17) and 8% (*n* = 10) sons. The caregivers had been providing care for an average of 4 years with 58% providing home care and 20% (*n* = 17) of the care recipients were residing in a nursing home with 17% or (*n* = 14) were living in assisted living facilities. Six percent (*n* = 5) were in another facility (e.g. hospital; Sanders, 2005, p. 62).

Sanders' research found that all the participants reported strain due to their caregiving role. Eighty-one percent (*n* = 69) reported that they had experienced gains during their caregiving careers. Sixteen individuals who provided caregiving without much support and isolation provided only strain responses. The research utilized a grounded theory approach to data analysis and derived three subcategories under the main categories of strain and gain.

The predominant themes under the category of strain were worries and uncertainty, balancing multiple demands, and being overwhelmed with care. The subcategory of worries and uncertainty included participants' responses associated with the limited control over their situations and the lack of understanding regarding what stage the care recipient was experiencing in the disease process (Sanders, 2005). Sixty-three percent of the daughters who were caregivers to a parent with dementia responded with themes of worries and uncertainty in comparison to 6% of the sons. The balancing multiple demands theme was comprised of participants' statements associated with maintaining daily care schedules and adjusting schedules for work and other caregivers. Furthermore, some caregivers reported that their caregiving role resulted in less time for their personal care and experienced a lack of individual freedom (Sanders, 2005, p. 66). Sixty-two percent of the daughters and 22% of the sons reported strain related to balancing multiple demands (Sanders, 2005, p. 65). The last theme, overwhelmed with care, was discussed by 61% of the daughters and 7% of the sons in the study (Sanders, 2005, p. 65). The overwhelmed with care subcategory was associated with the progression of the illness and the increasing emotional and physical demands of being a caregiver. Additionally, several caregivers identified the feeling of being overwhelmed with the need to accept the care recipients' failing health and mortality.

The themes associated with gain were related to the participants' feelings of self and their ability to complete a task that they did not initially think they could do. The three main categories under gain were spiritual growth and increased faith, personal growth, and feelings of mastery and accomplishment. The spiritual growth and increased faith themes were identified by participants as not only gains derived through being a caregiver, but their spirituality allowed them to cope with the strains of caregiving. Spiritual growth and increased faith was the "core gain experienced by the majority of the caregivers" (Sanders, 2005, p. 67). Forty-six percent of the daughters and 83% of the sons identified spiritual growth and increased faith as gains attained through being a caregiver to a parent with dementia. The second theme, personal growth, was linked with self-awareness and discovering unknown strengths and re-evaluating their lives to determine their priorities. Sixty-seven percent of the daughters and 14% of the sons identified themes of personal growth. The final gain expressed by the caregivers was accomplishments and mastery. The subcategory of accomplishments and mastery was associated with being able to complete caregiving responsibilities (e.g., toileting and bathing) that they initially felt they could not do and develop skills and interests that were not present before their caregiving experiences. Sixty-eight percent of daughters and 9% of sons voiced an accomplishment/mastery theme. Additionally, a few of the caregivers expressed that some of the newly acquired knowledge and skills derived from their caregiving role could be transferred to other areas of their lives.

The Sanders' (2005) study had several research methodology strengths that enhanced trustworthiness and transparency. The researcher provided the participants' demographics and presented findings that delineated between the responses provided by a daughter, son, wife, and husband. Additionally, the steps in data analysis were identified, including an outside gerontologist who developed themes from the data independently from the researcher and the use of expert validation to strengthen rigor. Expert validation, a process whereby "one or more experts (in the methodology and/or the subject matter) 'verify' or confirm the findings," was completed by two gerontologists and a director of a specialized Alzheimer's disease assisted living facility (Parahoo, 2014, p. 238; Sanders, 2005). Although the researcher utilized several strategies to enhance trustworthiness, she did not directly engage with the participants and could not clarify any respondent's answer or seek a deeper understanding of their experiences. Also, convenience sampling was used rather than purposive sampling, which is the preferred method of data collection in qualitative research (Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry, 2001).

Netto, Jenny, and Philip (2009) conducted a qualitative study with primary caregivers to individuals with dementia in Singapore. The researchers utilized a grounded theory approach using semi-structured, in-depth, face-to-face interviews for data collection. The 12 respondents were daughters (*n* = 8), sons (*n* = 2), wife (*n* = 1) and a niece (*n* = 1). Eleven of the respondent were Chinese, and one was Indian. Unlike Sanders' study, the participants were asked open-ended questions from an interview guide, and the research solely focused on caregiving gains.

Netto et al. (2009) derived three themes related to caregiver gains, which consisted of personal growth, gains in relationships, and higher-level gains. Personal growth was the most common gain and was mentioned by all of the participants and consisted of the subcategories of more patient and understanding, stronger/more resilient, increased self-awareness, and more knowledgeable. The most prevalent subcategory was "more patient and understanding" with six daughters identifying themes of patience and understanding in their responses (Netto et al., 2009). The daughters spoke of how they learned to be more tolerant of the care recipient as well as others. The personal growth theme was consistent with the findings of the Sanders' (2005) study.

The gains in relationship theme were comprised of the subcategories of a closer relationship with the care recipient, closer as a family, and improved interactions with older persons (Netto et al., 2009). The gain in relationship theme was not identified in the Sanders' (2005) findings. The most prevalent subcategory was "closer relationship with care recipient" with six respondents (daughter, *n* = 3, son, *n* = 2, and wife, *n* = 1) reporting that the caregiving experience had brought them closer to the care recipient with dementia.

The last theme, the higher-level gains, encompassed gains in spirituality and insight or enlightenment (Neto et al., 2009). The theme of higher-level gains was supported by the subcategories of positive change in philosophy, spiritual growth, and altruism. Spiritual growth was identified by eight respondents (daughter, *n* = 4, son, *n* = 2, niece, *n* = 1, and wife, *n* = 1) and was the predominant subcategory under this theme. The subcategories of the Neto et al. (2009) study within the higher-level gains themes were consistent with the Sanders' (2004) findings.

The Neto et al. (2009) study had several research methodology strengths. The researchers identified the demographics of the participants and explained the steps of their data analysis process. Furthermore, the participants' voices were integrated into the findings by using direct quotations from the in-depth interviews. The thick, rich descriptions of the respondent's experiences of being a primary caregiver to a person with dementia enhanced confirmability.

Although the study had strategies that addressed trustworthiness, there were some methodology issues. Like Sanders' study, the researchers utilized techniques from grounded theory; however, the steps of grounded theory were not completed to develop a theory from the data. Furthermore, a homogenous sample was used from one institution. A homogenous sample limits variability resulting in a limited view of the phenomenon. Additionally, a comparison of Sander's study with the Neto, Jenny, Philip's research must take into consideration that culture may have influenced the respective findings.

Sons as Caregivers

The quantity of research addressing the experiences of sons who adopt the role of primary caregiver lags other caregiving research. The research on male caregiving has focused predominantly on husbands or the different tasks performed by caregivers based on gender differences (Harris, 1998). The stereotypical views of caregiving as a woman's role and that caregiving opposes the norm of masculinity may have contributed to the paucity of studies that explore the experiences of sons as caregivers (Kramer & Thompson, 2001). Although sons may be becoming more active in caregiving, daughters have been found to step into the caregiver role twice as often as sons regardless of job status and childcare responsibilities (Grigoryeva, 2014).

Harris (1998) conducted a qualitative study of sons who were caregivers to a parent in the early, middle, or late stages of dementia. The researcher used a purposeful sample ($N = 30$). The demographic categories employed in the selection of the participants were race/ethnicity, work status, marital status, being only children or having siblings, the geographic location of siblings, socioeconomic status, and living arrangement of parents (Harris, 1998, p. 343). The sample included sons who were primary caregivers ($n = 13$) and those who were assisting a parent providing care for a spouse with dementia as secondary caregivers (*n* = 17). The researcher reported that the latter group of participants provided a level of care that exceeded the definition of secondary caregivers, and all participants were "actively involved in the parent's care" (p. 344). The participants provided varying degrees of assistance with IADLs and ADLs. Six of the sons' parents with dementia had died within a year before the study.

The demographic profile of the participants was 83% White, and 17% African American with the age mean of 50 years-old. Seventy-seven percent of caregiving sons had siblings, and 60% were married. The participants were caring for fathers (33%) and mothers (67%). The average age of the parent was 77 years, with a range of 63-96 years (Harris, 1998). Based on the son's descriptions of the care recipient's behavior, the parents were in the early to middle stages of dementia. Twenty-three percent of the care recipients were residing with their sons, 23% were living in nursing homes, 20% were living in their homes with a spouse, 7% resided in another's home, 7% were living alone in their homes, and 20% of the care recipients were deceased within the year of the study.

The data collection consisted of in-depth interviews and an interview guide consisting of questions about the son's role as caregiver, stress, and coping, interpersonal and family relationships, and meaning and motivation. The interviews lasted approximately 1.5-2 hours. A six-step content analysis was conducted on the 30 interviews. The researcher found common themes and common issues that emerged from the interviews and the responses to the questions in the interview guide. The common themes identified were: duty, acceptance, taking charge, common emotions, and work flexibility.

One of the most prevalent themes in Harris's (1998) study was a sense of duty to care for their parent with dementia. Twenty-two of the participants identified a filial obligation related to their caregiving. Eighteen sons discussed how they perceived themselves as being able to accept the dementia diagnosis earlier than other family members and how their acceptance resulted in planning for the care recipient's future. These statements were used to construct the theme of acceptance. Harris (1998) observed that acceptance did not mean the participants lacked emotional reactions to their parent's illness or their caregiving roles. The identified themes of emotions were love, pain and anguish, anger and/or resentment, and sadness mingled with compassion. Included within the emotional themes, 15 sons identified caregiver stress and burden, and all 7 sons that resided with the care recipient reported stress and burden. The caregiving sons (14 out of 23) discussed how they could help their parent with dementia due to the control and flexibility of their work schedules (Harris, 1998, p. 346). Work flexibility emerged as a common theme.

Through a content analysis of pre-selected interview questions, Harris (1998) derived the following five common issues among the caregiving sons: loss, sibling relationships, reversing roles, coping strategies, and positive outcomes. The theme of loss encompassed several areas, such as personal space, job opportunities, and personal freedom. Also, several participants spoke of the ambiguous loss or gradual loss of the parent to the disease process. Most sons reported that dementia caregiving had affected their relationship with their siblings. Some caregivers experienced a renewal of sibling rivalry while some sons became closer to their siblings. Three of the sons reported no change in their sibling relationships. In addition to changes in their sibling relationships for the majority of participants, the participants acknowledged the difficulty in adopting roles and completing tasks that their parents had done for them. Bathing and driving were especially problematic. The sons found taking the car keys away from a father who had taught them to drive was traumatic for both father and son (Harris, 1998, p. 347). As part of the pre-selected questions, the researcher asked the participants how they managed the issues of caregiving. The coping strategies used to manage the stress and burden of caregiving were as follows: problem-solving (n = 19), immersing in work (n = 11), confiding in their wives (n = 10), and finding support in their religious beliefs (n = 10; Harris, 1998, p. 347). Despite the negative aspects of caregiving described by the sons, positive outcomes of caregiving were also identified. The participants discussed three positive outcomes: a chance to pay their parents back for care, a sense of purpose and professional growth, and the importance of being a role model for their children (Harris, 1998, p. 347).

Harris (1998) reported that four types of son caregivers emerged from the data. The participants had the common characteristics that made up each theme; however, they also approached the role of caregiving differently. The types of son caregivers were the dutiful son, the son who goes the extra mile, the strategic planner, and the son who shares the care. The dutiful son's sense of obligation had motivated them to take on the caregiving role, and they may either be the sole caregiver, or they prompted their siblings to work together to provide care. The sons who go the extra mile type exceeded the dutiful son group by making multiple sacrifices. Harris (1998) equated their devotion to their parent with dementia as taking “on the role typical of a spouse caregiver” (p. 348). The sons who go the extra mile had moved the parents into their home or had moved in with their parents to be caregivers. They utilized very few, if any, outside resources to support their caregiving efforts. The sons who go the extra mile identified experiencing social isolation and stress; however, they were motivated to be caregivers by a sense of duty, and the anticipated guilt had they chosen not to help their parent with dementia. The third type of caregiving son is the strategic planner. The strategic planner carries out their caregiving roles utilizing the management skills and thoughtful planning learned from their jobs. Their “parents care became a special project to oversee, but one with which they were emotionally involved” (Harris, 1998, p. 349). As the name implies, the strategic planner strategized and planned for their parent’s care. The last son caregiver type, the son who shares the care, were partners in providing care and shared caregiving responsibilities with their partners and/or siblings. The sons who shared the care acknowledged the assistance they received from others.

The Harris (1998) study had several methodological strengths. A social worker with extensive experience in working with families and Alzheimer’s disease independently conducted data analyses from the researcher. Multiple-analyst triangulation enhances trustworthiness (Patton, 2014). Furthermore, the researcher provided the criteria used for participant selection and explained changes made to the interview questions, which increases dependability.

Sanders and McFarland (2002) conducted a grounded theory, phenomenology study with 18 Caucasian sons who identified as primary caregivers to a mother (*n* = 14) or father (*n* = 4) with Alzheimer’s dementia. The findings of the Sanders and McFarland (2002) study were consistent with several results in Harris's (1998) research. Sons discussed a sense of duty as a motivator for being a caregiver, strategizing for the recipient’s care, experiencing a range of emotions, adjusting to the role reversal, and the coordination of care with siblings (Harris, 1998; Sanders & McFarland 2002).

Sanders and McFarland (2002) found that 15 out of the 18 sons believed that other siblings or the well parent would be the primary caregiver. They had adopted the caregiver role due to their sibling's unavailability (e.g., relocation out of state) or unwillingness to take on the role of caregiver. Additionally, the sons reported that the females in their lives offered emotional support and assistance in decision-making; however, the women had “set clear boundaries on the amount of “hands-on” caregiving they would perform” (Sanders & McFarland, 2002. p. 69). The participants in the study identified interpersonal and professional conflicts as a result of their caregiving role. Interpersonal conflicts occurred with siblings when the caregiving role was shared and when the caregiving sons were attempting to meet the needs of their parent and their families. The sons reported feelings of anger, resentment, and guilt over how their caregiving roles had affected their children (Sanders & McFarland, 2002, p. 71). The professional conflicts discussed by the sons included putting their employment at risk and negatively influencing their professional development due to caregiving. Additionally, the sons acknowledged that their efforts to balance work with caregiving left them "feeling that they were doing nothing well." (p. 71).

Sanders and McFarland (2002) found that study participants accessed various community services. The services used included adult day care, home aides, respite, the office of aging, support groups, Alzheimer's Association, and long-term care. Although the sons acknowledged the importance of community services in helping them maintain the care recipient at home, they also noted several shortcomings. The men who attended support groups found them to be primarily female, and the groups did not supply needed information or education about being a caregiver. Moreover, several sons discussed how they had to educate aides and home care providers on how to provide care and crisis intervention to their parent with dementia.

Daughters as Caregivers

Several studies have indicated that spouses are at the highest risk for caregiver burden (Almberg, Grafstrom, & Winblad, 1998; Zarit, Reever, & Bach-Peterson, 1980), whereas other studies have identified daughters experiencing comparable levels of caregiver burden (Brodaty & Donkin, 2009; Chumbler, Grimm, Cody, & Beck, 2003; Simpson & Carter, 2013) or more caregiver burden (Chappell et al., 2014; Reed et al., 2014). Brody (1981) posited that the higher stress experienced by women caregivers was due to the phenomenon of "women in the middle." As the majority of adult daughters providing care are middle-aged, they feel the pressure of having multiple roles (e.g., parent, spouse, employee) competing for their time and attention that may lead to role overload. Role overload contributes to the burden of caregiving (Williamson, Shaffer, & Parmelee, 2000). Contradictory findings in other studies do not support the theory of "women in the middle" and suggest that different roles may enhance a caregiver's well-being (Scharlach, 1994; Skaff & Pearlin, 1992).

Ward-Griffin, Oudshoorn, Clark, and Bol (2007) researched the caregiving experiences of adult daughters and their mothers with mild to moderate dementia. The purpose of this Canadian study was to describe the relationship between mother and daughter during dementia care, shed light on the contextual factors that shaped these relationships, and explore the health experiences of the participants involved in dementia care. An additional focus of the research was on the fluctuating nature of the mother-daughter dyad over time. Feminist and life-course perspectives guided the study.

Ward-Griffin et al. (2007) selected 10 mothers and their 15 caregiving daughters from multiple sources (i.e., community centers, doctors' offices, community agencies, and word of mouth). The mean age of the mothers was approximately 85 years, and the average mean on the mothers' MMSE was 22/30. An MMSE score of between 21-24 is indicative of mild dementia, whereas a score between 10-20 is indicative of moderate dementia. At the time of the first interview, the mothers resided in either their own home, a daughter's home, or a retirement center. The mean age for the daughters was approximately 50 years. The majority of daughters were married (64%), had at least a post-secondary education (50%), and were employed full-time (50%) or part-time (14%). The daughters assisted an average of 3 days a week and had been caregivers to their mothers for an average of 49 months.

The data corpus of the study consisted of two audiotaped, in-depth interviews that were completed 6-9 months apart and field notes (Ward-Griffin et al., 2007). The interviews lasted approximately one hour, and the interviews were conducted individually rather than with mother-daughter dyads. The researchers asked non-directive questions to explore how the progress of dementia affects the mother-daughter relationship. Two mothers did not complete the second interview because their MMSE scores were lower than 17.

The data analysis was completed on verbatim transcripts from the participants' interviews and field notes, which consisted of the researchers' perceptions, insights, and observations (Ward-Griffin et al., 2007). Preliminary data analysis focused on characteristics, contextual factors, and health experiences of mothers and daughters. The researchers used NUDIST, a qualitative software program, for data analysis. After data analysis, two dialectical dimensions of the mother-daughter relationship were found: task focused-emotion-focused, and deficit-based-strength based. Two types of distinctive mother-daughter relationships associated with each of the dimensions emerged: Custodial, Cooperative, Combative, and Cohesive (Ward-Griffin et al., 2007). The researchers noted that the participants engaged in more than one type of relationship.

In the custodial relationship, a task-focused, deficit-based relationship, the mother-daughter view the caregiving role as a duty. Both mother and daughter report that familial caregiving expectations were the main reason for their interactions. The mother-daughter dyads in custodial relationships did not share an emotional attachment, and the lack of intimacy was a re-occurring theme throughout their lives. The daughter's role was to minimally meet the physical needs of the mother through task-focused care. The deficit-based relationship focused on the health-related physical and cognitive deficits of the mother. The primary health experience of a task-focused, deficit-based custodial relationship "is one of the objectification of the mother" (Ward-Griffin et al., 2007).

The mother-daughter combative type, emotion-focused and deficit-based relationship, exists due to the cognitive deficits of the mother. In this relationship, the daughter and mother struggle over control of dementia care. Dementia alters the power relationships in all mother-daughter relationships; however, the daughters in a combative type relationship more aggressively control their mother's behavior and activities of daily living as the mothers resist the control. Their long-standing conflictive relationship shapes the interactions between mother and daughter. As caregiving demands intensify, tension increases between the mother and daughter, and alienation of the mother may occur (Ward-Griffin et al., 2007). The escalating adversarial nature of their relationship, combined with the lack of caregiver support and increasing caregiving demands, may lead to elder neglect or abuse.

The cooperative mother-daughter, a task-focused and strength-based relationship, focus on completing tasks through the cooperation of mother and daughter (Ward-Griffin et al., 2007). The dyad works as a team to facilitate the caregiving process rather than concentrating on the mother's cognitive deficits or the daughter's caregiving burdens. They are flexible and attentive to each other's needs. Mother and daughter who share a cooperative relationship frequently have a strong, supportive family network. Furthermore, the caregiver and recipient voiced a high level of fulfillment and satisfaction in their caregiving process.

The last mother-daughter relationship is a cohesive relationship that is emotion-focused and strength-based. The daughter in the cohesive dyad acknowledges the mother's strengths and her desire for independence. A positive bond exists between the mother and daughter, and although the daughter has power, it is not "power over" as in the combative relationship. The mother and daughter engage in mutual problem-solving. The participants who shared a cohesive relationship identified mutual growth and self-actualization as an outcome of their caregiving experiences.

Ward-Griffin et al. (2007) used several research methods to strengthen credibility. The researchers used more than one data source (interviews and field notes), member checking, and peer reviewing. Additionally, the authors reported a prolonged engagement with the data. Limitations of the study were the restriction of participants who were mostly in the mild stages of dementia, and that topology may not apply to mother-father caregiving experiences. After reviewing the study, a literature search was conducted for father-daughter dementia caregiving studies; however, no published studies were found that explored their caregiving relationship.

Day, Anderson, and Davis (2014) researched compassion fatigue among daughters who were a primary caregiver to a parent diagnosed with dementia. Compassion fatigue, a possible component of caregiver burden, is defined as “the combination of helplessness, hopelessness, and an inability to be empathic, and a sense of isolation resulting from prolonged exposure to perceived suffering (Day et al., 2014, pg. 796). The researchers’ goal was to explore the factors that may put the adult daughters at risk for compassion fatigue.

The participants for the study were recruited as a sub-sample from another research project, Project ASSIST, regarding the efficacy of an intervention to decrease depressive symptoms and caregiver burden (Day et al., 2014). From the participant pool of Project ASSIST, 12 daughters who were caregivers to a parent diagnosed with dementia were selected based on stratified purposive sampling. The stratified purposive sampling was based on the number of years a potential participant had been caregiving. The timeframe of little (0-2 years), moderate (3-5 years), and considerable (6+years) time as a caregiver was used in the selection of participants to assure the representation of diverse experiences. The average mean of time of caregiving was approximately 3.3 years. Eleven daughters provided care for a mother with one daughter caring for the father.

The Day et al. (2014) study utilized semi-structured interviews with open-ended questions. After the data collection phase, the interviews were transcribed and coded based on a coding manual developed by the researchers and using a qualitative content analysis grounded in the concept of compassion fatigue. The data analyses revealed the emerging themes of uncertainty, doubt, attachment, and strain.

The theme of uncertainty was associated with the daughters' being unsure about the trajectory of the illness (Day et al., 2014). The participants frequently questioned if they were handling aspects of caregiving correctly and were concerned that the care recipient would suffer if they did not respond appropriately. Additionally, the daughters questioned whether they could effectively handle present and future problematic behavior.

The participants expressed doubt over their ability to care for their parent with dementia adequately and the discrepancy between the caregiver they were and the caregiver that they wanted to be (Day et al., 2014). Furthermore, several daughters felt that the care recipient deserved better than what they could provide and that the caregivers attempted to prevent their parent from feeling any distress over their symptoms of dementia. Day et al. (2014) asserted that the daughters' desire to spare their parents from suffering and the caregivers' exposure to suffering are factors in compassion fatigue (p. 798).

The adult daughters identified an attachment to the parent as a motivating factor to become a caregiver (Day et al., 2014). Despite the hardships described by the participants, they also shared satisfaction in their caregiving role. Although the disease process of dementia had altered their relationship, a connection or attachment continued, and the participants voiced an improvement in their relationship with the care recipient. Day et al. (2014) posited that attachment prompted and maintained the adult daughters in their caregiving roles, but it may also create a vulnerability to compassion fatigue.

The last theme, strain, was identified by every participant and was comprised of competing life demands (Day et al., 2014). The adult daughters discussed competing demands from spouses, employment, grandchildren, and social activities, such as church. The participants expressed feelings that they were missing out on things in other areas of their lives to care for their parent and some voiced feelings of resentment. In response to the burden, the participants identified several coping strategies, such as securing additional support from family and social service agencies and scheduling much-needed breaks from being a caregiver. Day et al. (2014) reported that these coping strategies might be buffers to prevent compassion fatigue.

The Day et al. (2014) study utilized several strategies to strengthen trustworthiness. A stratified purposive sampling based on the time that the adult daughters had been caregivers to a parent with dementia elicited a variety of responses. The use of a coding manual by the researchers during data analysis and member checking to review the participants' verbatim transcripts enhanced credibility. Furthermore, the researchers' documentation of the participant's direct quotations in the findings provided thick, rich descriptions of their caregiving experiences enhancing transferability. The Day et al. (2014) study discovered themes that were present in the caregiving experience, which are known to be contributing factors of compassion fatigue in health care professionals; however, the study did not confirm compassion fatigue in the participants.

Brief summary: daughter and son caregivers. Research findings have found similarities and differences between the caregiving experiences of adult sons and adult daughters who were caregivers to a parent with dementia. Several research findings suggested that adult daughters experience more caregiving burden than sons. Adult daughters express more themes of worry, uncertainty, and strain due to their multiple roles. Additionally, adult daughters reported being overwhelmed with their caregiving roles more than sons. Although some researchers have found a caregiver burden more prevalent among adult daughters than sons, daughters also voice more themes of personal growth and increases in self-esteem due to their caregiving roles.

Adult sons, like adult daughters, identified several positive outcomes of caregiving. Findings from several studies indicated that sons and daughters identified themes of accomplishment and mastery and spiritual growth (Peacock et al., 2010; Ribeiro & Paul, 2008; Sanders, 2005). The theme of spiritual growth and increased faith was voiced by more sons than daughters. Both progenies identified that residing with the care recipient increases their caregiving burden, and for some, the caregiving role is undertaken due to a sense of duty (Harris, 1998; Ward-Griffin et al., 2007).

Chapter I Summary

The research question of the current study was: What were the lived experiences of adult children who were primary caregivers to a parent with dementia? Chapter I discussed the history of dementia, the various forms of dementia based on the *DSM-5*

(APA, 2013) criteria, and offered a glimpse into the varied and expansive scholarly literature on adult children who were caregivers to a parent with dementia. Although there has been a multitude of studies addressing specific aspects of caregiving, such as caregiver burden, a paucity of research exists that examines the continuum of the caregiving journey from the perspective of the adult child who is no longer the primary caregiver.

CHAPTER II

METHODOLOGY

The goal of the current study was to identify and explore the caregiving experiences of adult children who were primary caregivers to a parent diagnosed with dementia and the meanings they ascribed to their caregiving. Although dementia caregiving is well-researched predominantly utilizing quantitative methodologies to study specific caregiving variables, there is a lack of studies that explore the caregivers' experiences throughout their caregiving journey. Furthermore, caregiving research has focused on aspects or outcomes of caregiving as the caregiver was actively involved in the caregiving experience. The research question for the current study was: What are the lived caregiving experiences of adult children who were primary caregivers to a parent with dementia? This chapter offers an overview of the methodological design, a descriptive phenomenological methodology utilized in this study.

Phenomenology as a Philosophy

Phenomenology originated as a philosophy from which numerous qualitative methods have evolved. This section offers a brief history of the major philosophical underpinnings of descriptive phenomenology, the specific phenomenology approach used in the current study. An examination of phenomenology through a philosophical lens may promote a better understanding of the shared tenets of phenomenology and descriptive phenomenology research.

History of Philosophical Phenomenology

The term phenomenology is a combination of two Greek terms, *phainomenon* and *logos*. The Greek word *phainomenon* is from the verb *phanethai* that means to "show oneself" (Broome, Harland, Owen & Stringaris, 2013). *Logos* is related to *legein,* which translates into "making manifest by speech" (Kockelmans, 2012). The goal of phenomenology is to study the essential features or structures of experience of a person's (or a collection of persons') lived experience. Spiegelberg (2012) hypothesized that the philosophy of phenomenology evolved through three phases: the preparatory phase, the German phase, and the French phase. In the preparatory stage, Franz Brenton (1838-1917), a German philosopher, asserted that phenomenology was a way to describe and explain the human experience without using the cause and effect theories of a quantitative paradigm (Spiegelberg, 2012).

The German phase of the phenomenological movement was led by Edmund Husserl (1857-1938) and Martin Heidegger (1889-1976). Husserl is known as the father of phenomenology, and his theories form the foundation of phenomenological research. Husserl took an epistemological stance throughout his philosophy and asked the question: "How do we come to know the world?" (Kockelmans, 1994). Heidegger, Husserl's colleague, initially adopted Husserl's epistemological approach; however, he moved into the ontological questioning of existence and being (Raffoul & Nelson, 2013). Heidegger asked the question: "How do we live in the world?" Despite Husserl and Heidegger's theoretical differences, they shared many of the same phenomenological foundations.

Husserl’s theories informed descriptive phenomenology, whereas Heidegger’s theories were the foundation of hermeneutical (interpretative phenomenology).

The third and final phase of the phenomenology movement, the French phase, occurred shortly after Husserl’s death. During this phase, groundbreaking philosophers such as Gabriel Marcel (1889-1973), Maurice Merleau-Ponty (1908-1961), and Jean-Paul Sartre (1905-1980) expounded on the theories of Husserl and Heidegger (Speigelberg, 2012). Perhaps the most significant contributions during this era were made by Maurice Merleu-Ponty and Amedeo Giorgi, who adapted the tenets of philosophical phenomenology to the qualitative research methodology.

Descriptive phenomenology. Edmund Husserl was the founder of the descriptive phenomenological approach to scientific inquiry. Husserl’s central concept was that consciousness is essential to all human experience and that personal biases interfere with experiencing pure consciousness. Husserl hypothesized that the *lifeworld*, the world that is experienced in everyday living, receives no reflective attention. Generally, people do not make their lived experiences in the lifeworld a focus of conscious awareness. People take their experiences for granted without considering whether things may be different or how things happen (Wapner, Yamamoto, & Minami, 2012). Husserl asserted that lived experiences might be discovered through one-to-one interactions between a researcher and the person or people who have experienced the phenomenon. To create a more enlightened representation of the phenomenon than what may have previously been known, the interactions between the researcher and the participants must involve active listening, interaction, and observation (Husserl, 1970).

Additionally, Husserl posited that an individual might describe the universal or essential structures of a phenomenon only through *transcendental subjectivity*. Transcendental subjectivity is an altered sense of consciousness, whereby the researcher suspends or sets aside his or her lived experiences to not influence the description or understanding of the phenomenon (Smith, 2013). According to Husserl, transcendental subjectivity may be achieved through the process of bracketing.

Bracketing is defined as the "process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon" (Polit & Beck, 2009, p. 268). Giorgi (2000) described bracketing as (a) separating the phenomenon from the world and inspecting it; (b) dissecting the phenomenon to unravel the structure, define it and analyze it; and (c) confronting the subject matter on its terms, to ensure that the researcher suspends his or her assumptions about the phenomenon while listening, interacting and analyzing the narratives of the participants. It is through bracketing that an individual may see the phenomenon with "fresh eyes" or a "naïve realism" and accurately describe it (Giorgi, 2000). Husserl did not view bracketing as a way to exclude reality from a phenomenological inquiry but as a means through which an individual explores the phenomenon with a new reflective attitude (Gallagher & Zahavi, 2013).

Bracketing is the first step in descriptive phenomenological methodology, as the researcher attempts to achieve the conscious state of unknowing so that he or she may be open to the phenomenon (Munhall, 1994). Bracketing may be completed in multiple ways, including using a reflective journal, a peer reviewer who challenges the researcher's methodology and insights, and the researcher's ongoing vigilance in understanding how their biases may be influencing the data analysis.

The second step in the process of descriptive phenomenology is *intuiting*. In intuiting, the researcher attempts to view the phenomenon unencumbered from prejudice as much as possible so that it can emerge and be precisely described and understood. Intuiting requires the researcher to be wholeheartedly immersed in the data and to be open to the participants' experiences of reality. Spielberg (2012) described intuiting as:

> One of the most demanding operations, which requires utter concentration on the object intuited without being absorbed in it to the point of no longer looking critically. Nevertheless, there is little that can be given by way of precise instructions beyond such metaphoric phrases as "opening his eyes," "keeping them open," "not getting blinded," looking and listening (p. 682).

Through intuiting, the researcher experiences moments of insight in which the phenomenon shows itself and comes into a clearer focus. These series of "aha experiences," small and great, combine to show patterns, relationships, and nuances of the phenomenon. Ultimately, through these moments of insight, the researcher gains an understanding of "what it must be like to walk in the participants' shoes."

The third step in the process of descriptive phenomenology is *analyzing*. The purpose of analyzing is to identify the essential features, the essence, of the phenomenon.

The researcher uncovers the essence of the phenomenon through extracting significant statements, categorizing, and constructing themes from the data collected from the participants. Data analysis methods frequently used in descriptive phenomenology are methods by Giorgi (2000) and Van Kamm (1966). Colaizzi's data analysis method was adopted for the current study. Colaizzi's data analysis method, consisting of seven systematic steps, provided a logical, rigorous framework to analyze the data consistently. This method is described in more detail later in this chapter.

The final step in descriptive phenomenology is describing. Describing entails offering a rich, textural description of the lived experiences of the participants complete with structural descriptions detailing how they experienced the phenomena based on personal, contextual factors (Smith, 2015). Additionally, the researcher acknowledges the commonalities and variations among the participants. During this step, the essential features of the lived experience are defined.

The Researcher's Demographics

I am a Caucasian female enrolled as a doctoral candidate in the Counselor Education and Supervision program at Kent State University, Kent, Ohio. Additionally, I am a Licensed Professional Clinical Counselor with a supervision designation in the state of Ohio and have approximately 29 years of experience as a counselor. I have provided counseling services to patients in an inpatient geriatric psychiatric unit and clients in an outpatient mental health program for older adults. During my employment in the outpatient geriatric mental health program, I also counseled adult children who were caregivers to a parent with dementia through a grant-funded program in Cleveland, Ohio. I have been in the role of a secondary caregiver and assisted a care recipient in the absence of the primary caregiver or when the primary caregiver needed respite. Additionally, I was primary caregiving to my parent; however, my direct caregiving experiences have not been in the care of a person with dementia.

Through a reflexive journal, I explored my professional and personal caregiving biases throughout this study. Additionally, I examined the findings from my literature review. I reflected on ways that the caregiving research influenced my thoughts and feelings on the caregiving career of an adult child who is a primary caregiver to a parent with dementia. I acknowledged the following assumptions about the caregiver role and the dementia disease process during my initial bracketing:

1. Dementia caregiving is more challenging physically, emotionally, and mentally than caregiving for other chronic illnesses due to the long course of the dementia disease process and its assault on an individual's cognition and physical well-being.
2. Dementia caregivers who cope with their loved one's troubling behaviors (e.g., wandering, hallucinations, aggressiveness, sleep dysregulation) will experience more physical and mental health issues.
3. Dementia caregiving affects every facet of the caregiver's life, including social, marital/family, financial, and career.
4. Adult children grieve the loss of their parent with dementia throughout the caregiving process (i.e., before death).

5. Community services are non-existent or insufficient in number to properly serve and support dementia caregivers.
6. Although they may have siblings, one adult child shoulders most of the caregiving tasks and responsibilities.
7. The role of the caregiver changes and evolves as the disease process progresses.
8. Dementia caregivers experience positive and negative aspects of caregiving. The positive aspects of caregiving may be feeling closer to the care recipient, learning skills to deal with challenging situations, and giving back to the person who cared for them. The negative aspects of caregiving may include: physical exhaustion, feeling overwhelmed in juggling multiple roles, and financial strain.
9. Adult children who are caregivers to a parent with dementia fear that they will develop the illness.
10. Dementia caregivers may experience embarrassment or shame due to their parent's diagnosis.
11. Adult children who are caregivers to a parent with dementia would benefit from supportive counseling during and after their caregiving careers.
12. Dementia caregivers frequently experience stress, anxiety, self-doubt, and feelings of being overwhelmed.
13. Dementia caregivers experience moments of happiness and joy during their caregiving roles.

The Co-Researchers

In agreement with Husserl's (1970) assertion that an individual can only know what is experienced, I chose a purposeful sampling method. Wood and Christy (1999) defined the characteristics of purposeful sampling as "informationally representative of the phenomenon, deliberately biased, and of sufficient size and composition to draw illustrative inferences" (p. 189). Participants in the current study were regarded as collaborators and joint investigators of the phenomenon of caregiving for a parent with dementia. In acknowledgment of being co-creators of the research, participants are referred to as co-researchers. The co-researchers were selected utilizing a criterion sampling that is consistent with the phenomenological research methodology (Creswell, 2012).

I chose co-researchers, who could provide in-depth and rich accounts of their caregiving experiences. Co-researchers were selected based on the following criteria: (a) the adult child was 21 years or older during their primary caregiving experience, (b) identified their relationship to the care recipient as a daughter, son, daughter-in-law, son-in-law, partner to the daughter, or partner to the son or an adult child who identified a grandparent in a parenting role, (c) self-reported as a former primary caregiver who provided the majority of direct care to his or her parent with dementia (a minimum of one activity of daily living (ADL) and three instrumental activities of daily living (IADLs), (d) the care recipient had been diagnosed with dementia by a healthcare provider and, (e) adult children who transitioned from being the primary caregiver to a secondary caregiver role (e.g., the parent required nursing home placement or another family member assumed the role of primary caregiver).

Recruitment process. The recruitment process for co-researchers began after Institutional Review Board approval was obtained from Kent State University, and a web page to the study was created (see Appendix A). Co-researchers were recruited with the assistance of administrators from two nursing homes in Jefferson County in Ohio. Additionally, recruitment occurred at The Counseling Center in Columbiana County in Ohio in cooperation with outpatient services, The Senior News (print publication and web version), and indeed.com website. Each recruitment organization received a copy of the IRB approval letter, a recruitment flyer, and an internet website recruitment posting (see Appendices A, B, and C). No potential co-researchers from The Counseling Center or the two nursing homes expressed interest in participating in this study.

Co-researchers were recruited through online recruitment advertisements (e.g., indeed.com, and a print publication, The Senior News. The flyer contained general information on the study, including my contact information, as well as a quick response code (QR code). The QR code is a “matrix code that enables a representation of binary-coded data to store information such as URLs, SMS, and texts” (Gardner, Haeusler, & Tomitsch, 2010, p. 30). The information encoded in the QR matrix may be accessed through a mobile phone or tablet device with a QR scanning application. For this study, a QR code inserted into the recruitment flyer was embedded with a URL code to the study’s web page. A potential co-researcher could scan the QR code with a mobile device and access an introductory letter (see Appendix D) that contained additional information on the current study. Additionally, potential co-researchers could access the study's webpage by inserting the study's web address found on the recruitment flyer into any computer web browser or use the hyperlink on the internet website recruitment posting (see Appendices B and C).

The study's website consisted of the introductory letter and the screening assessment (see Appendices D and E). After reading the introductory letter, a potential co-researcher could continue to the screening assessment (see Appendix E). Co-researchers' responses on the screening assessment were sent over a Secure Socket Layer encrypted connection. The individual could exit from the survey website at any time without penalty and was not required to complete any instrumentation.

Potential co-researchers who did not utilize the QR code or directly access the study's webpage contacted me via email or phone. Individuals who responded by email were emailed the introductory letter and the screening assessment as attachments. Also, a hyperlink to the current study's website was provided in the email. Potential co-researchers had the option to complete the instrumentation by phone, email, or online via the hyperlink to the survey's website. The recruitment process continued for approximately two months after the recruitment materials were posted.

Selecting co-researchers. During the recruitment process, 43 people contacted the researcher by phone and email and voiced their interest in participating in the current research. Twenty-one individuals who met the inclusionary criteria were directed to the study’s website and invited to complete the web screening informed consent form (see Appendix F) and screening assessment, whereas twenty-two individuals did not meet the inclusionary criteria. Six individuals were currently providing care to their parent/parent-in-law, three lived out-of-state, and were unavailable for face-to-face interviews, and twenty-two individuals were caring for residents in nursing home facilities, but were never primary caregivers to their parent with dementia. Those individuals who did not meet the criteria were emailed a letter of appreciation for their interest but were not selected for the study (see Appendix G). Fourteen of the twenty-one individuals who were invited to the study’s website completed the informed consent form and the online screening assessment.

I reviewed the 14 respondents’ information from the online screening assessment and selected co-researchers who represented various demographic variables (e.g., age, geographic location of caregiving, race/culture, relationship to the care recipient, and employment status while caregiving; see Appendix E and Table 1). The goal of reviewing the online screening assessments was to maximize variability and capture the diverse voices of adult children who were primary caregivers to a parent with dementia.

Historically, qualitative researchers have debated about the number of participants needed to illuminate the experience adequately. Sandelowski (1995) suggested a sample size of 6 to 12 co-researchers for a phenomenological study, whereas Giorgi (1985) recommended a minimum of 3 participants to capture the variation of the essences of experience. Creswell (2012) asserted that 5 to 25 co-researchers comprised an adequate sample for a phenomenological study.

Although some qualitative theorists offer general guidelines for choosing a sufficient number of participants, others contend, such as Patton (2014), that "there are no rules for sample size in qualitative inquiry" (p. 311). When considering the number of participants to recruit, I aspired to have a sample large enough to capture the essential perceptions of caregiving for a parent with dementia but not too large as to create redundant, extraneous data (Morse, 2010). In agreement with Lincoln and Guba (1985) that data saturation determines the number of participants, I reserved the option to recruit additional co-researchers if data saturation had not occurred during data analysis. A list of 4 unselected participants from the 14 respondents who had met the inclusionary criteria during the recruitment process was retained should additional participants be needed to achieve data saturation. These possible participants were emailed participation status letters informing them that they were not selected for the study; however, they may be contacted at a later time if more participants were needed (see Appendix H). Data saturation was reached after the data analysis showed no additional themes, and subsequent findings were redundant. The four unselected, possible participants were not recruited for the current study.

***Initial contact with the selected co-researchers*.** After reviewing the screening and demographic information, I emailed 10 co-researchers who met the inclusionary criteria and represented a range of demographic variables (e.g., relationship to the care recipient, employment status during their caregiving role, geographic location) and invited them to participate in the study. In the email correspondence, I reiterated the purpose of the study, verified the co-researcher's preferred contact information, and encouraged them to ask any questions they had regarding the research process. Additionally, the study's informed consent form was included as an email attachment for the potential co-researcher to review (see Appendix I). Ten individuals consented to complete two face-to-face and audio-recorded interviews and to provide feedback on my preliminary interpretations of their first and second interviews as part of the data analysis (member checking); however, two individuals opted-out of the study before the first interview. One respondent opted-out due to other commitments, and the other reported that he was, upon reflection, "still too emotional" to discuss his caregiving experiences. The final sample was comprised of eight people who agreed to be co-researchers (see Table 1). The date and time of the first interview were determined through the mutual agreement as well as the location of the interview. All the interviews occurred in local community settings (e.g., library conference rooms, and quiet spaces in hospitals).

I sent the co-researchers via email the interview guide (see Appendix J). Each question in the interview guide was asked of each participant, and additional follow-up questions were asked based upon the co-researcher's responses.

Phenomenological Interview

Although qualitative studies frequently use interviews in data collection, a descriptive phenomenological methodology may integrate Husserlian principles into the interview process. Bevan (2014) contended that contextual, descriptive and structural, and imaginative variation questions contextualize, capture, and clarify the meaning of a phenomenon. Contextualization questions may be used to explore the co-researcher's life-world and natural attitude, and to contextualize the phenomenon. Descriptive and structural questions may be asked to identify the modes of appearance of the phenomenon, thus capturing the various ways that phenomena are experienced. Lastly, imaginative variation questions may elicit responses that clarify the meaning of the phenomenon.

Contextualization. Husserl (1970) posited that experiences of the life-world, become figure against the background of the horizon (context), with the individual's history, adding meaning to the experience. Thus, there can be no meaning-making or understanding without the researcher exploring the context in which the experience occurred. For example, the researcher may ask co-researchers about their experiences of being a primary caregiver to a parent with dementia; however, without understanding the context of the caregiver's biography such as the caregiver's prior relationship to the care recipient, their duties and responsibilities beyond their caregiving role, and available social supports, a co-construction of meaning cannot occur. Bevan (2014) believed that contextualizing questions "enables a person to reconstruct and describe their own experiences as a form of narrative" (p. 139). Furthermore, contextualization questions may elicit richer descriptions by asking for specific examples of actual events, behaviors, or activities that illuminate the experience (Bevan, 2014). "What was your relationship like with your parent before you became their caregiver?" was an example of a

Table 1. Demographic Data on the Co-Researchers

Co-researcher (pseudonym)	Gender	Parent Who Received Caregiving	Race	Type of Dementia	Residential Status During Caregiving
Edna	Female	Father	African American	Substance-Induced (Alcohol)	Care recipient resided with the primary caregiver until nursing home placement
Molly	Female	Mother-in-Law	White	Alzheimer’s	Care recipient resided at home until nursing home placement.
Joseph	Male	Mother Father	White	Alzheimer’s Alzheimer’s	Care recipient resided with the primary caregiver (Father was placed in a nursing home)
Beth	Female	Father	White	Parkinson’s Disease Dementia	Care recipient resided in his home until nursing home placement.
Allyssa	Female	Mother (biological grandmother)	African American	Dementia Due to a Medical Condition	Care recipient was placed in a nursing home after diagnosis due to declining health. Caregiver assisted with hospice care.
Diane	Female	Mother (biological grandmother)	White	Alzheimer’s	Care recipient lived with her caregiver.
Scott	Male	Father	White	Alzheimer’s	Care recipient lived with caregiver
Meg	Female	Father-in-Law	White	Alzheimer’s	Care recipient lived with caregiver

Table 1-Continued

Name (pseudonym)	**Age at the Time of Being the Primary Caregiver**	**Relationship Status**	**Employment Status**
Edna	39	Single, but cohabitating with significant other	Full-time employment (Healthcare Office Coordinator)
Molly	38	Married	Not employed (Employment Training Specialist)
Joseph	60	Single	Not employed (Hospital Administrator)
Allyssa	35	Married	Full-time employment (Healthcare Management)
Beth	50	Single, but cohabitating with significant other	Full-time employment (Licensed Social Worker)
Diane	30	Single, but cohabitating with significant other	Full-time employment (Healthcare Patient Advocate)
Scott	53	Married	Disabled, unable to work (Skilled Tradesman)
Meg	54	Married	Retired (Government/County Social Service Worker)

contextualization question used in this study (see pp. 130-137) for the co-researchers' responses).

Descriptive and structural questions. According to a tenet of phenomenology, the experience of a phenomenon is not static, and the modes of appearing are known in many variations (Schmicking & Gallagher, 2009). Modes of appearing means that the phenomenon is experienced in multiple ways and from different perspectives (Bevan, 2004, p. 137). For example, a caregiver experiences the meaning of caregiving when they are dressing their parent, speaking to a healthcare professional, attempting to de-escalate an angry mother voicing paranoid thoughts, or experiencing role-reversal (e.g., when the adult children felt as if they were in the parental role and their parent was the child). It is through these multiple modes of appearing that the phenomenon is constructed. Asking open-ended questions that capture an event or specific activity helps the researcher discover how the co-researchers construe their experiences. For example, when a co-researcher identified experiencing role-reversal in their caregiving careers, I asked descriptive and structural questions to understand how adopting a parenting role in their relationship with the care recipient impacted their caregiving experiences (see pp. 180-181 for the co-researchers' responses.)

Imaginative variation questions. King and Horrocks (2010) define imaginative variation as "the process of imaginatively altering aspects of a phenomenon to clarify which are essential to the experience of it" (p. 184). The goal of imaginative variation is to discover the invariant aspects that belong to the identity or essence of a thing (Moran, 2002). Husserl (1970) described the process of imaginative variation through how an individual perceives a table. Through the imagination, the attributes of a table are altered until it can no longer be identified as a table. For example, can an item be defined as a table without legs? Does a table need to have a surface? Does a color define what makes an item a table? The essential features that must be present to retain the identity of the table comprise the essence of the table. The process of imaginative variation is completed during data analysis and bracketing. However, this method may also be utilized during the data collection phase.

Bevan (2014) posited that imaginative variation questions might be used with contextual descriptions to clarify the invariants or essential features of experience. The goal of using imaginative variation questions is for the co-researcher to reflect on a phenomenon and explain how it would change if certain aspects were altered (King & Horrocks, 2010). The researcher using this form of questioning must exercise caution not to lead the co-researcher or "unbracket," a researcher's bias (Bevan, 2014, p. 142). Although several co-researchers requested clarification on the imaginative variation questions, I was mindful of paraphrasing the questions and not provide examples of possible responses.

Bevan (2014) recommended that imaginative variation questions be derived from each co-researcher's interview and grounded in his or her experiences. "Would your caregiving experiences have been different if you were the secondary caregiver and your sibling (or another family member) was the primary caregiver?" is an example of an imaginative variation question that was asked to each co-researcher. Each of the co-researchers responded that they would have continued to provide care to their parent with dementia; however, four of the eight offered examples of how their lives would have been different if they had not assumed the primary caregiving role. For example, Joseph shared:

> If my sister had been the primary caregiver…I would've still been over there, but not as much. I would've done the same things that I used to do. Go out. Date girls. Things like that. I was always a party guy, and that went away. I would've kept working. I would've lived like before.

Co-Researchers' First Interview

I met face-to-face with each co-researcher in a private area in local community settings. At the beginning of the initial interview, I reviewed with each co-researcher the informed consent form (see Appendix I). I informed the participants, verbally and in writing, of (a) the purpose of the study, (b) the research process, (c) how I would utilize the research findings, (d) the types of questions that will be asked, (e) participant's confidentiality, (f) possible risks and benefits of participation and, (g) data management and security. After each co-researcher had signed the consent form to participate in the study and the audio recording consent form (see Appendix K), we began the initial audio-recorded interview.

The interview was conducted in a semi-structured format. It was comprised of a set of pre-determined, open-ended questions, with additional questions emerging from the interaction between the researcher and the co-researchers. Co-researchers had the right to "pass" on any question and not respond. Furthermore, they could terminate the interview and their participation in the study at any time without penalty. The standardized questions from the interview guide were asked of each participant (see Appendix J).

The duration of the first interview averaged 58 minutes with the minimum interview time of 55 minutes and the maximum interview time of 65 minutes. Before concluding the interview, I asked each co-researcher if there was any additional information that he or she would like to share and scheduled the time and place for the second interview. Additionally, each co-researcher received a $15 gift card (Walmart, Amazon, or Target) in appreciation of their participation at the end of the first interview. After each first interview, I documented any insights regarding how the interviews progressed, formulated follow-up questions for the co-researcher's second interview, identified data patterns, and explored my feelings and biases in a reflexive journal.

Co-Researchers' Second Interview

The second interview was scheduled after the preliminary, individual thematic findings from data analysis of the first interview were completed and occurred approximately four to six weeks after the first interview. At the beginning of each interview, I shared the themes that emerged from their first interview. The purpose of the second audio-recorded interview was threefold: (1) to conduct member checking, (2) complete the second set of questions in the interview guide (see Appendix J), and (3) to ask follow-up questions based on the co-researcher's first interview.

The second face-to-face interviews averaged 55 minutes with the minimum interview time of 48 minutes and the maximum interview time of 63 minutes. Each co-researcher received a $15 gift card after the completion of their second interview in appreciation for their participation. As I did after the first interview, I documented my thoughts on the co-researcher's responses to the interview questions, identified data patterns, and completed bracketing in my reflexive journal. Additionally, I documented my impressions of each of the co-researcher's responses to the member checks from their first interviews.

Member Checking

Member checking consisted of getting feedback from each co-researcher on my interpretations (thematic findings). The first round of member checking occurred during the co-researchers' second interview. It consisted of the co-researcher receiving a printed copy of the themes that emerged from their first interview, a brief overview, and explanation on the concept of themes, and a discussion of the initial findings from their first interview. The second round of member occurred through email exchanges approximately six weeks after the co-researchers' second interviews. Each co-researcher received an email that described their themes from the second interview as well as themes that emerged across all of the co-researchers. Each of the eight co-researchers responded to the following questions for the two member checks :

1. How do the themes or main points from my interpretation of your interview match your experiences as a caregiver?
2. How do the themes or main points from my interpretation of your interview differ from your experiences as a caregiver?

Any additional member checking questions were derived from the interaction between myself and the co-researcher. The co-researchers were encouraged to respond with any additional information to clarify their caregiving experiences and corroborate themes. I reviewed the transcript and coding against any misinterpretation identified by a co-researcher and made changes as supported by the data.

The eight co-researchers agreed the themes reflected their caregiving experiences. For example, Joseph responded in his member checking through email, “You nailed it. I did all those things. Absolutely, right.” Allyssa described the thematic findings from her interview as “summing up her caregiving experiences accurately and nicely.” Beth responded in her email member check, “Your points [themes] were right. I spent so much time advocating for him [father]. They [nursing home staff] just don’t care.”

Two co-researchers provided additional information to clarify their responses. During Molly’s first member check, she shared additional information about her decision-maker role and utilizing her daughter to assist with ADLs:

> I did remember after our interview. I don’t know if I told you, but my oldest daughter, she [mother-in-law], would allow her to help a little more. They had a special relationship, and that really helped.

Diane discussed during her first member check the empathy or longing she had to understand what her grandmother was experiencing:

> I wanted to understand where she was. What it was like for her. Like where are you? What are you thinking about?

The purpose of member checking was to solicit each co-researcher’s input regarding the credibility of the researcher’s interpretation of his or her caregiving experiences based on the data collected from their two interviews. Furthermore, member checking served to guard against researcher bias (Heppner, Wampold, Owen, Thompson, & Wang, 2015).

Data Analytic Steps

I completed an inductive analysis of the transcripts from the two rounds of interviews utilizing NVivo 11, a computer software package for qualitative data analysis. NVivo was used to organize and retrieve the coded data. The inductive analyses were data-driven, and the coding categories were not pre-determined. I analyzed the data informed by Colaizzi's descriptive phenomenological method (see Table 2). The focus of the Colaizzi method is to uncover the meaning of the "lived experiences" through the transcribed text, with the goal of enhancing the understanding of the meaning of an experience (Colaizzi, 1978). I completed the first four data analytic steps for each co-researchers' verbatim transcripts. After theme development and refinement, Colaizzi's 5-7 steps were completed using the themes that emerged across the eight co-researchers.

Step 1: Becoming familiar with the data. I listened to each audio-recorded interview before beginning the transcription process. In agreement with Hardy and Bryman (2009) that the transcription is part of the analytical process, I transcribed the recordings into verbatim accounts of the interviews. I assigned to each interview (two interviews per co-researcher) an attribute code comprised of the co-researcher's pseudonym, demographics, and dates of the interview to each interview. The completed transcripts were checked against the recordings for accuracy, and I corrected any transcription errors such as the omission of a word and a misheard word spoken by a co-researcher. I read the transcripts repeatedly to grasp the uniqueness of the experiences of adult children who had been primary caregivers of a parent with dementia.

Step 2: Identifying the significant statements. I reviewed my assumptions regarding being a primary caregiver to a parent with dementia (see pp. 95-96) and bracketed any additional biases in my reflexive journal. Bracketing was completed before any qualitative coding to suspend my judgments about caregiving and promote immersion in the data.

In this stage of the analysis, significant statements and phrases related to the co-researchers' experience of being a dementia caregiver were extracted from each transcript. The identified significant statements were saved to an NVivo file. Included with each significant statement was the pseudonym of the co-researcher, the interview date, and the location of the significant statement on the page of the transcript. As per Auerbach and Silverstein's (2003) recommendation, I referred to a copy of my research question throughout this step to guide my selection of significant statements.

Additionally, as part of my data analysis, I adapted several of the following questions recommended by Emerson, Fretz, and Shaw (1995, p. 146) to assist in the extraction of the significant statements of the co-researchers:

1. What did the caregiver do? What were they trying to accomplish for the care recipient?
2. How did the caregiver do this? What specific means or strategies did they use?
3. How did the caregivers talk about, characterize, and understand his/her caregiving?

Table 2. Colaizzi's Seven Steps in Data Analysis.

Morrow, R., Rodriquez, A., & King, N. (2015). Colaizzi's descriptive phenomenological method. The Psychologist, 28(8), 643-644.

Steps	Description
1. Becoming familiar with the data	• Reading through the data several times
2. Identifying the significant statements	• Identify all statements in the data that are relevant to the phenomenon being studied
3. Formulating meanings	• Reviewed each significant statement and identified meanings that were relevant to the phenomenon • Bracketing assumptions about the phenomenon
4. Clustering themes	• Clustering the formulated meanings into themes. Themes were derived from each co-researchers interviews (interviews 1 and 2) • Bracketing assumptions about the phenomenon.
5. Develop an exhaustive description	• Complete a detailed description of the phenomenon, including the themes derived from step 4.
6. Identify the fundamental structure of the phenomenon	• Condense the exhaustive description into a concise description that captures the essential structure of the phenomenon
7. Validate the description of the lived experience	• Member check with the participants to determine whether the fundamental structures capture their experiences

Step 3: Formulating meanings. I reviewed each significant statement to determine the underlying meaning of the quotation. I considered both the explicit and implicit meaning of co-researcher's words. Following Colaizzi's (1978) recommendation, I restated the co-researcher's significant statements into my own words and into a more general statement. After the significant statements were developed into meanings, I compared the formulated meanings with the corresponding significant statements in the context of the transcript to ensure the consistency of the description. Table 3 shows examples of significant statements selected from three co-researcher's (Beth, Joesph, and Edna) transcripts, the formulated meanings derived from the significant statements, and the subsequent theme that was assigned to each of the formulated meanings.

Step 4: Clustering themes. During this step, I grouped the formulated meanings identified in each co-researchers' verbatim transcripts into categories and constructed themes. Any formulated meaning that did not fit into a category was saved to an orphan file in NVivo for negative case analysis. I completed analytic memos as a way to question each emerging theme and to explore the evidence and rationale for creating or merging the themes based on the 16 interview transcripts. Additionally, I bracketed my caregiving assumptions before constructing the themes to minimize the influence of my knowledge and experiences of the dementia caregiving experience (see Bracketing subsection).

Step 5: Develop an exhaustive description. During this step of data analysis, I integrated the significant statements, formulated meanings, and clustered themes into a coherent, comprehensive account of all the co-researchers' experiences of being a primary caregiver to a parent with dementia. This step was completed with data collected from across the eight participants (i.e., 16 interviews).

Table 3

Sample of Significant Statements, Formulated Meanings, and Themes

Significant Statements Extracted From the Co-researchers Interviews	**Formulated Meanings**	**Theme**
"I went to the nursing home because he was sleeping and sleeping and sleeping. And the first couple of days, they gave me some bullshit. So, I got her [doctor] on the phone, and she had him admitted to the hospital, and he was dehydrated. And I guess maybe you use less Depends when you're dehydrated." (Beth, interview 1)	I needed to be an advocate for my father due to the inadequate care that he was receiving in the nursing home.	Advocate
"Like in the morning. Should I feed her breakfast? Should I get her washed and then feed her breakfast? What was more comfortable for her? (Joseph, interview 2)	I have to adjust when I do care based on the care recipient's level of functioning.	Direct Care Provider for ADLs
My older sister, she worked in insurance. And, actually, that's how she actually kind of came into the picture because I brought her in because she did work in insurance for years, like 30 years. (Edna, interview 1)	I decided when to utilize family support in my primary caregiving role	Decision-Maker

Step 6: Identify the fundamental structure of the phenomenon. The goal of this step was to identify the essence, the essential features of the phenomenon. I reviewed the findings and removed any incorrect or redundant descriptions. Additionally, I compared the constructed fundamental structures with the co-researchers' verbatim transcripts to ensure that the constructed essences accurately reflected the lived experiences of the co-researchers.

Step 7: Validate the description of the lived experience. The co-researchers were asked to compare their caregiving experiences with the preliminary findings report generated through NVivo. The co-researchers performed the second round of their member checking on the data analysis from their own interview data as well as the themes developed from the data collected from across the co-researchers (See Figure 2. Steps in Data Collection and Data Analyses).

Theme formation. The formation of themes derived from the significant statements occurred after the data analysis of each co-researcher's interviews. The co-researchers reviewed the themes that emerged from their respective interviews in both rounds of member checking. The data analysis of the 16 interviews resulted in 13 emerging themes across the co-researchers. I reviewed the themes and explored any relationship between the themes and how they may relate to the guiding research question. Themes that were interrelated and captured the caregiving experiences of the co-researchers were merged into broader themes. Through member checking, consultations with the peer reviewer, and re-reading the verbatim transcripts, 11 themes were consolidated into 5 themes, (1) advocate/protector, (2) liaison, (3) decision maker, (4) direct care provider for ADLs, and (5) mourner/griever. Each of the themes had related subthemes. Within the theme of advocate/protector role, the subthemes that emerged from the data analysis were (a) the medical community, (b) the care recipient's safety, and (c) protecting the care recipient within the family. The theme of liaison included the subthemes of (a) liaison with the medical community (b) liaison in the care recipient's community, (d) liaison to the care recipient's memories, and (e) connecting others to the memory of their pre-dementia parent. The theme of decision-maker consisted of the subthemes of (a) utilizing community services, (b) utilizing familial support, (c) nursing home placement of the care recipient, and (d) consequences of decision-making. Within the theme of direct care provider of ADLs, the subthemes were (a) adjusting care based on the care recipients' level of functioning, (b) challenges of the direct care provider for ADLs, and (c) support for the direct care provider for ADLs. The fifth theme, mourner/griever, consisted of the subthemes of (a) loss of a parent/parent-in-law who was physically present, (b) reversal of the parent-child roles, and (c) the physical death of the care recipient (See Table 4. Themes and Subthemes).

Standards for Evaluating Qualitative Studies

For approximately 25 years, researchers have sought ways to define what constitutes a robust qualitative study, identify steps taken in a rigorous methodology, and describe ways to assess the merits of a qualitative study (Klenke, Martin, & Wallace, 2016; Sandelowski & Barroso, 2007). Klenke et al. (2016) proposed that qualitative researchers fall within three positions when defining rigor and value in a study. The first position that a qualitative researcher may adopt is a quantitative or positivistic approach whereby a study's merit is based on the concepts of validity, reliability, generalizability, and position objectivity (Klenke et al., 2016, p. 37). Some qualitative theorists, however, argue that the quantitative measures of quality are incompatible with a qualitative line of inquiry due to the experimental (e.g., hypothesis testing, manipulation of an independent

Table 4.

Themes and Subthemes

Theme	Subthemes/Contexts
1. Advocate/Protector Role	A. Advocate/ Protector in the Medical Community B. Advocate/Protector for the Care Recipient's Safety C. Advocate/Protecting the Care Recipient within the Family
2. Liaison Role	A. Liaison Role to the Medical Community B. Liaison Role to the Care Recipient's Community C. Liaison Role to the Care Recipient's Memories D. Connecting Others to the Memory of Their Pre-dementia Parent
3. Decision-Maker	A. Decision-Maker in Utilizing Community Resources B. Decision-Maker in Utilizing Familial Support C. Decision-Maker in Nursing Home Placement of the Care Recipient D. Consequences of Decision-Making
4. Direct Care Provider for ADLs	A. Adjusting Care Based on the Care Recipient's Level of Functioning. B. Challenges of the Direct Care Provider for ADLs C. Support for the Direct Care Provider for ADLs
5. The Mourner/Griever	A. The Loss of a Parent/Parent-in-Law Who was Physically Present B. The Reversal of the Parent-Child Roles C. The Physical Death of the Care Recipient

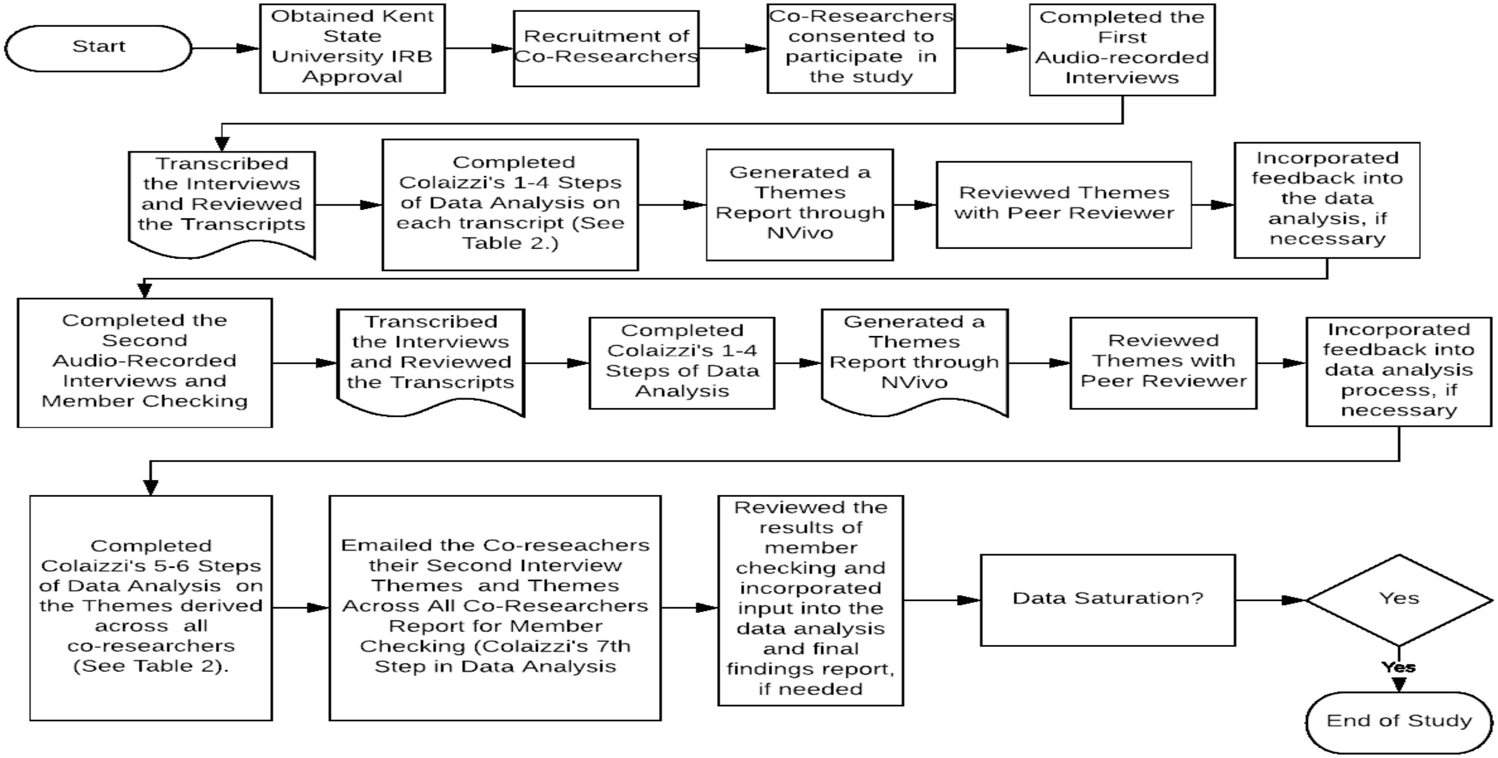

Figure 2

Steps in Data Collection and Data Analyses (variable) and the standardized nature of the quantitative paradigm (Flick, Kardoff, & Steinke, 2004). Researchers who agree that quantitative measures are inadequate may adopt the second position, which is to support the use of separate criteria tailored to qualitative research that parallel the quantitative techniques. Lastly, the third position held by some qualitative researchers is to reject any predetermined criteria (Klenke et al., 2016, p. 38).

For the current study, I selected Lincoln and Guba's (1985) criteria for trustworthiness to enhance the rigor and value of this research. Lincoln and Guba's theory of trustworthiness is comprised of the concepts of credibility, transferability, dependability, and confirmability, which correspond to the criteria used to evaluate quantitative research.

Credibility. Given (2008) defined credibility as "the methodological procedures and sources used to establish a high level of harmony between the participants' expressions and the researcher's interpretations of them" (p. 138). Credibility is measured by the extent to which the reader has confidence that the qualitative research methods can produce truthful and accurate findings and is analogous to the construct of internal validity in quantitative research (Polit & Beck, 2013). I enhanced credibility through member checks (previously discussed), bracketing, negative case analysis, and peer review.

Bracketing. Bracketing was completed from the inception of the study to the final report. I consciously and deliberately identified and questioned my assumptions (see pp. 95-96) about the caregiving experiences of adult children who were caregivers to a parent with dementia before and during the literature review as well as after each interview in a reflexive journal. Additionally, one function of analytic memoing during data analysis was to acknowledge how my assumptions may have influenced the coding process and the interpretation of the data. For example, in one analytic memo, I acknowledged my assumption that dementia caregiving affects every facet of the caregiver's life, including social, marital/family, financial, and career. I assumed that it negatively impacted relationships and was seeking significant statements in the data to confirm that assumption. However, after bracketing, I found more instances of spousal and family support than the anticipated discord.

Negative case analysis. Rubin and Babbie (2010) define negative case analysis as a strategy to improve trustworthiness whereby the researcher looks for "disconfirming evidence within the data that does not conform to the researcher's interpretations" (p. 452). Negative case analysis was completed throughout the data analysis process. I reviewed the transcripts for data that differed from the findings of the literature review, my assumptions, and the coding or thematic structure that was emerging through the data analysis. Each negative case analysis provided disconfirming or discrepant evidence (Padgett, 2008). I reviewed the discrepant evidence and refined or expanded upon the interpretation of the data. I requested assistance in two instances from my peer reviewer during initial theme development and refinement. The first request was regarding a co-researcher's description of assisting with ADLs as less taxing than other aspects of her caregiving experience, which differed from the other co-researchers. Additionally, excerpts from a co-researcher's transcript were reviewed based on her questioning if her parent would have received better care at a nursing home, which was contradictory to those co-researchers' significant statements who maintained the care recipient in their home and chose not to do a placement.

Peer review. A peer who was not involved in the research design or data collection was recruited for the role of the peer reviewer. Peer reviewing is a reflexive technique whereby a peer "serves as a mirror, reflecting the investigator's responses to the research process…serving as a devil's advocate, proposing alternative interpretations to those of the investigator" (Morrow, 2005, p. 254). Peer reviewing was used to enhance credibility.

The peer reviewer was a colleague of the researcher, an assistant professor of Counseling and Human Development, and knowledgeable of phenomenological research. I exchanged two emails with the peer reviewer during the initial data analysis based on 16 co-researchers' interviews (approximately 2 months after the conclusion of the interview process) and one email seeking assistance for theme refinement. We reviewed: the guiding research question, excerpts from co-researchers' transcripts, and the significant statement reports generated through NVivo. The tasks of peer reviewing entailed: (a) assessing the wording of the preliminary themes, (b) examining the overall accuracy of the themes, (c) evaluating if select co-researchers' quotes supported the chosen themes, and (d) identifying any biases or assumptions of the researcher.

My peer reviewer indicated that my themes and subthemes/codes represented the main points of the data (transcripts). She shared the following:

What a thorough job you did, especially with developing very clear

> descriptions/definitions of your codes, which made it very easy for me to follow. You consistently captured significant data units that align with your codes and research topic.

Additionally, she responded to my inquiry regarding the accuracy of the themes:

> I totally agree with all the themes/different roles played by caregivers; the interview excerpts you extracted from the interviews clearly support the themes (Peer Reviewer, Personal Communication, November 30, 2018).

My peer reviewer provided helpful suggestions, such as recommending that I use the same terms for consistency (e.g., direct care provider or hands-on care provider) and guided me in refining the liaison and direct care provider themes. Additionally, she shared the following regarding a subtheme within the mourner/griever theme:

> Loss of parental relationship. Based on the excerpts, I think the parental relationship still exists, but it's reversed. I suggest replacing the word relationship, but I can't come up with an alternative.; maybe 'status' or role. Sorry. Or change it to 'parental role reversal.' (Peer Reviewer, Personal Communication, November 18, 2018).

Transferability. Transferability is comparable to generalizability and is the "degree to which the findings from a qualitative study can be applied to 'fit' other situations" (Rees, 2016, p. 54). Lincoln and Guba (1985) asserted that the researcher could not determine a study's transferability because it is the reader's responsibility to determine if the research findings apply to other contexts. Transferability is strengthened through the work of the peer reviewer, co-researchers who represent diverse perspectives and experiences, and the association of the research findings with theoretical frameworks (Lincoln & Guba 1985; Miles, Huberman, & Saldana, 2013). Transferability was enhanced in this study by identifying the characteristics (e.g., demographics and caregiving background) of the co-researchers; working with a peer reviewer; using thick, rich descriptions from each co-researcher's verbatim transcripts; and completing detailed analytic memos (Bloomberg & Volpe, 2015; Miles et al., 2013).

Dependability. Dependability is analogous to the concept of reliability in quantitative research and asks the question: "Would the study findings be repeated if the study was replicated using similar participants and the same research methods?" Dependability is assessed by evaluating the soundness of the researcher's conceptualization of the study, the data collection method, and the interpretation of the findings (Flick, 2014). I enhanced dependability by member checking at the beginning of the second interview and by email after the second interview. Additionally, I explicitly reported the research methods utilized in the current study.

Confirmability. The concept of confirmability parallels objectivity in quantitative research. Confirmability is the degree to which the research findings are shaped by the participants or co-researchers and not by the researcher's bias or agenda (Bloomberg & Volpe, 2015). To meet this criterion, the researcher must reflect each co-researcher's voice and offer an in-depth description of the research methods (e.g., recruitment, data collection, data analysis) in the findings. Confirmability was enhanced by my immersion in the data, using a peer reviewer in the role of the devil's advocate, negative case analysis, and bracketing my biases throughout the research process in a reflexive journal and analytical memoing.

Phenomenology Trustworthiness

In addition to applying Lincoln and Guba's (1984) criteria for trustworthiness to the current study, I viewed qualitative rigor through a phenomenological lens informed by Polkinghorne (1983). Polkinghorne suggested that trustworthiness in phenomenology has the following characteristics:

1. A vividness that draws in the reader.
2. It generates a sense of believability and reality.
3. The reader can enter the interpretation cognitively and emotionally.
4. The descriptive has economy and poignancy (p.189).

The researcher's immersion in the data (e.g., transcribing the interviews, reading and rereading the transcripts), member checking, and thick, rich descriptions from accurate transcripts contributed to a vivid, believable, and poignant study.

Chapter II Summary

In Chapter II, I discussed the descriptive phenomenological design that was adopted for this study to explore the experiences of adult children who were primary caregivers to a parent with dementia. In this qualitative study, I recruited co-researchers through fliers posted in nursing homes, online postings, and a senior living newspaper advertisement. Co-researchers were chosen using criterion sampling. The selected co-researchers completed two audio-recorded interviews. The data sets were analyzed after each round of the two interviews, and the findings were member-checked by the co-researchers and examined by a peer reviewer. I utilized the NVivo 11 program to categorize and search for themes within the data sets and to generate the findings reports.

Chapter III reports the findings of the study and attempts to faithfully capture the co-researchers’ voices as well as the collective, shared experiences of the caregivers. The interpretation of the data sets, including thick, rich descriptions from the co-researchers and universal themes of caregiving, are identified and explored.

CHAPTER III

RESULTS

The purpose of this descriptive phenomenological study was to learn about the experiences of adult children who were primary caregivers to their parent with dementia and the meaning they assigned to those experiences. The research focused on exploring the recalled experiences of eight caregivers after the caregiving journey had concluded to uncover persistent meanings and themes after a period of possible self-reflection. The terms caregiver and co-researchers are used interchangeably. The guiding research question was: What are the lived experiences of adult children who were primary caregivers to a parent with dementia?

This chapter will introduce the care recipients and co-researchers. The findings of five core themes and their subthemes/contexts are explored in detail. Furthermore, excerpts from the co-researchers' interviews are provided to support the themes and subthemes/contexts and to capture the co-researchers' experiences in their own words.

The Care Recipients

The eight co-researchers provided care to eight parental care recipients: four mothers, three fathers, one mother-in-law, and one father-in-law. The title parent and care recipient are used synonymously. One co-researcher was the primary caregiver to his mother and father, two co-researchers provided care to a biological grandmother whom they identified as their mother, and two co-researchers were primary caregivers to the same care recipient (daughter-in-law adopted the primary caregiving role from the son as the care recipient's needs intensified). Each of the care recipients had been diagnosed with a form of dementia from a healthcare professional (Alzheimer's disease, n=5; Parkinson's with dementia, n=1; dementia due to a medical condition, n=1; and substance-induced dementia, n=1.) Of the eight care recipients, five parents were admitted to nursing care facilities, whereas three were maintained in the community. All care recipients were deceased at the time of the current study.

The Co-Researchers

Eight co-researchers (six women and two men) were recruited from five counties in Northeastern, Ohio, who met four inclusionary criteria and represented a diverse demographic (see Table 1, Chapter II). Inclusionary criteria were: (1) an individual who was 21 years or older at the time of caregiving (2) the individual self-reported as a former primary caregiver to a parent who was diagnosed with dementia by a healthcare provider (3) the adult child identified their relationship to the care recipient as a daughter, son, daughter-in-law, son-in-law, partner to daughter, or partner to the son and (4) the adult child provided assistance with at least one activity of daily living (ADL) and three instrumental activities of daily living (IADLs). Additionally, adult children who were primary caregivers to a grandparent who served in a parenting role were also eligible to participate, as well as adult children who transitioned from being the primary caregiver to a secondary caregiver role (e.g., another family member assumed the role of primary caregiver). Each co-researcher completed two semi-structured, individual, and face-to-face interviews and provided member checking on each of their interviews. Additionally, the co-researchers provided member checking on the themes that emerged from across all the co-researchers.

The following provides a brief overview of each of the co-researchers, their demographic information at the time of their caregiving experience, the co-researchers' views of their parental relationship before caregiving, and details regarding the precipitating event(s) that resulted in the adult child adopting the role of primary caregiver to their parent with dementia. The purpose of describing each co-researcher is to offer a glimpse into contextual factors that may have influenced their caregiving careers. A pseudonym was assigned to each participant to maintain their anonymity and privacy.

Edna

Edna is an African-American female who was 39 years old when she became a caregiver to her father. She describes her feelings for her father as "I loved my Daddy to death." Edna juggled multiple roles during her caregiving experience, including full-time employee, partner to her significant other, mother to her two adult children who lived independently, and an adolescent son (who resided with her and her father), and a grandmother. Edna recounted the day when she began her caregiving career:

> My sister called me out the blue and said, "Dad's been sick, and he says he wants to come and be with you for a little bit." And, actually, up until that point, I really didn't have a lot of interaction with my dad, but because he provided like he did for us growing up, and because he's my daddy, when she called and said, "Dad's

> been sick; he wants to come with you." I was out that day, picking my daddy up and bringing him home with me. You could tell that life had all of a sudden been a lot more challenging for him, but he had all his faculties at that time. He moved in with me immediately.

Approximately three years after moving in with Edna, her father was hospitalized and diagnosed with Substance-Induced (Alcohol) Dementia.

Molly

Molly, a White female, was 38 years old when she became a primary caregiver to her mother-in-law, who was diagnosed with Alzheimer's dementia by a nurse practitioner. Molly was balancing the roles of being a wife and mother to her four children, as well as being a caregiver to her husband, who had recently been diagnosed with cancer. Additionally, Molly was an advocate for people with disabilities and shared with others her experience living with Cerebral Palsy. There was not a defining moment when Molly became a primary caregiver, but her mother-in-law's increasing forgetfulness required additional care and monitoring. Molly explained:

> So, this stuff started happening where she would take off to go someplace, and she'd end up in a different place. One time, she was coming over to our house, and I guess, she ended up going to another town and the woman where she had actually stopped happened to know my husband and called my house and said, you know, "Your mother-in-law is here, and she was saying that she was on her way to your house and she got lost." She was totally going in the wrong

> direction.

Molly viewed her relationship with her mother-in-law as: "I kind of became the daughter because I just kind of came into the family and took them on as my parents, just like they were my own parents. So, we always had a really good relationship."

Joseph

Joseph, a White, single male, was 60 years old when he became a primary caregiver to his father with Alzheimer's dementia. He described his relationship with his father as "pretty close." Joseph was working in an administrative position in a healthcare facility in another state and shared how he returned home to be a caregiver:

> I came home to visit. His memory was shot. Gone. I walked in. He said, "[the co-researcher's name]." They were amazed he even knew my name because he couldn't remember who his wife was or his grandkids. He grabbed me and said, "You gotta come home. I don't know these people. I don't know what they're doing to me." I sat down with my sister and my mother and said, "Okay, I'll come home." Didn't really want to, but my Catholic conscience got me again.

After the death of Joseph's father, Joseph returned to work in a healthcare administrative position. While away from home, his mother was diagnosed with Alzheimer's dementia, and initially, Joseph's sister became her primary caregiver. Joseph recalled the phone call that began his caregiving journey with his mother:

> My sister said, "I'm done. I can't do this anymore. I'm putting her in a nursing home." I said, "No, I'll take care of her." And my mother used to say before she

had Alzheimer, “I want to die at home, and I want to die with you around.” Joseph described his relationship with his mother before the onset of her Alzheimer’s dementia as:

> My mother was my god when I was little. She wasn't a very nice person. She really didn't want me. I went to a psychologist when I was 19. He asked me, “How do you describe your childhood?’ Duck. Duck and run. She would smack me. My sister said that she [mother] used to beat the crap out of me.

Allyssa

Allyssa, an African American female, was 35 years old when she became the primary caregiver to her grandmother, whom she identified as a mother figure: “She raised me.” Concurrent with her caregiver role, Allyssa was a full-time healthcare employee, a wife, and a mother. She described her relationship with her grandmother as:

> Very strong. I think we had a feisty relationship. She could, yeah, she would tell me things that I didn't like and didn't want to hear, but sometimes needed to hear and think about. And often, you know, I wouldn't be as patient with her as I should have been sometimes, but we had a really strong relationship.

In hindsight, Allyssa noted that her grandmother had experienced some forgetfulness, but it was one evening that she realized:

> Something was not right because my grandmother wasn't dressed, and she was very proud. Like I said, very prideful, she would never allow anyone not to see her fully dressed, and she didn't have any bottoms on. But she said that she was

> fully dressed, and she was ready to go. She had locked herself in her room. The room was a hot mess like it looked like a tornado went through there. My grandmother kept her house like a museum. And that's not like my grandmother. Not at all.

Medical testing revealed that Allyssa’s grandmother had several brain tumors due to metastatic breast cancer, and the hospital doctor diagnosed her with dementia due to her medical condition.

Beth

Beth, a White female, was 50 years old when she became a caregiver to her father diagnosed with Parkinson’s with dementia. During her caregiving career, Beth was a mother to her adult daughter, a partner to her significant other, and worked full-time as a licensed social worker. Beth characterized her relationship with her father as:

> It wasn't that great. Actually, it made everything way harder. My dad was an alcoholic who had stopped drinking various times in his life. And my dad was just…was just a dick in so many ways, but then, I always knew that my father loved me the best he could.

Beth identified several initial changes in her father’s cognition and behaviors that resulted in her adopting the primary caregiver role:

> He told me some boys had come to his door, and he was sure they wanted to steal from him, and I just don't think that happened. He would say there was money missing, but nobody had been there but me. So, those kinds of little things. He

> stopped being able to deal with the television remote…he had quit drinking, but he would still like to go to the bar that he liked and have a ginger ale, and he stopped doing that. And then he just gradually stopped doing a lot of things.

Diane

Diane, a White, 30-year-old female, became a primary caregiver to her grandmother, who was diagnosed with Alzheimer's dementia by her physician. She characterized their relationship as mother and daughter. During her time as a caregiver, Diane worked full-time in the medical field, raised two children, and was single, but cohabitating with a significant other. Diane described her relationship with her grandmother as close, and "I tell everybody, I thank her for the woman that I've become." Diane reported that she had been in denial about her grandmother's dementia diagnosis, but as her grandmother's memory impairment increased, she required more assistance and care. Diane explained:

> When she lived on her own, and she would forget. Like I can't find my keys or where did I put my pocketbook? And I'm like, "Oh grandma, everybody forgets." And then she started forgetting what she ate for breakfast. Forgot to pay a bill. You know little things. So then, when she...I was in denial. And then I would look at her, and I'd say, "Remember when we went to the store?" and she'd say, "I don't remember that." It would really break my heart.

Scott

Scott, a 53-year-old White male, was a primary caregiver to his father. At the time of his caregiving, Scott was a husband, a father to three adult children, and was disabled and unable to work. Scott described his relationship with his father as “loving.” Scott’s father began showing signs of Alzheimer’s disease shortly after the death of Scott’s mother, who also had a diagnosis of Alzheimer’s dementia. Scott remembered the event that resulted in his father requiring more monitoring and care:

> Then one day, he went to go to Walmart, and he was gone for three days. And we didn't think we were going to get him back, but we did. We had to start taking care of him and stuff like that, and as it went on, it got worse.

Scott was his father’s primary caregiver until his father required more assistance with care. At that point, Scott’s spouse, Meg, another co-researcher in the current study, assumed the primary caregiving role, and Scott provided support in a secondary caregiver role.

In addition to sharing his caregiving experiences, Scott reported that he was recently diagnosed with mild cognitive impairment. He reported that he has lapses in his short-term memory (e.g., forgetting dates and times of his appointments); however, he reported his long-term memory remains intact. The changes in his short-term memory did not impact his participation. Scott responded thoughtfully and relevantly to the interview questions of the current study.

Meg

Meg, a 54-year-old white female, became a primary caregiver to her father-in-law, Scott’s father, as symptoms of his dementia, progressed, and he required more care.

Meg was a wife, mother, and worked full-time in social services. As Meg's caregiving activities became more intensive for her father-in-law and her aging parents, she retired early from her job. She reported a close, positive relationship with her father-in-law. Meg recounted when she assumed the primary caregiving role, "I switched roles with him [Scott]. I was his [father-in-law] caregiver. He [Scott] isn't a bodily fluid-type person, so when he got to that point, I did all the necessities. When he [father-in-law] needed more care, it was me."

Data Analysis and Thematic Findings

Data analysis was informed by Colaizzi's descriptive phenomenological method (see Table 2, Chapter II). Selection of significant statements from each co-researcher's interviews was guided by the following three questions adapted from Emerson, Fretz, and Shaw (1995):

1. What did the primary caregivers do, and what were they trying to accomplish for the care recipient?
2. How did they do this, and what strategies did they utilize?
3. How did the primary caregivers talk about, characterize, and understand their caregiving?

Significant statements were organized using NVivo 11, a qualitative data analysis computer software program. Significant statements were converted into formulated meanings, and those meanings were developed into themes.

The findings of the current study consisted of five core themes representing the experiences of being an adult child as a primary caregiver to a parent with dementia. Emergent core themes captured different roles inherent throughout the caregiving career and subthemes. These core themes, the prominent caregiving roles adopted by the co-researchers in the current study were: (a) advocate/protector; (b) liaison; (c) decision-maker; (d) direct care provider for ADLs; and (e) mourner/griever. Within the theme of advocate/protector, Each of the themes had related subthemes. Within the theme of advocate/protector role, the subthemes of the medical community, the care recipient's safety, and protecting the care recipient within the family emerged from the data analysis. The theme of liaison included the subthemes of the medical community, the care recipient's community, the care recipient's memories, and connecting others to the memory of their pre-dementia parent. The theme of decision-maker consisted of the subthemes of utilizing community services, utilizing familial support, nursing home placement of the care recipient, and consequences of decision-making. Within the theme of direct care provider of ADLs, the subthemes of adjusting care based on the care recipients' level of functioning, challenges of the direct care provider for ADLs, and support for the direct care provider for ADLs were identified. The fifth theme, mourner/griever, consisted of the subthemes of loss of a parent/parent-in-law who was physically present, the reversal of the parent-child roles, and the physical death of the care recipient.

The next section provides a detailed presentation of the themes and subthemes. Additionally, excerpts from co-researcher interviews are provided as supporting data for the themes and to offer rich descriptions of the co-researchers' caregiving experiences in their own words.

Theme 1: Advocate/Protector

The first theme, advocate/protector, represents the experiences of serving as advocates/protectors of their care recipients. As the dementia disease process progressed and the care recipient experienced more memory impairment and behavior dysregulation, the co-researchers were advocates/protectors in regards to (a) the medical community, (b) the care recipient's safety, and (c) protecting the care recipient within the family. All eight co-researchers adopted the advocate/protector role for the vulnerable care recipients in one or more of the subtheme categories. Their advocacy was consistent with Huber, Nelson, Netting, and Borders' (2007) definition of elder advocacy as "vigilant efforts by or with, or on behalf of older persons to influence decision-makers in structures of imbalanced power and to promote justice in providing for, assisting with, or allowing needs to be met" (p. 4).

The medical community. Co-researchers discussed their interactions with medical providers (e.g., primary care providers, hospitals, nursing care facilities, and hospice workers) in working with their care recipients. The primary caregivers' advocacy/protector role began when the care recipients' cognitive impairment impeded their ability to describe their symptoms accurately and comprehend the instructions of the primary care provider. Co-researchers frequently identified this role occurring during the middle and late stages of their caregiving careers. Excerpts from Scott, Molly, Edna, Allyssa, and Beth's interviews provide a glimpse into their experiences in the advocate/protector role in the medical community.

Scott reported that he would "take Dad to all of his doctor's appointments and make sure he got what he needed, you know. I'd let him [the doctor] know what was going on because Dad couldn't." Similar to Scott, Molly would be her mother-in-law's voice during her appointments and explained her introduction to the advocate/protector role:

> I would take her to all of her doctor's appointments. I would always tell them, you know, her behavior is getting really different than it was previously, and they would change things [medications]. When they upped her medication, she would get unstable and fall. I would tell them that she's getting worse. "Oh, she's acting this way. Let's push more meds." Then she'd have problems from the medication. Dizziness. I'd schedule another appointment and tell them. I had to talk for her. She couldn't remember what had happened.

Perhaps the advocate/protector role within the medical community proved to be more demanding for those primary caregivers who did nursing home placement in the late stages of their caregiving careers. The five primary caregivers who chose nursing home placement for the care recipient (Molly, Edna, Joseph, Allyssa, and Beth) all discussed the need to monitor and advocate for adequate care in the nursing care facility.

Molly described her advocacy/protector role in the context of monitoring the care of her mother-in-law:

> I was in there a couple times of week making sure she was okay, and making sure they were doing what they were supposed to be doing and everything because it was actually the county home, and so I would go into kind of, you know, make sure that she had what she needed.

Edna reported that her advocacy/protector role consisted of frequent, unannounced visits to the nursing home to monitor the care of her father. Additionally, she addressed the importance of building positive relationships with the nursing home staff and setting quality care expectations:

> Yes, sad to say, I think that Dad got better care because they knew that we were always there. We would always be around, and we would show up…very rarely did we call ahead of time. We would just go. And that is, actually, something that they said they appreciated because they said so many folks would get put in these facilities and would be abandoned. Like would have no visits or very few visits. And so, they really appreciated the fact that we were present and involved and active as much as we were. But it also helped to create that relationship with them, as well. You know, so knowing first names and, "Hi, you know, what did you do over the weekend" kind of thing, I think that was also just as important is to get that rapport going with the staff that cared for my dad. Because daddy had to be taken care of so no, if, ands or buts about it. So, that was extremely important to make sure that they knew that and to know that we were there, and we loved him very much and wanted to make sure that he was getting the best

care that he could get.

In contrast to Edna's experiences with the nursing home staff, Allyssa described her feelings toward her grandmother's care providers as "Being angry with them. Really angry with them." Allyssa reported that the medical staff had restricted her and her family from visiting her grandmother for approximately three months due to her grandmother's accusations of familial abuse and agitation. Allyssa explained what proved to be an impediment and impetus to her advocacy/protector role:

> Yeah, I think what upset me the most about the nursing home is they knew her diagnosis when she came in. And you would think at an institution that is considered one of the best that they were taking her word for what she was saying, and basing her care, and putting visitation restrictions on the family because of what she would say. But you have a diagnosis of dementia and full-on Stage 5 breast cancer that has metastasized to her whole body. Well, she wasn't in her right mind. But, yeah, the things she was saying, they were taking at face value and restricted the family. And I just could not believe it. She was saying things like, "Oh, they locked me in the house, and they beat me." And that's not true. I understand that when we came and called, she would get really agitated. So that put a little bit more stress on their caregivers to calm her down or get her more stable.

Although restricted from visiting for three months, Allyssa continued in her role as an advocate/protector. She stated that she contacted the long-term care ombudsman, who advocates for residents of nursing homes and assisted living facilities, “several times” regarding the visitation restriction, but “no one got back to me.” Additionally, Allyssa recounted how she continued to monitor that her grandmother’s needs were being met in the nursing home:

> I’m calling there [the nursing home] 3-4 times a day. And, I actually snuck up there and literally had a cap on and would go down the hallway and pretend that I’m going to visit another patient just to even walk past her room and just see her.

Similar to Allyssa, Beth described a contentious, angry relationship with the nursing home staff during her advocacy/protective role. Beth recounted:

> I don't think they gave him enough water. They pretty much hated me because one time he ended up in the hospital. He was dehydrated, and I like flipped on them because I get the fact that they may withhold water so they don't have to change people as often, but that's not okay.

In addition to Beth advocating for improved care, she supported her father’s religious beliefs and advocated for him to receive the last rites. Beth remembered:

> My father was very religious in his own way, and this was a Catholic place, and he was doing really, really badly, so I wanted the priest to come, and it was midnight, and they wouldn't wake the damn priest up. That was his only job. There was nothing else for him to do there besides say Mass and if somebody was dying, but they wouldn't wake him up because it was just before midnight, and they told me to call the parish priest. So, I did. He didn't come either, but, at least

> he told me that he had already been there. Oh, I hated that place [the nursing home] so bad.

The care recipient's safety. Primary caregivers described their experiences as protectors of their parent or parent-in-law from her or himself. In this role, the co-researchers had observed how their care recipient's impaired judgment, poor memory, and for some, physical frailty could put their parent/parent-in-law at risk for harm. The co-researchers reported the protector role for the care recipient's safety mostly occurred during the middle to late stages of their caregiving career, and the primary goal was to prevent the care recipient from engaging in behaviors that would result in self-harm. Five of the eight co-researchers described experiences when they intervened to keep their loved one safe (e.g., disabling vehicles, redirections of the parent to prevent wandering from home and disconnecting stoves). Each of the co-researchers was mindful of using interventions that would not trigger the care recipient's agitation and would preserve their parent's dignity.

Joseph's mother had an unsteady gait and was at risk for falls. He asked her not to walk unassisted for fear that she would fall and fracture her hip like his father; however, due to her memory impairment, she would forget his request and walk unassisted while Joseph was sleeping. Joseph remembered the precipitating event that resulted in his adoption of the protector role and how he intervened to help keep his mother safe:

> I heard her screaming. Tone of voice, you know, I jumped up. She was on the

> floor [in the bathroom], and we already had a safety thing around it. She grabbed that thing and went down, pee all over her. I cleaned her off, and I took her back to bed. I was helping her walk, and I was like, “Ma, does your hip hurt?” “A little bit.” She didn't break it. She just bruised it. Thank you, Lord. So, I developed this thing because I wasn't ever going to go through that again. She would sleep in bed. I'd put her in bed, and I had a tether. Like those tethers that you put on little kids. I'd put it on her ankle, and I put it through the bottom of the bed, and I would sleep on the other side on top of the bed wearing the other end. So at night, I'd be [moves his leg], “Do you want to go to the bathroom?”

Scott adopted this advocate/protector role after his father did not return after going shopping. Scott waited until the next morning and then filed a missing person’s report with law enforcement, and a local television station broadcasted the story to elicit information about his father’s whereabouts. Meg, Scott’s wife, tearfully recalled how her father-in-law’s confusion put him in a potential danger:

> He was found [in a major city approximately one hour away] walking in the middle of the street. A bad neighborhood. Two ambulance drivers found him, looked at his driver’s license, and called the police department. A nurse said, “You’re so lucky that these men found him because they would have killed him for the $12 Timex [wristwatch] that he has on, put his body in a dumpster, and he would’ve been in New York by now.” He never drove again.

Scott explained how he was able to keep his father out of the driver’s seat creatively and safe:

> The hard part was I had to disable his vehicle. He always wondered how come it would start for me and not him. Because he'd be out there, and then the next thing, he would be knocking on the door and say, “My truck won't start again.” I said, “Oh, well, I'll come up and look at it. Where do you need to go?” “I want to go to Wal-Mart and get dog food.” I said, “Okay, Dad, could you go in the house and get me something.” He'd go in the house, and I’d open the hood real quick and put the fuse in. When he came out, I'd have it running, and I'd drive him.

Molly had expressed worries that her mother-in-law’s Alzheimer’s dementia was putting her and others at risk when she would drive. Molly shared that her mother-in-law had driven over a mailbox, was stopped by the police for driving the wrong way down the street, and was getting lost going to familiar places. Although the care recipient’s three sons would make the ultimate decision, Molly described advocating for her mother-in-law to no longer drive:

> I was the one that always found out about these situations. I would have to tell them because at first, her other two sons didn't want to believe it. I don't think that they were thinking that I was making anything up. I think they were thinking that I was exaggerating because they didn't see it. They were on the phone with her. And I finally had to say, “Give me the phone,” and I was talking to my brother-in-law. I said, “Look,” I said, ‘This is what's going on here. This is the situation with the car.” I listed everything that happened. He finally understood.

Additionally, Molly described how she protected her mother-in-law after the care recipient's impaired judgment resulted in her inability to discern if her food was spoiled.

> She'd get mad at me for throwing out food. "Did you throw? That's still good. I'll eat it." "Mom, it smells like turpentine. It's not good." Then I had to start doing things on the sly [putting spoiled food in the garbage] because you know, you don't want to upset her, but yet you don't want her to get sick either.

Protecting the care recipient within the family. Two of the eight co-researchers assumed the role of advocate/protector for their parent with dementia due to physical abuse or suspected neglect and financial abuse of their parent perpetrated by a family member. Diane and Joseph reported a history of conflicts and disagreements within their respective families before becoming primary caregivers. In this role, each co-researcher utilized community supports to assist in protecting their vulnerable care recipient.

Diane adopted the advocate/protector role of the care recipient within the family when her maternal grandmother would spend time with Diane's biological mother. Diane had expressed concerns that her biological mother would be neglectful by "putting my grandmother in a chair in the living room and leave her" and had suspicions that she was mismanaging her grandmother's finances. Diane reported:

> I, honestly, I called Area for Aging several times on my [biological] mother. I mean, like I said, I don't care if it's family or not. I was. I'm an advocate for any child or elder person. If something's wrong, whether you're my mother or father,

> I'm going to notify someone. So, there was a lot of heartaches.

Joseph described his parents as having a tumultuous relationship throughout their marriage, and “it wasn’t unusual for them to fight.” Joseph recounted when he adopted the role of advocate/protector within the family after he suspected his mother was physically abusing his father:

> I came home one day, and I noticed bruising on my father's arms. He was real quiet. I said, “Dad, what's the matter?” I said, "Is she doing anything to you? Tell me.” He didn't say anything. So, I went to work one day and didn't go to work. I came back. I snuck in the apartment. I stood in the foyer. She was hitting him with a stick because he wouldn't get out of bed and wouldn't do what she said. Before I came [moved] home, he hit her with a cane [after his dementia diagnosis], broke her nose, and gave her a scar. Mother said he was getting pretty violent with her. They never got along anyway, but she had the upper hand now. That's when I decided to put him in the nursing home.

Joseph’s advocate/protector role of the care recipient within the family did not end with nursing home placement for his father. The co-researcher reported how his mother did not accept his father’s placement in a care facility:

> I called the police on her once. She was there taking him, taking him out of there. She wanted him back home. Like you're beating the crap out of him, you can't take him. I come running in there. “I'm taking him home. I got his clothes.” I said, “Put his clothes back. You're not taking him.” “Yes, I am.” “No, you're

> not." Called the police. Police took the clothes and made her go home.

It was within this role that Joseph, upon reflection, observed what he believed were the beginning symptoms of his mother's Alzheimer's disease. Joseph explained:

> She wasn't all there anymore, either. Not realizing it. I just thought it was that mean, nasty, self of hers, but she wasn't. She [mother] ended up getting this...this look. I could see that her mind wasn't processing. I remember I said, "I'm calling the cops on you. You're not allowed to take him." "Yes, I am, and they're not going to stop me." "Mom, I'm the boss, the guardian. It's me now. You're not it. Okay? He's not going." She didn't get it. First time I ever saw her like that.

Theme 2: Liaison Role

Each of the eight co-researchers adopted the liaison role in the context of at least one of the subthemes throughout their caregiving careers. During this role, the primary caregivers were connectors or bridges between their parents with dementia and (a) the medical community, (b) the care recipient's community, and (c) the care recipient's memories. Additionally, the co-researchers connected others with memories of their pre-dementia parent.

The medical community. The role of liaison within the medical community evolved throughout the co-researchers' caregiving careers. Initially, this role consisted of linking their care recipients with their primary care provider(s) and, when needed, the hospital system. Each of the eight co-researchers scheduled, provided transportation, and attended doctor's appointments or hospital emergency room visits with their parent or parent-in-law. Additionally, the co-researchers translated the content of the appointments (e.g., doctor's instructions and prognoses) into understandable language and prompted the care recipient to follow the doctor's plan of care. The liaison role is differentiated from the advocate/protector role in that the co-researchers were linking the care recipient to medical services and plan of care. In the advocate/protector role (Theme I, described earlier), the co-researchers were being "the voice" of their parent/parent-in-law and ensuring that quality care was provided. Diane and Beth shared their experiences with the medical community liaison role in the early stages of their caregiving careers. Diane remembered:

> In the beginning, it wasn't too bad. I'd take her to her doctor's appointments. You know, talk to her about what the doctor said. 'The doctor says I have Alzheimer's.' She would cry. "I know, Gram. I know. Don't forget to take your medication." Things like that. Made her appointments.

Beth described similar experiences in the medical community liaison role as Diane's experiences. However, Beth, found it more challenging due to her father being "difficult":

> I would take time off of work to take him to the doctors. With the Parkinson's, he had quite a few appointments. I'd pick up his medications. I started to do that, really, after my mother died. I would remind him to take his medication like the doctor said. He did whatever he wanted, so that made it hard.

In the middle phase of their caregiving career, the liaison role evolved to accommodate changes in the care recipient's functioning. As their parent's forgetfulness and confusion increased, the co-researchers no longer attempted to explain the medical treatment or prompt the parent to follow the treatment plan. Although the co-researchers continued to link the care recipient with medical services, they were more proactive in helping the care recipient complete medically necessary tasks. For example, in the early stages of dementia, the co-researchers may have verbally prompted their parents to take their medication or fill a pillbox reminder to assist them in keeping the medication schedule; however, as their parents' cognition declined, the co-researchers would give their parents' their medication. Joseph described the evolution of the role in regards to his father:

> They [mother, sister] would tell him to take his medication. He would. No problem. But when he didn't know them no more, he didn't trust them. My father never forgot me. Got to the point where he would only take his pills from my hand.

In the later phase of the co-researchers' caregiving career, the liaison role did not appear to change significantly from the mid-caregiving career activities for those co-researchers who maintained their parent in the community. Two of these three co-researchers noted an increase in linking their parent to additional medical appointments or to in-home support services (e.g., home health care, hospice). For those co-researchers who placed the care recipient in a nursing care facility, the task of linking their parent to medical care was assumed by the nursing home; however, the liaison role did not end upon admission. Four of the five co-researchers who did nursing home placement identified a liaison relationship with the care facilities whereby they were contacted to assist the nursing home staff in working with their loved one. The care facility staff would contact the co-researchers when their parent's behavior or cognitive deficits resulted in treatment issues or problems with the staff and other residents.

Joseph reported that he moved his father to three different nursing homes within one month until he found a care facility that provided the quality of care he was seeking. At each of the nursing homes, Joseph remembered his liaison role:

> It got to the point that I would be the only one that he would listen to. The only one. Even the nurses would call me and put me on the phone with him. "Could you tell your father to take his pills?" "Pop." "Yes, son." "That lady is going to give you pills to take." "Okay, I'll take them."

Molly's liaison role with the nursing home was the result of her mother-in-law's combative behaviors. She recounted:

> I was on the call list to be called for any sort of problems, and that was the funny thing. I felt like I had another child because I [laughter], literally, got phone calls from the nursing home. "Your mother-in-law got in a fight with this person, and she kicked this guy in the shins," you know, just different things. I never got phone calls for my children for that reason, but I got phone calls for her, and she'd be swearing at the nurses and staff. I'd try to calm her down.

Allyssa's experience in the liaison role was similar to Molly; however, it was within the hospital system. Allyssa explained:

> I was the only one who was able to calm her down. I remember in the middle of the night, many times, the nurses would call me and be like, “I hate to bother you, but she's not letting us do this. Can you please come up and help us?” And I would go up, and she would be fine.

The care recipient’s community. Four of the eight co-researchers reported being a liaison to the care recipient’s community. In this role, community members (e.g., neighbors, friends, pastors) or community service (e.g., law enforcement) contacted the co-researcher to inform him/her of observed changes in the care recipient’s behavior or cognition. The community connection most frequently occurred when the care recipient was seen as wandering, lost, and/or confused by members of the community. During this mid-caregiving career role, the co-researchers voiced a better understanding of their parent’s challenges and symptoms due to community interventions. In the early stages of caregiving, the co-researchers described missing the signs of dementia or misinterpreting their parent’s symptomology as normal aging; however, with the input from community members, they had a clearer understanding of the deficits and needs of their parent. Additionally, the primary caregivers appeared to better grasp the gravity of their parents’ dementia and used the information to inform their level of caregiving. Edna and Scott provided examples of their experiences in their liaison role in the community.

In Edna’s interviews, she described her father as an “active man who loved to be outside” and an avid bicyclist. Edna remembered her introduction to the liaison role in the community when contacted by the police:

> So even when he came to move in with me, he did have a bike at that time, and that's when I actually started realizing problems with him because police started showing up at my house, or I was getting calls because they would stop him because there was this elderly-looking man on this bike and it's 1:00, 1:30 or 2 in the morning and they'd question him, and he couldn't answer them in complete sentences that would make sense to them. And, so, that's when the challenge started happening with him.

Scott reported how his level of caregiving was informed through being a liaison in the care recipient's community:

> I pretty much moved up there and had to start staying with him because he would wander out in the yard in his pajamas and stuff. So, the neighbor calls you up and says, "Hey, your dad's walking the field out here in his pajamas."

The care recipient's memories. This liaison role primarily occurred in the middle and late stages of the co-researchers' caregiving career and consisted of the co-researcher connecting the care recipient to activities and experiences that the parent/parent-in-law enjoyed before the onset of dementia. Seven of the eight co-researchers described engaging and, at times, participating with their loved ones in the care recipients' favorite pastimes. The co-researchers identified the goals of adopting this liaison role to the care recipient's memories as helping the care recipient revisit their pre-dementia life, aspiring to bring joy to their apathetic parent/parent-in-law, and to perhaps, as Diane wished, to cue her loved one's memory so "maybe she'd remember and be back." Diane described her experiences in this role:

> She would find humor in everything. She would laugh, tell jokes, and dance. After the dementia, she would sit in her little chair, and I'd say, "Come on, Grandma, let's get up and dance." We would listen to Lawrence Welk, and she would even still sing songs. You remember a song, but you don't remember who I am.

Edna, who also discussed being a liaison to her father's memories, wanted to link her father to an activity from his past; however, due to the progression of his dementia, he was unable to participate. Edna shared how she attempted to reconnect her father to an earlier time and place:

> He did like to fish, but he stopped wanting to fish, but what I would do is, I would take him to this lake, and we would just go there, and we would just sit there for hours. We just spent the day there because I think that probably represented, reflected most of what he had when we were growing up, you know, being out in the country, being able to just go and fish when he went outside.

The co-researchers identified linking their care recipients to various pre-dementia activities, including gardening, going to garage sales, shopping, dining in their favorite restaurant, visiting the beach, and attending church. Additionally, six of the seven co-researchers who reported linking the care recipient with memories discussed the importance of maintaining the care recipient as a valued and loved member of the family. These co-researchers recounted ensuring their parent/parent-in-law were present for family celebrations and holidays. For those who did nursing home placement with the care recipient, three of the five co-researchers stressed the importance of keeping the parent connected to the family after placement.

Connecting others to the memory of their pre-dementia parent. The eight co-researchers described the liaison role of connecting others to the memory of their pre-dementia parent/parent-in-law as part of their experiences as primary caregivers. During their caregiving career, four of the eight co-researchers seemed to adopt this role in the context of a parent/parent-in-law's problematic behavior (e.g., aggressive/combative behaviors, uncooperative with nursing home staff, inappropriate language or comments) and consisted of the co-researcher connecting others to their memories of the parent before the onset of dementia.

Molly was identified as the emergency contact person for her mother-in-law at the nursing home. She would receive phone calls from the care staff when her mother-in-law would become verbally and/or physically abusive to staff and/or other residents. Molly reported feelings of embarrassment for her mother-in-law’s behavior and would share with the nursing home staff the essence of her mother-in-law before dementia :

> My mother-in-law would have never done anything like that. I mean, it was really out of character for her because she was a very loving woman. I mean, she was a church-goer. She was great with kids. She used to be a noon aide

> at the school when her kids were growing up. She was a wonderful person.
>
> She still was, but it was dementia.

The findings from the current study revealed that all co-researchers participated in this liaison role, connecting others to the memory of their pre-dementia parent after their caregiving careers had concluded. Each co-researcher was asked to describe their relationship with their parent/parent-in-law before becoming a primary caregiver; however, in their face-to-face interviews, each co-researcher additionally shared unsolicited memories (e.g., history/background, skills, physical abilities, and personality) of their pre-dementia parent. The co-researchers affirmed their participation in this liaison role at their respective member checks. They provided the following rationales for adopting this role after the conclusion of their caregiver careers: to share with others the essence of their parent before dementia affected their memory, personality, behaviors, and physical abilities; to reminisce about happier times, and to educate others on the devastating symptoms and loss associated with dementia.

Diane described fulfilling the liaison role of connecting others to the memory of her healthy mother (biological grandmother):

> I did my grandmother's eulogy. I wrote this big paper, and I was trying to explain to the people that didn't know my grandmother, you know, all the traits that she had. Who she was before the Alzheimer's. When I was a teenager, we'd get pizza every Friday night. Sunday, she'd put a roast in, and we'd go to church. All these memories, but yet, looking at my grandmother, I was someone that she didn't ever

remember meeting.

During his first interview, Joseph shared a short history of his father to provide a glimpse into the life of his younger, healthy parent:

> My father, he went to probably the 4th grade. When he was 18, he was on the road with Hank Williams, Sr. He could play guitar, bass fiddle, clarinet, and saxophone. He cut a record. [Joseph sings] "There's a little log cabin." That was my father.

Meg described her father-in-law's personality before the onset of his Alzheimer's dementia as: "My father-in-law was a delight. He was sweet. He was kind. Loved children. Loved them."

Theme 3: Decision-Maker

The third theme, decision-maker, represents the experiences of the co-researchers as they made choices for their care recipients. Each of the eight co-researchers discussed engaging in the decision-making process regarding the utilization of community resources, utilization of familial support, and nursing home placement of the care recipient. Molly and Meg, the daughters-in-law, assisted the sons and other family members in making major informed decisions due to their knowledge of the care recipient's level of functioning and the level of care required. Five of the six co-researchers who identified as the son or daughter of the care recipient reported making the final care choices for their parent and discussed the last of the decision-maker subthemes, the consequences of decision-making.

Utilizing community resources. Seven of the eight co-researchers had to make decisions regarding the use of community resources during the middle to late stages of their caregiving careers; whereas, one co-researcher reported that she was unaware of available resources. In the middle phase, the primary caregivers voiced the need to spend more time in their primary caregiving roles as the care recipient needed more assistance with their activities of daily living (ADLs). The precipitating factors in considering the addition of community resources (e.g., paid companions, home health aides, adult day care programs, and respite programs) appeared to be the following: to relieve the role strains (e.g., partner, parent, employee) imposed by the increased time needed for caregiving, provide respite for the co-researchers to engage in self-care activities, and for the care recipient to receive the level of care needed.

Joseph had resigned from his job and returned home to be the primary caregiver to his mother. He described a time when he sought employment due to the financial strains of being a full-time caregiver. He explained his experience in recruiting home health aides to be with his mother after he accepted an employment offer:

> I tried them all. They all want money, and I didn't have it...didn't have the extra money to give them. And, uh, I met with a bunch of care providers, this one and that one, and I'm thinking, man, it's going to cost me almost like 30 grand a year to have somebody stay with her every day, and then if I get overtime, they gotta stay over extra and then…hmm, is this worth it at all. Tried the Office on Aging, you know, for the elderly. They did nothing. They gave me pamphlets. Thanks

> for nothing. So I turned it down. Phoned. “Sorry, I can’t take the job.”

Meg described a different experience when seeking a home health aide to help with her father-in-law; a difference that she attributed to her employer:

> Had I not worked where I worked [government social service agency], I would've never known about this chore grant. There was a grant out of the Department of Aging that gave a caregiver [a community-based caregiver to assist in the home], and income didn't matter. He was way over income for anything. And he really liked the girl that would come. Having the support…it helps with the physical, but it doesn’t help with the mental. We wouldn’t have to worry about chasing him downstairs.

Scott, Meg’s husband, concurred that having a home health aide reduced the physical strain of caregiving and added what it meant to their relationship, “It gave us a break. It gave us a date night. We'd go out to a movie or just go out to dinner and relax.”

Beth utilized paid caregivers as her father’s dementia and Parkinson’s disease progressed, and he could not be safely left alone.

> Nothing was ever quite good enough. The lady didn't cook as well as he did. He said, “She was lazy.” The lady didn't have to do anything much to do, but talk to my father, and make him lunch and dinner. I would hold my breath every day, hoping that the caregivers would make it…be there. They were, for the most part.

In contrast to the other co-researchers who sought assistance with their caregiving tasks, Allyssa did not want to utilize any homecare services and continued to complete ADLs for her grandmother when she was in hospice care. Allyssa explained how her decision was based on the severity of her grandmother's dementia symptoms:

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> No, I wouldn't have allowed it. I had even talked to my husband about if we had to really tighten our budget, and me taking a leave of absence from work in order to be the only one taking care of her. Like I said, she was very agitated, very combative, you know. She didn't want me around and would yell and scream at me. I had to put it aside and say this is not encompassing of our whole relationship. This is not encompassing as a person that she is. This is where she is right now in life, and I had to put that aside because I knew if I took it personal even though I wouldn't, but what if because she's yelling and screaming at me, now I'm not going to clean her up, and I just let her sit in her waste, or I don't feed her because she couldn't feed herself. That's not right. That would be abuse. So, I had to put that aside. And so, I think that's where my fear of hiring someone came from. Yeah, I wouldn't want that to happen.

Utilizing familial support. All eight co-researchers reported that they made the decisions when and how to utilize other family members in their primary caregiving roles. Similar to the utilization of community resources, the timing of requesting family support for caregiving appeared to occur in the middle to later stages of their caregiving careers. For three of the eight co-researchers, they described requesting assistance from a sibling because they had more knowledge and experience for a specific need (e.g., legal assistance for advanced directives and understanding medical bills) than the primary caregiver.

Edna had been taking care of her father without assistance from her five siblings for the beginning of the middle phases of her caregiving career. During her second interview, she identified feelings of anger and explained:

> I didn't have the support from my other siblings and not understanding why. So, you know, anger. And, too, because I just feel like they were missing out. And for me still…this is our dad like he gave us a good life. Like where are you at? It's not like I needed them to do anything because I was able to, thank God, I was in a position to be able to provide for my dad in whatever way I needed to. But this is dad, like where you at?

Edna shared that her father required more medical care as his symptoms of dementia increased and that she felt inundated with medical bills and paperwork. Edna contacted her sister for assistance. She recounted being the decision-maker and utilizing familial support:

> My older sister, she worked in insurance. And, actually, that's how she actually kind of came into the picture because I brought her in because she did work in insurance for years, like 30 years. So, she could read a medical form and know exactly why. That was her language. And, so, Dad didn't bring her, I kind of brought her in.

Whereas Edna asked her sister to assist with the medical/financial aspect of caregiving, Diana requested help from her sister to complete an ADL for the care recipient. She explained:

> I did everything for my grandma except I was very uncomfortable with like bathing her. I just...I couldn't bring myself, like, my sister would come in and do it. She would do the shower nights. I just, I don't know why. Like I would put her in her pajamas, but I couldn't like actually give her a bath.

Five of the eight co-researchers discussed requesting help from their adult or adolescent children to assist with the IADLs (e.g., housekeeping) and ADLs (e.g., dressing and bathing) of the care recipient. Three of the five co-researchers who received help from their children reported that their child had a special relationship with the care recipient and speculated that this bond resulted in the parent/parent-in-law being more cooperative and receptive to assistance from their grandchild.

Molly recounted that her mother-in-law had always doted on the co-researcher's daughter because she was the first grandchild and the first girl in two generations. She described how her daughter helped with caregiving:

> My daughter was a really good help because she'd just go over and, "Come on, Grandma, let's go do this. Let's brush your teeth. Take a bath." Those kinds of things. Because they had a relationship where they would always joke around with each other and have a good time. I think that bond kind of helped her. On occasion, it would be hard on my daughter, too, but she didn't have to be constantly helping my mother-in-law to do everything, so it was a little bit easier because she was coming in and just "Come on, grandma, come on, do this with

me."

Similar to Molly, Beth remembered the relationship between her daughter and the care recipient:

> Nothing was ever good enough for my dad. My daughter would clean for her grandpa. He was really nice to her. So, I got her to clean for him, and she would do his laundry. She would take it home and do it.

Seven of the eight co-researchers recounted receiving familial support when requested; however, Joseph, remembered times that his sister refused to help with caregiving:

> My sister took him [father] in for a while and put him in her cellar. The cellar is finished, and my mother wouldn't have that. He's not going to live in your cellar. I got into a big fight with my sister, and we didn't talk. I didn't have a lot of support with my dad after that. She said, "I'm done with her. You do whatever you want." So, I was the one who made all of the decisions for everyone. For both of them. I'd call my sister and say, "You gotta come up," and she'd say, "I'm not coming up. It's your problem. Bye." I hated her guts.

Nursing home placement of the care recipient. Each of the eight co-researchers discussed the decision to place their parent/parent-in-law in a care facility or to maintain them in the community. Five care recipients were admitted into nursing care facilities, and three remained in the community. The co-researchers who decided to do nursing home placement voiced struggling with their choice and provided unsolicited reasons that supported their decision to do a placement. The co-researchers cited the following reasons that supported their nursing home placement decision: safety concerns, a physically inaccessible home (e.g., too many stairs, inaccessible bathroom), financially unable to leave the workforce to be a full-time caregiver, the physical limitation of the co-researcher (e.g., unable to lift the care recipient), and the level of care required by the care recipient could not be provided in their home.

Edna and her significant other worked full-time, resulting in her father being left unattended and without supervision. Her adult children were unavailable to assist with caregiving due to school or work demands. Edna described her father as “always on the go” and that “even though he wasn’t in his right mind, he would still feel like he could come and go.” Edna recalled her experience in making the decision for nursing home placement:

> I was worried because I did not want to get a phone call that they found my dad somewhere in a back alley or something. And so, as difficult as that was to come to that decision because again this is a man that was a free bird. He loved being outside. I knew with having to put him in the facility that he was going to lose that freedom. And, so, it was very, very, very hard to make that decision at that time to have to put him in a facility.

Allyssa had not wanted to do a nursing home placement with her grandmother; however, the physical layout of the home and being respectful of her grandmother influenced her decision. She explained:

> She always took pride in how her house was. It was, kind of, almost like a museum…very clean. And towards the end, it got a little…but it wasn't a place where I could easily be able to wash her up and get her toileted where she still felt…had pride and dignity in the house. And then at my house, the only bathroom was upstairs, and there would have been no way.

Similar to Allyssa, Beth reported the physical layout of the home as being problematic to maintaining her father in the home; however, she noted several other factors. Beth shared:

> I still couldn't do it [keep him at home] even though he wasn't going to trot up and down the stairs anymore. His Parkinson's really affected him. He could have stayed on the second floor, but first of all, he was too big for me to handle, and I had to work. He had his days and his nights mixed up. It wasn't like a life choice to do.

The co-researchers who decided not to do nursing home placement appeared to make the decision earlier in their caregiving careers than those who did placement. The co-researchers' choice to maintain their parent or parent-in-law in the community seemed motivated by their prior experiences with nursing home facilities and the desire to honor their care recipient's wishes to remain in the home.

Meg had worked part-time as a caregiver at a local nursing home, and when her mother-in-law required skilled nursing care, she contacted her previous employer for placement. Meg believed her past positive relationship with the nursing home staff would result in her mother-in-law's needs being met; however, when Meg returned three days after her mother-in-law's admission, she discovered that she hadn't been bathed and her clothes hadn't been changed. At another visit, her mother-in-law was found on the floor and was "naked as a jaybird." These experiences, as well as her belief in family home care, contributed to Meg's decision to encourage Scott to maintain his father in the home. She discussed her thoughts on nursing home placement for her father-in-law:

> We didn't want him in a nursing home because no one can care for family like you can care for your family. I mean, if you truly love your family. Nursing home was never an option for him. Absolutely not. Bad care.

Similar to Meg, Joseph discussed the quality of care that his father received in the nursing home. Joseph recounted one experience that influenced his decision to maintain his mother at home:

> I come in after work, and he's gone in his pants. The lights on and no one's coming. I clean him, take the dirty diaper, walked to the nurse's station holding the diaper, and said, "Excuse me, can you?" They're not paying any attention. Said, "Excuse me, can anyone tell me how long my Dad's been in this? No?" I slammed the diaper on the desk. "I'll come clean it up when one of you can tell me. "

Joseph explained his decision to keep his mother at home: "My mother never wanted to die in a nursing home. What I saw happen to my father, I didn't want it to happen to her. I would never want that to happen to anybody besides, especially my mother.”

Consequences of decision-making. Seven of the eight co-researchers identified the consequences or outcomes of making decisions for their care recipient. Six of the co-researchers expressed doubts and/or regrets over their caregiving decisions. For several co-researchers, they questioned if they had done what the care recipient would have wanted because their parent could no longer articulate their needs due to their advanced dementia. Whereas some co-researchers identified specific regrets, others appeared to generally question if their daily caregiving choices met their parent/parent-in-law’s needs throughout their caregiving career. Three co-researchers described both caregiving regrets and also questioned their daily caregiving choices.

Edna reported experiencing stress during her caregiving role “because I worried if I was giving him what he needed.” Edna continued to question in post-caregiving if she provided the care that her father needed and tearfully reflected:

> I still think about that stuff. I'm just hoping that I did give, you know, what he needed. Because I mean he wasn't able to. My dad wasn't a man of words anyways, you know, and then not knowing if he knew himself what he needed. And just trying to work really hard to give him what I thought.

Beth, similar to Edna, questioned if the daily decisions she made as her father’s primary caregiver “were enough.” However, unlike Edna, Beth wondered if the negative feelings that she had toward her father from the past impacted her ability to be an effective caregiver.

Dissimilar to Beth and Edna's worries regarding daily caregiving choices, Joseph doubted an end of life choice that he made for his father. Joseph's father had fractured his hip after a fall in the nursing home. After surgery, his father was re-admitted to the nursing home and was in intractable pain. After the second day of his father "screaming bloody murder" from the pain, Joseph decided to request hospice:

> So, I made the mistake. Now I'm probably… not a mistake, but I called hospice. I didn't know what hospice really was. I can term hospice as Dr. Kevorkian in a week. They came in to put liquid morphine under his tongue. She handed me a book. She said that he won't be in any pain, and he went, "Ahhh." But three days later, he went into a coma, and a week later, he died. I read the book. It outlines everything, and I thought, I just killed my father." Maybe I should have tried to get him through the pain.
>
> For the five co-researchers who decided to do a nursing home placement, three, upon reflection, would have delayed their parents' admission to a nursing care facility. One co-researcher, Allyssa, expressed regret that she placed her grandmother in a nursing home and reported that she would have utilized in-home hospice care, whereas, Diane questioned if her grandmother would have received better care if the family had admitted her into a nursing home.

Scott was the only co-researcher to identify being satisfied with one of his caregiving decisions. He reflected on his caregiving career:

> I feel proud with what I was able to do. The little that I did do because I had help.

> But, I was glad that I didn't put him in a nursing home and stuff like that because he always wanted to stay home. But, I'm proud of what we did.

Theme 4: Direct Care Provider for ADLs

As part of the inclusionary criteria of the current study, the co-researchers were required to complete one activity of daily living (e.g., feeding, dressing, toileting, or continence care). Each of the eight co-researchers described their experiences in completing ADLs in the middle and later stages of their caregiving career. The co-researchers discussed this role in the context of (a) adjusting care based on the care recipient's level of functioning, (b) challenges of the direct care provider role for ADLs, and (c) supports for the direct care provider role for ADLs. The co-researchers' primary goal in the role was to complete their caregiving tasks with a minimum of resistance and emotional distress from the care recipient.

Adjusting care based on the care recipient's level of functioning. Five of the eight co-researchers identified ways that they adjusted their caregiving based on the care recipient's level of functioning. As dementia progressed and symptoms worsened, the co-researchers found ways to provide care based on the parent/parent-in-law's cognitive and physical abilities. Additionally, for those care recipients who experienced agitation, the co-researchers were mindful to choose ways to interact with the care recipient that would not trigger combative behaviors. The co-researchers reported finding ways to adjust to the care recipient's level of functioning primarily through trial and error and received no instruction or assistance from community resources. The co-researchers identified several ways that they adjusted their caregiving: changing their communication style with the care recipient, completing care at times that the care recipient was more receptive, and changing the way they did a personal care task.

Similar to other co-researchers who voiced frustrations with the care recipients refusals to complete personal care tasks, Meg struggled with her father-in-law's lack of bathing. She reported that by adjusting her communication style, her father-in-law would be willing to bathe:

> It was frustrating. You know, after the third day, I'd say, "Hey, dad, you know, you really need to take a shower, or you're not smelling good." And then on the fourth day, I'd say, "Dad, your ass stinks. You need to get a bath." And I would say it just like that. It was the only way that he would do it. I'd have to get stern with him. The only way that he would hear me.

Dissimilar to Meg, Molly chose a less direct communication style to avoid escalating her mother-in-law's agitation when completing ADLs. Molly explained that a soft tone of voice, gentle prompting, and "making it seem like it was her idea" were ways that made her mother-in-law more agreeable to care.

Several co-researchers discussed how they would schedule some of the personal care tasks based on the care recipients' receptiveness to care. For the care recipients who experienced sundowning, the co-researchers were mindful of providing personal care in the morning. Joseph described how, through trial and error, he structured his day to complete care when his mother was most receptive:

> Like in the morning. Should I feed her breakfast? Should I get her washed and then feed her breakfast? What was more comfortable for her? What worked better in her routine, you know. And should I turn on her game shows after that? Should I make her do her respiratory thing now? Like what times are best for her to say, “Oh, okay” instead of “No, I’m not doing it.’

Two co-researchers described how they changed the way they did a particular personal care task such as bathing and toileting based on the client’s symptoms of dementia. Allyssa provided an example of how she accommodated her grandmother’s needs by adjusting how the care was done:

> The nursing home staff would give her sponge baths, and it ticked off my grandmother. Whenever I was there, I literally put on my bathing suit. I put her in the wheelchair, took her down the hall to the big shower, and put her in one of those shower things, and me and her just got wet, and I washed her. That's what she wanted. But for them, they didn't have the staff to do that or the time. And I'm like, that agitates her because she doesn't feel clean. And my grandmother was always a clean woman. And, so, I just did it twice a day. I came in the morning, I put on a bathing suit, and we’d go in there. I’d soap her down and then take her back to her room.

Challenges of the direct care provider for ADLs. Five of the eight co-researchers discussed their challenges in providing ADL direct care. These challenges were identified primarily occurring in the late middle and the late phases of the co-researchers caregiving careers. The two challenges most frequently identified by the co-researchers during this role were the co-researchers'/primary caregivers' emotional discomfort providing hands-on care and the care recipient being resistive to personal care.

Three of the five co-researchers who identified challenges in this role found it difficult to complete hands-on care with their parent. Both sons in the current study voiced being uncomfortable with changing adult diapers and cleaning up their incontinent parent. One of the sons, Scott, relinquished his primary caregiving role to his wife, Meg, due to his inability to "be around bodily fluids." Scott stated, "I'm not good with diapers. I've changed one poopy diaper in my life, and I puked my guts out. And I can't be around when diapers are being changed." Additionally, Scott described being uncomfortable assisting Meg in bathing his father.

Joseph discussed the personal care that he completed with his parents. Although he was uncomfortable at times in this role, he did so because of the lack of familial and professional support. Joseph shared the challenge in cleaning up his father, "I can't stand crap. I can't stand it. I used to clean up my father, and I'd be gagging."

Joseph described his continence care as being challenging with his mother because he wasn't "used to female hygiene," and he had the additional task of digital disimpaction. Due to the side effects of opioid medication, Joseph's mother would experience constipation and painful fecal impactions that resulted in several emergency room visits. Joseph did manual disimpactions on the instruction of the emergency room doctor to clear the impaction and avoid the emotional and financial stressors of future hospital visits. Joseph discussed doing the digital disimpactions:

> Before being her caregiver, I hadn't even seen my mother naked before. You know what it took for me to stick my finger up her butt for the first time? I didn't know how I was going to do it without throwing up, but I did. Did it two and three times a week. Like I said, I hate crap.

Joseph, Beth, Meg, and Edna were primary caregivers to an opposite-sex care recipient. Beth reported feeding her father and was relieved that she never needed to "change his Depends" or bathe him. Meg, on the other hand, voiced no issues with providing continence care or bathing her father-in-law. Meg's comfort level may be partially attributed to her experience in providing personal care in a nursing home. Lastly, Edna reported that her significant other would do toileting with her father and "clean him up when he had accidents." She expressed no comfort or discomfort in being a direct care provider for ADLs.

Support for the direct care provider for ADLs. Seven of the eight co-researchers shared stories of support that they received from family and the community. Three co-researchers, Beth, Scott, and Meg, utilized paid caregivers, and one co-researcher, Allyssa, commended hospice care for their support. For familial support, the co-researchers identified their spouses, significant others, and their adult/young children as being helpful with the completion of ADLs. One co-researcher, Diane, identified her sibling as being supportive in this role.

Allyssa recognized the contributions that her husband made in providing care to her grandmother. She described how they worked together being mindful of her grandmother's dignity:

> He helped like when I needed to change her Depends and stuff. He still wanted to respect her and respect me, so he just kind of helped by holding her over on one side while I cleaned her up. He didn't want her to know just because it could've sent her into another world.

Meg expressed her appreciation for her husband's assistance with bathing her father-in-law. Although she had personal care experience working in a nursing home, she explained her need for assistance:

> We bathed him together. He had to be there to help out with him. He was dead weight. I mean, I'm strong, but it's too hard to roll somebody over on their side and hold them up while you're bathing them and trying to scrub. I'll tell you right now, and I take pride in this, the man never had a sore.

Molly struggled with motivating her mother-in-law to bathe. She questioned if the difficulty could be accounted for because she was not her biological child, but also noted that her mother-in-law tended to "listen better to men." Although her husband did not assist with hands-on care, he would intervene when his mother would refuse to complete personal care. Molly shared: "He'd call her over and say, "Mom, you need to take a bath. She's going to take you in there and get it done. Mom, you need to brush your teeth." With her husband prompting his mother to cooperate with personal care, Molly was able to do the tasks associated with her role as a direct care provider for ADLs.

The co-researchers reported feeling supported in their direct care provider roles not only by their loved ones assisting with care but also by their acceptance and understanding of the demands of caregiving. At the beginning of their caregiving careers, the co-researchers reported having fewer demands on their time. They were able to complete IADLs without causing much disruption in their various life roles. The addition of ADL tasks increased the co-researchers' caregiving responsibilities resulting in less time maintaining their roles within the family and in their careers. Four of the female caregivers identified experiencing role conflicts when juggling their caregiving roles with their employment and family roles. In contrast, the two male co-researchers did not discuss family role conflicts. As mentioned previously, Joseph described how his full-time caregiving responsibilities prohibited him from adopting a much-needed employee role.

The co-researchers noted that feeling supported in the direct care provider role for ADLs extended beyond receiving assistance with personal care tasks. Four of the female co-researchers described being supported in this role when a spouse/significant other had assumed one or more of the co-researchers' role-associated tasks within the family (e.g., husband cooking dinner, family keeping the home clean). Furthermore, those co-researchers felt supported when others understood the demands of their caregiving role and adjusted their role expectations of the co-researcher.

Allyssa was a wife and mother to a young child when she was a primary caregiver. She expressed how her family adjusted their role expectations:

> I felt supported probably several different times with my immediate family with my husband. And even though my son was really young, he didn't really question a lot like why I wasn't at home or didn't ask his dad, “Where’s mom?” He kind of just knew. So, I felt supported that even though they knew that I was missing out on time with them that Grandma was important to me.

In another interview, Allyssa reported how her husband offered her support in her direct care provider role:

> He didn't pressure me if dinner wasn't done, and I forgot about other things. You know, I wasn't emotionally, physically, or sexually there for him, and he did not pressure me at all. He made sure our son's homework was done, and that was kind of like my role in the house. I check homework with my son and stuff, and he did that. He didn't complain about it.

Beth discussed the pressure of maintaining a full-time job as a social worker and being a primary caregiver; however, similar to Allyssa, she felt supported by her significant other when his role expectations of their relationship did not conflict with her caregiving role. Beth stated, “I’m really lucky because my significant other is a really laid-back, easygoing guy. If I didn’t get home until 8:30, he didn’t care. If I didn’t have the time to do things around the house, he understood.”

Theme 5: The Mourner/Griever

The fifth theme, the mourner/griever, represents the feelings of loss identified by the eight co-researchers throughout their caregiving careers. Six of the eight researchers noted the grief they experienced primarily in the late early stages through to the completion of their caregiving journey. The co-researchers discussed mourning in regards to (a) the loss of the parent/parent-in-law who was physically present, (b) the reversal of the parent-child roles, and (c) the physical death of the care recipient. Whereas the co-researchers appeared to find the direct provider role for ADLS predominately physically draining, mourning was associated with emotional and mental exhaustion. Additionally, three of the five co-researchers who addressed the loss of the parent/parent-in-law who was physically present questioned the legitimacy of grieving for a living parent/parent-in-law.

The loss of the parent/parent-in-law who was physically present. Five of the eight co- researchers shared their feelings of loss for the parent who was physically present. As dementia progressed, the co-researchers discussed grieving for the loss of their parent/parent-in-law’s cognition, personality, and physical capabilities. It appeared that one of the most grievous losses expressed during the late-middle to the late stages of their caregiving career was the loss of the person, the essence of the care recipient. Five co-researchers described their parent/parent-in-law during this time in terms of being gone or not there anymore.

In both of her face-to-face interviews, Diane discussed the feelings of loss and grief that she experienced as a primary caregiver due to her grandmother’s declining cognition. She identified one moment when she acutely felt the loss of her grandmother/mother who was physically present:

> I brought my son over for a visit when he was about one and a half years old. She kept looking and staring over there at him. He was kind of afraid of her, but not much because he saw me interact with her. “Grandma, there’s my baby,” and she's like, ‘What's that little doggy doing in here?’ I remember sitting on the couch, crying. She thinks my son is a puppy. Now, it's like, okay, you don't even recognize a human. You're just gone. You're gone.

Similar to Diane, Beth expressed feelings of loss at her father’s cognitive decline, however, she also addressed his physical decline. She described her father as “being strong as a bull” and how the Parkinson’s with dementia resulted in his “disappearance.” At times, her father would be confused and believed that she was his mother or her mother. Additionally, he would hallucinate. Beth recounted a visit to the nursing home: “I was walking right up to him, and he yelled, ‘Look out,’ like at the top of his lungs. What? He's like, ‘Jesus Christ, that beam almost hit you.’ Steel beam. Oh, you're at work. So that was pretty awful.” Beth described how she grieved for her father, although he was physically present:

> I would feel so sad. From the minute I walked out of the nursing home, I would feel sad and teary in my car. It was like a 15-minute ride home, so I would cry for about half of that time. And then, I'd spend the other half pulling myself together

and just check-out for the rest of the night.

The reversal of the parent-child roles. Four of the eight co-researchers shared what they perceived as the reversal of the parent-child roles and the subsequent mourning for the loss of the parental relationship. During this late stage in their caregiving career, four co-researchers (Meg, Beth, Molly, and Shelly) described the care recipients in similar ways as regressing to infancy and requiring infant care (e.g., feeding, dressing, bathing and changing diapers) and the loss of the pre-dementia parental relationship. Meg summed up the late stages of dementia caregiving as “It’s like caring for a child. It’s just on a bigger scale. Instead of little diapers, you have big diapers.” The co-researchers, daughters/daughters-in-law, who acknowledged the reversal of the parent-child roles, appeared to view their caregiving as being more maternal than those co-researchers who did not and expressed feelings of loss over the parent-child relationship. The two sons in the current study did not identify the reversal of the parent-child roles in their interviews.

Molly was the primary caregiver to her mother-in-law while also caring for her husband with an advanced cancer diagnosis. During this time, Molly identified the reversal of parent-child roles. She recounted how her mother-in-law could not be supportive of her husband during his medical treatment because although she would visit him in the hospital, she would “show no real emotion.” Molly noted that her relationship with his mother-in-law changed with her mother-in-law’s advanced dementia: “Everything transferred during that time. His mom became like a child to us. You don’t want to treat them like a child, but you take care of them like a child. Telling them to brush their teeth. Get a bath." She acknowledged the grieving she experienced for her mother-in-law due to the role reversal:

> We used to do things all the time together [before dementia]. We'd go shopping, talk about the kids and what they were doing, you know, and when you get to that point when you're the parent, and they're the child, they resent it. She resented me. Telling her what to do. It was never the same. I missed our talks. Missed her.

Similar to Molly, Beth acknowledged the reversal of the parent-child roles with her father and how she viewed her primary caregiving role as being "maternal." She believed some of the maternal feelings were due to seeing her father regress physically and mentally. He was no longer the strong man "who once lifted the back of a car up for someone," but a vulnerable individual whom she felt needed protection and compassion. Beth stated, "At times, he would confuse me for his mother. He wasn't the same person anymore, although some of my negative feelings were still there. I felt more maternal feelings toward him than anything else." In her second interview, Beth shared her feeling of loss:

> It's weird. I grieved my father way harder than I grieved my mother, who I adored. I just, I don't know. I think it [dementia] made our [parent-child] relationship like…unresolvable. That it was always going to be what it was.

The physical death of the care recipient. Five of the eight co-researchers shared how they experienced their parent's death and their current feelings of loss associated with the physical death of the care recipient. The primary caregivers who expressed experiencing the loss of the parent who was physically present reported no diminished feelings of grief at the physical death of their care recipient. Additionally, three of the five co-researchers discussed how the death of a loved one to dementia was different from the death of an individual due to another medical condition.

Allyssa described her primary caregiving experiences during the end of her grandmother's life and how her symptoms of dementia impacted this time of loss:

> I mean, it's one thing to see someone actively dying, but it's another thing to be in the moment of someone who is actively dying, and they don't remember you or they are extremely combative when you get around, or throw things and say things. It's like so many layers on top of the fact that you're still trying to be there for them in their last few days.

Diane, who voiced mourning for her grandmother who was still physically present, shared her feelings of loss at the physical death of her grandmother. After her grandmother's death, she recounted, "It's weird. Even at her funeral, I'm thinking about comforting and protecting her." Furthermore, she described why the physical death of her grandmother was a more profound loss than the loss she experienced due to her grandmother's loss of cognition:

> Like I said before, my grandmother was already gone. Someone else.

> It was more grief and me missing seeing her physically. Like if I knew she was sitting in that chair, I was okay because I got to see her whether her mind was there or not. I physically got to see my grandma. But when she was gone, I missed seeing her face, so I was lost that way, and I was mad.

Joseph was sitting next to his mother when she died approximately three years before he participated in this study. He recounted a time in his young adulthood and a conversation with his parish priest that summarized his feelings regarding the loss of her mother:

> “[Priest] Come see me when she [mother] dies because you're going to need help.” He [priest] goes, "Because your god, your boss, your leader, and you're everything is dead now, and you're not going to know what the fuck to do." He used that exact term. “You're not going to know what the fuck to do.” When she died, that's the way I felt. Now what? And I'm still there. I'm kind of lost, I guess, is the word.

The co-researchers who discussed their mourning or grieving the physical death of the care recipient described feelings of being lost, “stuck,” and continued feelings of grief. The co-researchers viewed these feelings in the context of losing a person who was an integral part of their lives, a guiding influence. They did not identify their primary caregiving role as a factor in mourning the physical death of their care recipient.

Chapter III Summary

This chapter reported the findings of the current descriptive phenomenological study of the experiences of adult children who were primary caregivers to a parent with dementia. Five themes emerged from the data analysis consisting of prominent roles, each of the eight co-researchers adopted during their primary caregiving careers. The roles identified were: (a) advocate/protector, (b) liaison, (c) decision maker, (d) direct care provider for ADLs, and (e) mourner/griever.

Chapter IV examines these five themes in relation to the current scholarly literature of adult children who were primary caregivers to a parent with dementia. Implications for counselors and other mental health providers, as well as counselor educators, are identified. Limitations of the current study and recommendations for future research are discussed.

CHAPTER IV

DISCUSSION

The majority of dementia caregiving research has examined the effects of dementia caregiving, defined and quantified these effects, or measured the efficacy of specific interventions (e.g., caregiving support programs, adult day care programs) to alleviate the adverse effects or burdens of dementia caregiving (Loboprabhu, Molinari, & Lomax, 2006). Additionally, researchers have investigated dementia caregiving through the lens of culture and ethnicity (e.g., Dilworth-Anderson et al., 2005; Dilworth-Anderson, Williams & Gibson, 2002; Liew, 2015). For approximately four decades, researchers have primarily investigated being a caregiver concurrent with the caregiving experience and explored specific variables using quantitative research methodologies. Unlike previous studies, the current research study adopted a descriptive phenomenological approach to explore the experiences of adult children who were primary caregivers to a parent with dementia from the inception to the conclusion of their caregiving journey. By investigating the co-researchers' experiences in *post*-caregiving, persistent meanings and themes were captured after years of possible self-reflection.

The research question that guided this study was: What are the lived experiences of adult children who are caregivers to a parent with dementia? Findings in the study suggest that the co-researchers adopted several roles within their primary caregiving careers. This chapter provides a discussion (a) adopting caregiver roles; (b) the discussion of the prominent roles found in this study; (c) implications for clinical mental health counselors, other social service providers, and counselor educators; (d) delimitations and limitations of the current study; (e) recommendations for future research, and (e) chapter summary.

Adopting Caregiver Roles

Findings of the current study suggest that the primary caregivers (co-researchers) adopted five roles that evolved throughout their caregiving careers: advocate/protector, liaison, decision-maker, direct care provider for ADLs, and mourner/griever. These roles were adapted to address the changing needs and experiences of the co-researchers and the care recipient. In this chapter, the terms *care recipient* and *parent/parent-in-law* are used interchangeably. The following section offers a brief discussion on acquiring the caregiving role or, perhaps more accurately, the caregiving roles.

Role Making

Suitor and Pillemer (1994) suggested that taking on the caregiver role is similar to other major life transitions, such as marriage or becoming a parent. The adoption of the caregiver role(s) requires changes in the traditional patterns of behavior and role expectations between the caregiver and care recipient. Schumacher (1995) posited that an integral part of acquiring a caregiver role is through role making. Unlike other social roles that are well-defined within the family with norms and set behavioral expectations, the caregiver role does not hold a hierarchical place in the family (e.g., parent, sibling, grandparent) and has few behavioral expectations or norms (Meleis, 2018). The caregiver role is created and changes through interactions between the caregiver and the care recipient (Meleis, 2018). It is through these interactions that the caregiver adopts caregiving behaviors and attitudes specific to the care recipient's evolving needs and the caregiver's perceptions of the caregiving role (Schumacher, 1995). Although the caregiving role(s) is predominantly co-constructed between the caregiver and the care recipient, those who share a social bond with the caregiver and care recipient (e.g., spouse, sibling, co-workers) may also play a part in shaping the caregiver role (Stryker & Statham, 1985).

Aneshensel, Pearlin, Mulan, Zarit, and Whitlach (1995) identified three stages of role development for caregivers: *role acquisition*, *role enactment*, and *role disengagement. Role acquisition* occurs when the individual acknowledges the need to become a caregiver and assumes responsibility; *role enactment* is the performance of caregiving tasks at home or a long-term care facility, and *role disengagement* occurs at the ending of caregiving, and the start of focusing on other areas of life. During role acquisition, the individual learns the caregiver role, redefines family dynamics, and plans for the future. Role enactment involves learning and completing direct care tasks, managing dementia behaviors, learning how to access available resources, and continuing to engage the care receiver in meaningful and enjoyable activities. Aneshensel et al. (1995) viewed role disengagement as the end of the caregiving career, whereas others believed that discarded aspects of caregiving occur throughout the caregiving career (Barney & Perkinson, 2015). For example, if the caregiver can no longer sustain meeting the direct care needs of the care recipient, they may find appropriate home health care providers and disengage from that caregiving role. Additionally, role disengagement tasks may involve: finding and selecting a long-term care facility, being an advocate with care providers, supporting end-of-life needs, and grief and bereavement.

Re-engagement has been proposed as the fourth stage of role development in caregiving (Perkinson, Hilton, & Perlmutter, 2011). The tasks of re-engagement are comparable to what some researchers identify as occurring in the role disengagement stage. In this stage, caregivers establish new roles and return to established old roles, strengthen social ties, and transition to a new life.

The unique interaction between the primary caregiver and the care recipient is one factor that may account for the variation found in adopting the primary caregiver role (Meleis, 2018). Research findings show additional factors that may contribute to variations in the caregiving role include the diversity of the family (e.g., race, ethnicity, socioeconomic status), the duration of the caregiving role, transitions in care experienced throughout the caregiving trajectory, the timing of the caregiving role (i.e., the age of the caregiver), and the prior relationship between the care recipient and the caregiver (Schulz & Eden, 2016; Sherrell, Buckwalter & Morhardt, 2001; Whitbeck, Holt, & Huck, 1994).

The Discussion of the Prominent Roles

Researchers have found much heterogeneity in the primary caregiving role; nevertheless, findings of the current study suggest five prominent roles were adopted and adapted by the eight co-researchers across the trajectory of their caregiving careers (Pearlin et al., 1990; Schulz & Eden, 2016; Schumacher, 1995; Van der Lee et al., 2015). In the next section, the following roles are discussed (a) advocate/protector, (b) liaison, (c) decision maker, (d) direct care provider for ADLs, and (e) mourner/griever.

Additionally, specific subthemes and contexts of these roles will be explored as well as how these themes and subthemes compare and contrast to the scholarly literature.

Advocate/Protector

Research findings have shown that caregivers adopt the advocate/protector role when the care recipient is no longer able to articulate their needs due to increasing cognitive deficits resulting in the care recipient's vulnerability (Gauthier & Poirier, 2007; Gladstone & Wexler, 2000). In this current study, the co-researchers described being "the voice" of the care recipient in the middle to late stages in their primary caregiving careers. The advocate/protector subthemes in the current study were (a) advocate/ protector in the medical community, (b) advocate/protector for the care recipient's safety, and (c) advocate/protector to the care recipient within the family

Advocate/protector in the medical community. Vick et al. (2017) identified communication as "the fulcrum on which all healthcare pivots: it is the process by which patients and clinicians establish a therapeutic relationship, exchange health information, and make treatment decisions" (p. 3). Communication impairments associated with dementia (e.g., memory impairment; intellectual impoverishment resulting in vague speech or meaningless repetition of words; and aphasia, which is an inability to understand and articulate speech) create challenges for the medical community, the care recipient, and the primary caregiver. Seven of the eight co-researchers discussed taking on the advocate/protector role in response to the breakdown in communication between the primary care physician and the care recipient, which is consistent with previous research findings (Boltz & Galvin, 2015; Lipton & Marshall, 2012).

The co-researchers voiced frustration in working with a primary physician who did not offer ways to manage the care recipients' problematic behaviors (e.g., anger sundowning, wandering) and memory or provide community resources to assist them in their primary caregiving. The co-researchers were not expecting a cure for dementia but desired concrete ways to help their parent/parent-in-law and were disappointed and frustrated when the primary physicians’ answers to treatment were solely medication. One co-researcher described how medication decreased his mother's problematic behaviors so that he did not need to do a nursing home placement. However, the majority of co-researchers discussed ways that the care recipients' prescribed medication for memory loss or to reduce problematic behaviors resulted in side effects that made primary caregiving more challenging, such as lethargy, increased fall risk, agitation, and insomnia.

Although most of the co-researchers acknowledged needing to know more about dementia symptoms and their progression, primary physicians provided little to no education. Co-researchers reported an increase in advocacy as the care recipient’s dementia symptoms increased and that physicians did not respond to the care recipient’s needs, such as side effects from a medication.

Researchers have explored the triadic working relationship between the caregiver, the care recipient, and the primary care physician. Belmin et al. (2012) found that fewer than 50% of dementia caregivers received assistance in managing behaviors or making referrals for community support programs for caregivers. Physicians identified the following factors for not providing psychoeducation in behavior management and referrals to support programs for dementia caregivers: lack of time, low reimbursements, and lack of knowledge of community resources (Hinton et al., 2007; Jennings et al., 2015).

Yaff, Orzeck, and Barylak (2008) found that Canadian physicians were comfortable in caring for patients with dementia; however, these physicians asserted that much of the care should come from community programs, but had little knowledge about dementia caregiving programs and little interest in learning about them. Hinton et al. (2007) posited that time constraints and lower reimbursement resulted in the reactive care of dementia patients with a focus on medication rather than the more time-consuming proactive interventions, such as psychoeducation on behavior management. A physician's lack of knowledge about community resources may hinder primary caregivers from receiving necessary referrals, but the systemic limitations of the healthcare system contributed to a scarcity of interventions other than medication (Hinton et al., 2007).

Findings of the current research suggest that one task associated with the advocate caregiving role is to provide the physician with accurate information regarding dementia symptoms. Vick et al. (2017) found that physicians were most interested in hearing information that was actionable and obtaining "just the right" amount of crucial social information. Physicians reported that caregivers shared too much information about the care recipient that was irrelevant to treatment. The co-researchers in this study wanted to provide a comprehensive account of their care recipients' symptoms, including those that the primary care physician could not alleviate (e.g., incontinence, inappropriate social behaviors). The primary caregivers did not feel listened to when physicians did not share their priorities resulting in caregivers participating more in the advocacy/protector role. The co-researchers described increasing their advocacy by seeking medical second opinions, changing medical providers, requesting appointments sooner than the physician had thought necessary, and requesting rationales for a physician's treatment plan.

Advocate/protector for nursing home care. The five co-researchers who placed the care recipient in a nursing home appeared to spend more time in the advocate/protector role than co-researchers who maintained the care recipient in the community. Four of the co-researchers described how their parent/parent-in-law received inadequate, neglectful care at their respective nursing homes. Whereas one co-researcher, Edna, voiced the importance of having a positive relationship with her father's professional caregivers, the other four co-researchers acknowledged an adversarial relationship with the nursing home staff, which they attributed to insufficient care for their loved one, an unwillingness of the staff to address the co-researchers' care concerns, and an unwillingness to provide co-researchers with physical or mental health status changes of the care recipient (e.g., falls resulting in bruises and lacerations, increase in combative behaviors, hypersomnia). The four co-researchers, who described an adversarial relationship with the nursing home staff, identified feelings of distrust, anger, disappointment, and resentment toward the nursing home staff. They also reported high levels of distrust in the staff's ability to care for their parent/parent-in-law adequately. Their animosity continued throughout the stay of the care recipient or until the care recipient moved to another nursing home. Regardless of their relationship status with the nursing home caregivers, each of the co-researchers who did nursing home placement reported continued monitoring of their parent/parent-in-law's care after placement.

Researchers exploring the relationships between nursing home staff and family caregivers have found similar findings to those in the current study (Boogaard, Werner, Zisberg, & Van der Steen, 2017; Legault & Ducharme, 2009). The erosion of caregiver trust described by the co-researchers in the current study may have occurred for the following reasons (1) negative first impression of the nursing home, (2) unfavorable comparisons with other nursing homes, (3) lack of interest shown by the nursing staff toward the care recipient, (4) staff being unresponsive to the caregiver concerns, and (5) staff not being transparent in the event of accidents or incident (Legault & Ducharme, 2009). Co-researchers in the current study did not identify a negative first impression or an unfavorable comparison of the nursing home; however, four co-researchers angrily described the lack of interest, unresponsiveness, and lack of transparency on the part of nursing staff. Ultimately, the caregivers' lack of trust in nursing staff increased the caregivers' role of advocate/protector to ensure their parent was receiving proper care.

Boogaard et al. (2017) found a positive correlation between a high level of caregiver trust and a high level of nursing home care satisfaction. Edna, who voiced a positive relationship with the nursing home staff, also trusted that her father was receiving proper care. She used what Legault and Ducharme (2009) defined as a diplomatic communication style in her interactions with the nursing home staff. Edna's communication style consisted of being mindful of her tone of voice (e.g., friendly), selection of words that would not question the quality of nursing care (e.g., not accusatory), and using questions rather than making demands (Legault & Ducharme, 2009). In contrast to Legault and Ducharmes' (2009) findings, Edna did not appear to adopt this communication style in fear that her advocacy would result in the mistreatment of her father, but as a friendly way to engage the nursing home staff to provide quality care. Her belief seemed to align with the old European idiom, "You can catch more flies with honey than vinegar" (Concise Dictionary of English Combined Idioms, Phrases, Proverbs, Similes, and Metaphors [Editorial Board], 2015).

Findings from other studies have suggested that family caregivers are concerned that criticisms during their advocacy role may result in retribution to the care recipient. However, this finding was not supported in the current study (Hertzberg & Ekman, 2000; Hertzberg & Elkman, 1996; Legault & Ducharme, 2009). No co-researcher who described actively advocating for their parent/parent-in-law voiced concerns of retaliation against the care recipient.

Advocate/protector to the care recipient within the family. Two co-researchers, Diane and Joseph, described the need to protect the care recipient from perceived abuses from other family members. The abuses identified consisted of physical, emotional, and financial exploitation. It was a logical expectation that primary caregivers would have to provide for the safety of the care recipient based on cognitive impairments and problematic behaviors that could potentially lead to unsafe situations (e.g., wandering, fires from cooking). The need to protect the care recipient from other family members was unanticipated.

There is an absence of research studies investigating family members protecting the care recipient from possible elder abuse from other family members. This is surprising due to the prevalence of elder abuse. Lachs and Pillemer (2015) estimated that elder abuse happens to approximately 1 out of 10 older adults; however, the number is probably higher due to family members and victims under-reporting the abuse. Researchers investigating elder abuse have consistently found that family members are most often the perpetrators, and abuse occurs more frequently in the home (Simone, Wettstein, Senn, Rosemann, & Hasler, 2016; Lachs & Pillemer, 2015).

In the current study, Diane suspected her grandmother was experiencing emotional and economic abuse from Diane's biological mother. Diane reported the abuse several times to the proper agency. Joseph did not report his mother's physical and emotional abuse of his father; however, he moved his father into a nursing home to protect him from additional abuse. Joseph described years of domestic violence between his parents; however, their physical aggression increased with the progression of his father's dementia. His father became increasingly confused and physically aggressive toward his wife (i.e., Joseph's mother), and she, in turn, aggressively responded. Joseph strongly condemned his mother's physical abuse of his father but believed, at times, she was "hitting back." Grafstrom, Nordberg, and Winblad (1993) found that caregivers who self-reported as abusers conceptualized their aggression as a response to the care receiver's aggressive behavior. There was "mutual aggression" between the care recipient and the primary caregiver. Joseph appeared to be explaining, in part, the concept of mutual aggression between his parents. Findings from a study of 82 dementia caregivers revealed that 35% of the caregivers reported mutual verbal abuse with the care recipient, and 6% reported mutual physical abuse between the caregiver and the care recipient (Cooney & Lawlor, 2006).

It is noteworthy that Diane and Joseph cited previous dysfunctional family relationships (e.g., conflicts between the primary caregiver and other family members). Additionally, they described how adopting this role created more tension and, in some cases, the severing of family ties. For Diane, the family continued to assist with care; however, Joseph reported that he no longer received support from his sister or mother in the care of his father.

Liaison

The primary caregiver served as a bridge or a link between the care recipient and the medical community, and their parent/parent-in-law's neighborhood community. Additionally, in this role, the primary caregiver was the "memory keeper." They would link the care recipient with memories from their past as well as connect others with the memory of their pre-dementia parent/parent-in-law. The liaison role was one of the first roles adopted as the primary caregivers connected the care recipient to medical care (e.g., scheduling appointments and providing transportation). The role occurred throughout the primary caregiving career and into post-caregiving (i.e., connecting others to the memory of their pre-dementia parent/parent-in-law after their death). Subthemes identified were: (1) liaison to the medical community, (2) liaison to the care recipient's memories, (3) liaison to the care recipient's community, and (4) liaison to the memory of their pre-dementia parent/parent-in-law. The latter two subthemes are discussed further because the findings are somewhat unique.

Liaison to the care recipient's community. Half of the co-researchers in the current study described being a link between the care recipients' community and the care recipient. Co-researchers assumed this role in the middle stages of their caregiving career when the care recipients' memory and decision making were increasingly impaired, and co-researchers were mostly providing assistance with instrumental activities of daily living (e.g., meal preparation, paying bills, taking medication). Members of the community would contact the co-researchers to intervene in the care recipients' risky behaviors (e.g., wandering a busy highway) or report incidences of confusion. Co-researchers observed this aspect of the liaison role as providing insight and clarity into the severity of the care recipients' dementia. It is noteworthy that when others acknowledged the cognitive decline in the care recipient, the co-researchers no longer dismissed the parent/parent-in-laws' changes as “normal” aging, which in turn changed the intensity in caregiving (e.g., parent/parent-in-law no longer lived alone). The co-researchers were appreciative of community involvement and appeared to find it reassuring that others were keeping a watchful eye on the care recipient.

The liaison role assumed by dementia caregivers is not represented in the research literature. Findings from earlier research suggested that neighbors do provide dementia caregiving assistance; however, these studies represented neighbors as informal caregivers who provided direct assistance to the care recipient (Tuokko, MacCourt, & Heath, 1999; Webber, Fox, & Burnette, 1994). Morgan, Semchuck, Stewart, and D’Arcy (2002) found that caregivers viewed the closeness of a rural community and the willingness to “to keep an eye out” for the care recipient as positive; nevertheless, they also expressed privacy concerns. Co-researchers in the current study did not describe the lack of privacy in association with the liaison role. Additionally, co-researchers from rural, suburban, and urban areas identified the monitoring of the care recipient in favorable terms. Neighbors keeping “a watchful eye” was a finding in a mixed qualitative and participatory study conducted in Great Britain, Scotland, and Sweden (Ward et al., 2018). Similar to the findings of the current study, Ward et al. (2018) described how neighbors to people with dementia stepped in when there was a potential for harm; however, their interventions were with the person with dementia and not the primary caregiver, as represented in the current study.

The Ward et al. (2018) research findings show community involvement in caring for individuals with dementia. However, a research gap exists that examines the relationships between the community members, the primary caregiver, and the care recipient. Also, future researchers may study how the liaison role in the community informs and shapes the primary caregiving role.

Connecting others to the memory of their pre-dementia parent/parent-in-law. This subtheme of the liaison role occurred in different contexts in the middle to late stages of the co-researchers’ caregiving careers, as well as post-caregiving. The inception of the role appeared to occur mostly in a care setting (e.g., hospital or nursing home) when the care recipient exhibited inappropriate social behavior. Co-researchers expressed feelings of shame and embarrassment and were fearful that others would mistakenly ascribe the problematic behaviors to the care recipient rather than rightfully attribute to the disease of dementia. Co-researchers described sharing specific characteristics (e.g., kind, generous, gentle) of their pre-dementia parent to inform staff in the care setting that the behaviors they witnessed did not reflect the essence of their parent/parent-in-law. This aspect of the liaison role appeared to serve two purposes: to separate the care recipient, the person, from the dementia-related behaviors, and to alleviate the co-researcher's embarrassment.

There is an absence of research regarding the primary caregiver connecting others to the memory of their pre-dementia parent/parent-in-law in a care setting. However, researchers have explored co-researchers' experiences of shame and embarrassment, which may be attributed to stigma. Crocker et al. (1998) defined stigmatized individuals as "possessing (or are believed to possess) some attribute or characteristic, that conveys a social identity that is devalued in a particular social context" (p. 505). Similar to the current study, MacRae (1999) found caregivers' feelings of shame, embarrassment, and humiliation are associated with dementia behaviors that breach normative standards (e.g., physical aggression, screaming profanities, inappropriate sexual remarks). Additional results from other studies across different cultures (e.g., Arab, Hispanic, African American, Asian, Persian) consistently show caregivers' feelings of embarrassment and shame regarding the care recipients' dementia-related behaviors (Abojabel & Werner, 2016; Montoro-Rodriguez, Koslowski, Kercher, & Montgomery, 2009; Navab, Negarandeh, Peyrovi, & Navab, 2012; Zhan, 2004).

It is noteworthy that the co-researchers adopted this aspect of the liaison role during specific contexts of caregiving. The contextual adoption of this role may be explained by discreditable or discredited stigma. In the seminal work of Ervin Goffman

(1963), Goffman posited that stigma could be discreditable or discredited. Discreditable occurs when the person has a stigma that is not apparent or hidden, whereas a discredited individual has a stigma that is visible or known. Both discreditable and discredited stigma can cause shame and embarrassment (Aminzadah, Byszewski, Molnar, & Eisner, 2007; Walmsley & McCormack, 2016). Furthermore, research demonstrated a positive correlation between stigma and caregiver burden (Chang & Horrocks, 2006; Werner, Mittelman, Goldstein, & Heinkik, 2011).

Montoro-Rodriquez et al. (2009) investigated social embarrassment resulting from discreditable and discredited stigma. In discreditable stigma, Montoro-Rodriquez et al. (2009) theorized that a caregiver finds strategies to manage the care recipient's behavior, such as having someone stay with the care recipient while the caregiver shops or making people aware that the cause of the behavior is health-related. Discredited stigma may be more challenging to resolve because an individual who is interacting with the caregiving dyad is familiar with the care recipient's dementia diagnosis. The labeling of the problem does not change the discredited stigma. Montoro-Rodriquez et al. (2009) observed that part of dementia stigmatization is the lack of knowledge of the symptoms and etiology of dementia. Thus, caregivers who provide dementia education to the community may relieve discredited stigma.

Co-researchers in the current study experienced discreditable and discredited stigma. Co-researchers identified being embarrassed and humiliated when care recipients would “act up” in public places, such as restaurants and grocery stores. This discreditable stigma appeared to decrease with the progression of dementia, as the primary caregiver would isolate the care recipient. However, at no time while experiencing discreditable stigma did the co-researchers describe engaging in this aspect of the liaison role.

The liaison role of connecting others to the memory of their pre-dementia parent/parent-in-law occurred in nursing homes or other care settings where the staff was expected to know the care recipient's diagnosis and understand associated behaviors. In discredited stigma, Montoro-Rodriquez et al. (2009) suggested that education may reduce discredited stigma; however, rather than provide information on dementia, co-researchers "educated" staff on the essence of the care recipient before the onset of dementia. Goffman (1963) stated that stigma reduces someone "from a whole and usual person to a tainted, discounted one" (p. 4). This aspect of the liaison role may serve as a reminder of the "whole person" before dementia and relieve the embarrassment related to discredited stigma.

Decision-Maker

Findings of the current study reveal the primary caregiver as the person in the care recipient's life who made the final decisions on all facets of caregiving. It is noteworthy that daughters-in-law, who were primary caregivers in the study, did not make major decisions (e.g., not permitting the care recipient to drive, nursing home placement); instead, the biological sons of the care recipient did. Nevertheless, the daughters-in-law provided insight into the care recipient's level of functioning that resulted in timely, responsible decisions. Decision-making involved four types of actions and experiences, each regarded as a subtheme of the decision-maker roles: (a) utilizing community services; (b) utilizing familial support; (c) nursing home placement of the care recipient, and (d) consequences of decision-making.

The responsibility of the decision-maker was not taken lightly, and the co-researcher continued to question if they made the correct decisions into post-caregiving. Nursing home placement is discussed further below, as it was considered one of the most challenging decisions for the co-researchers in this study. Furthermore, the choice to transition the care recipient to a nursing home influenced the advocate/protector role (e.g., monitoring nursing home care) and the liaison role (e.g., the nursing staff contacting the co-researcher for assistance with a care recipient's refusal to take medication.)

Decision-maker for nursing home placement. Co-researchers described how the nursing home placement was the most challenging decision made throughout their caregiving careers. Each of the co-researchers described their rationale for nursing home placement or maintaining the care recipient at home. The co-researchers who placed the care recipient in a nursing home expressed regret for placement or for not keeping the care recipient home for a more extended period. The co-researchers who maintained the care recipient at home voiced satisfaction with their decision except for one co-researcher who questioned if her mother would have received better care in a nursing home.

Co-researchers identified a combination of precipitating factors that resulted in nursing home placement of the care recipient, including safety concerns, reduced mobility, a physically inaccessible home, full-time employment, and physical limitations of the co-researcher (e.g., lifting the care recipient). Researchers who have investigated the factors in nursing home placement have primarily viewed the variables from the perspective of the care recipients' deficits (e.g., physical limitations, dementia-related behaviors; Gilley et al., 2004; Kunik et al., 2010; Toot, Swinson, Devine, Challis, & Orell, 2016); however, co-researchers in the current study conceptualized their decision-making through the lens of their deficits, such as what limitations they could not transcend to keep the care recipient at home.

Findings from the scholarly literature generally align with the experiences of the co-researchers, whereas some findings are conflicting. Luppa et al. (2012) suggested that care recipients'mobility impairments did significantly increase the risk of nursing home placement, which was indicated by the co-researcher as not being able to provide a physically accessible home. In contrast, Gilley et al. (2004) found that mobility issues did not increase or decrease the risk of nursing home placement.

The co-researchers described how the care recipient required more assistance with ADLs and experienced riskier dementia-related behaviors with disease progression (e.g., aggression, wandering). These changes required more time for hands-on care and monitoring of the care recipient's behaviors. Four of the five co-researchers who did nursing home placement worked full-time and could not withdraw from the workforce to provide 24-hour care. If given financial freedom, three of the four researchers shared that they would have left their careers and retained the care recipient at home.

Findings of the current study are consistent with existing research indicating that behavioral and psychological symptoms of dementia (BPSD) are associated with an increased risk of nursing home placement (Gibbons et al., 2002; Gilley et al., 2004; Kunik et al., 2010; Scarmeas et al., 2007; Toot et al., 2016). Care recipients who experienced aggression, disruptive behaviors, and hallucinations are at higher risk for nursing home placement (Gaugler et al., 2000; Gilley et al., 2004; Kunik et al., 2010). Although there is a significant correlation between BPSD and nursing home placement, the association between ADLs and placement is not as clear. Several researchers have found that an increase in ADLs dependency is a risk factor for nursing home placement (Bharacha, Pandav, Shen, Dodge, & Ganguli, 2004; Gaugler, Kane & Newcomer, 2005; Harboun et al., 2008). Other research has found no significant correlation between the care recipient's level of ADL dependency and placement (Andel, Hyer, & Slack, 2007; de Vugt, Stevens, Aalten, & Lousberg, 2005).

Co-researchers in the current study who decided to maintain the care recipient in the home appeared to make the decision early in their caregiving careers. Furthermore, the decision against nursing home placement was independent of the care recipient's level of functioning. Co-researchers described the pre-dementia parent's wish to remain in the home as well as prior negative nursing home experiences as the driving forces in their decision-making to forego nursing home placement.

Direct Care Provider for ADLs

All eight of the co-researchers described their role as the direct care provider to assist the care recipient in completing their activities of daily living (e.g., feeding, toileting, bathing). It was not surprising that this role emerged as part of the data analyses because inclusionary criteria required participants to assist with a minimum of one ADL. Additionally, the co-researchers had been active primary caregivers during times when the tasks of completing ADLs became more prevalent, arduous, and time-consuming. In the later stages of dementia, there is a “piling up” of caregiving ADLs and IADLs. For example, if a primary caregiver is bathing the care recipient, then there must be soap (shopping/IADLs) and clean towels and clothing (laundry/IADLs), warm water (utility bills paid/IADLs), and after bathing, perhaps assisting with dressing (ADLs) and personal grooming (e.g., nail and hair care/ADLs).

The co-researchers described their role as a direct care provider for ADLs in terms of the following subthemes: (a) adjusting care based on the care recipient’s level of functioning, (b) challenges of the direct provider role and (c) supports for the direct provider role of ADLs.

Six of eight co-researchers described trying to balance the needs of their care recipient with the competing needs of their family, friends, and workplace. As the care recipients’ cognitive, physical, and emotional health worsened, the co-researchers had to spend more time in caregiving and away from their other roles and responsibilities (e.g., family and employment). Co-researchers recalled times when they could not “be there” for family or loved ones and when they were, they worried that they “were not there” for the care recipient, resulting in role conflict. Pandey and Kumar (1997) defined role conflict as “the simultaneous occurrence of two or more role expectations such that compliance with one would make compliance with the other difficult or impossible” (p. 191).

In addition to role conflicts, the co-researchers described feeling overwhelmed by juggling the physically and emotionally demanding role of direct care providers for ADLs. The introduction of this role, combined with role expectations outside of the primary caregiver role (e.g., mother, employee), appeared to be a tipping point for role overload for several co-researchers in the current study. Role overload occurs “when the time and resources allotted for a certain role are insufficient to meet role expectations” (Friberg & Creasia, 2013, p. 54). Role overload has been found to have a positive correlation with caregiver burden (Bastawrous, 2013; Van der Lee, Bakker, Duivenvoorden, & Droes, 2015).

The co-researchers identified family members or loved ones as significant supporters in assisting them in completing their roles as direct care providers for ADLs. The simplest acts, such as assisting in rolling a care recipient for continence care or cajoling the care recipient to agree to care, were appreciated and appeared to offer relief to the co-researchers. Surprisingly, despite the physical toll of completing ADLs (e.g., lifting, repositioning the care recipient) expressed by the co-researchers in this study, they appeared to value more that family members were willing to adjust their role expectations of the co-researcher than the hands-on care assistance. The adjustment in role expectations occurred in two ways: a significant other no longer presumed the co-recipient would act on the role expectation (e.g., the husband expecting dinner to be waiting) or adoption of a co-researcher’s role expectation (e.g., helping a child with homework).

A unique difference between those co-researchers who identified as White/Caucasian and those who identified as African American/Black was the significance of respect. The African American co-researchers, Edna and Allyssa, discussed the importance of being respectful and preserving the dignity of the care recipient while completing ADLs. Furthermore, when a spouse or a significant other showed respect to the care recipient (e.g., a son-in-law looking away during his mother-in-law's incontinence care), this, in turn, was being respectful to the co-researcher. The White co-researchers in the current study did not voice this extension of respect in triadic caregiving.

Mourner/Griever

Findings in this study suggest the co-researchers experienced the mourner/griever role. Several co-researchers initially engaged in mourning or grieving for their care recipient in what they defined as the later part of the early stages of dementia (mourning for a parent who is physically present) whereas other co-researchers initially identified their mourning/griever role occurring in the middle to late stages of the care recipient's disease (the reversal of the parent-child roles, the physical death of the care recipient). Co-researchers identified feelings of anger, loss, helplessness, frustration, hurt, denial, disbelief, and numbness within the mourner/griever role.

The loss of the parent/parent-in-law who was physically present. Findings from this study suggested that co-researchers experienced grieving for the care recipient who was physically present and under their care. The five co-researchers who addressed this aspect of the mourner/griever role described the loss of the care recipient "in pieces and parts," "disappearing before my eyes," and "she was there, but she wasn't there anymore." During these experiences, the co-researchers expressed being "on an emotional roller coaster." Additionally, they described surprise and puzzlement as they grappled with understanding how their parent/parent-in-law experienced times of clarity and regressed to states of forgetfulness and confusion within minutes or hours. These experiences are consistent with the scholarly literature that defines ambiguous loss (Boss, 1999, 2009; Boss & Kaplan, 2003; Dupuis, 2002). The co-researchers were not describing anticipatory grief and experiencing feelings associated with the impending death of the care recipient but discussed the loss of the person who was physically present but psychologically and emotionally absent (Boss, 1999).

Dupuis (2002) identified three phases of ambiguous loss: *anticipating, progressive,* and *acknowledging*. Co-researchers did not express features of the phase of anticipating loss (e.g., concerns about the future and their ability to cope with the care receiver's physical and mental decline); however, co-researchers voiced experiences consistent with the progressive and acknowledging loss phases. Feelings of emotional pain from watching the cognitive decline of their parent/parent-in-law, ensuring the care recipient was present for family functions, and remembering the person before they had symptoms of dementia were discussed by the co-researchers and identified as themes consistent with the progressive loss phase (Dupuis, 2002). The primary caregivers in the current study who grieved the loss of a parent/parent-in-law who was still alive had glimpses of their pre-dementia parent during the progressive loss phase. They speculated that despite dementia, the essence of their loved one remained. Three co-researchers discussed attempts at engaging their care recipient in favorite pastimes or family activities in hopes of reconnecting with their pre-dementia parent. These attempts resulted in feelings of disappointment, renewed loss, and hopelessness when their parent/parent-in-law's symptoms of dementia persisted unabated.

Dupuis (2002) noted that in *acknowledging loss*, the caregiver had acknowledged the psychological loss of the care recipient. This loss was evidenced by the caregivers using pronouns of “she or he” rather than a mother or father, speaking of the alive care recipient as if they were deceased, and questioning if visiting the care recipient in the nursing home was meaningful. Similar to the Dupuis’ (2002) findings, the use of pronouns was evident in co-researchers’ descriptions of their parent/parent-in-law. For example, Diane stated, "She was already gone. I lost her twice. Once to Alzheimer's and then she died."

Additionally, the co-researchers voiced the psychological death of the care recipient before their physical death. Unlike Dupuis’s (2002) findings, the co-researchers in the current study who did nursing home placement did not question the meaningfulness of their nursing home visits. Perhaps their visits were significant due to other roles adopted within the nursing home context, such as advocate/protector or liaison.

Co-researchers who experienced ambiguous loss questioned how they could grieve for someone alive. The duality of the parent/parent-in-law being physically present and psychologically absent was confusing, and they opted not to share their feelings of loss with friends and family for fear they would be misunderstood or reminded that they were "lucky they still had" their parent. Co-researchers discussed denial (e.g., minimizing increasing dementia symptoms, believing the parent/parent-in-law was misdiagnosed) as their primary coping strategy in coping with ambiguous loss. The primary caregivers' use of denial is consistent with the findings of other research

(Blandin & Pepin, 2016; Boss, 1999; Noyes et al., 2010; Sanders & Corley, 2003).

The reversal of the parent-child roles. Boss, Caron, Horbal, and Mortimer (1990) defined boundary ambiguity as "a state in which the family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system" (p. 2). Each of the co-researchers in the current study described how they struggled to understand the new demands associated with their new role as a primary caregiver. Four co-researchers, all-female, conceptualized the later stages of caregiving in the context of taking care of a child. Furthermore, they believed familial roles had reversed and that they, the primary caregiver, had moved into the parental role. Dunham and Cannon (2008) found that role reversal was an expectation of the caregiver and a way to understand care.

Whereas some scholars acknowledge the parent-child role reversal, others view the concept as inaccurate. Brody (2006) viewed the theory of a parent-child reversal as simplistic because the caregiver experiences very different meanings when a child is dependent as opposed to an aging parent. Brody contended that caregivers have different reactions when providing care as part of healthy development. For example, a mother's feelings about bathing her child are different from an adult child's feelings who bathes a parent. Silverstone (1994) described the change in the parent-child relationship not as a reversal but as the adult child changing from being dependent on the parent to be dependable for their parent.

The four female co-researchers described the parent-child reversal in the context of their mourning/grieving role. Co-researchers identified grieving the following losses:

the relationship they shared with their parent/parent-in-law, mutual past experiences, and unresolved issues between the adult child and the parent. Ziemba and Lynch-Sauer (2005) revealed the theme of parent-child reversal in a study that examined factors that influenced the preparedness of daughters for caregiving to a parent with various chronic illnesses, including dementia. Similar to the findings in this study, participants identified the parent-child reversal and subsequent feelings of loss.

The physical death of the care recipient. Three co-researchers, Joseph, Allyssa, and Diane, reported continued intense feelings of mourning/grieving for the death of their parent. The co-researchers described an inability "to move on" or being "lost" since the death of their parent. At the time of the second interview, Joseph and Allyssa were three years into post-caregiving, whereas Diane was five years post-caregiving. Joseph and Allyssa appeared to describe living in limbo, whereby they could not return to their pre-caregiving lives or envision a new life. Aneshensel, Pearlin, Mulin, Zarit, and Whitlach (1995) theorized that after disengagement from the caregiving role, the caregiver could re-engage in self, such as renew or develop social relationships, re-establish occupational goals, or pursue special interests. Joseph and Allyssa had disengagement from their caregiver role but had not re-engaged in self. Diane had taken steps toward re-engagement of self (e.g., increased socialization); however, the feelings of loss and sadness could be overwhelming.

Co-researchers described mourning/grieving characteristics that may be compatible with symptoms of complicated grief. Schulz, Boerner, Shear, Zhang, and Gitlin (2006) identified the following critical components of complicated grief: (1) sense of disbelief regarding the death; (2) anger and bitterness over the death; (3) recurrent pangs or painful emotions, with intense yearning and longing for the deceased; (4) preoccupation with thoughts of the loved one, often including distressing and intrusive thoughts related to the death; and (5) avoiding situations and activities that are reminders of the loss (p. 651). Additionally, Boerner and Schulz (2009) observed that these symptoms make it challenging to develop relationships and engage in fulfilling activities.

In addition to the previously discussed symptoms of complicated grief, the co-researchers reported experiencing anhedonia, the inability to experience pleasure, which impacted their relationships and quality of life. Research findings indicate that complicated grief occurs in approximately 20% of dementia caregivers; however, the co-researchers in the current study did not identify being a primary caregiver to a parent with dementia as a factor in their continued, intense grief (Holland, Currier, & Gallagher-Thompson, 2009). Instead, the co-researchers reported that it was their prior relationship with their pre-dementia mother that resulted in their prolonged grief. The three co-researchers described their mother as an influential, dominant figure in their life (e.g., “a force of nature”). Diane and Allyssa identified their biological grandmother as their mother figure who stepped in and assumed a parenting role. Joseph, who reported a conflictive relationship with his mother, described his mother in controlling, domineering ways, whereas Diane and Allyssa explained their mother-daughter relationship in favorable terms.

Previous researchers identified predictors for complicated grief including being a spousal caregiver, caregiver burden, younger at the age of bereavement, cognitive impairment of the care recipient, pre-death depression, and African American ethnicity (Boerner, Schulz, & Horowitz, 2004; Chan, Livingston, Jones, & Sampson, 2012; Holland et al, 2009; Schulz et al., 2006). Allyssa, who expressed feelings and behaviors consistent with complicated grief, identified as African American, a possible predictor of complicated grief (Holland et al., 2009). Allyssa and Diane, who were primary caregivers to a biological grandmother, were considered younger at the age of bereavement, another possible predictor of complicated grief.

Previous research findings have not found an association between a primary caregiver's prior relationship, before the parent's onset of dementia, and complicated grief. Additional research is needed to explore the effect, if any, that the pre-dementia relationship between the primary caregiver and the care recipient may have on complicated grief and the grief process. Future research may also address the bereavement of adult children who were primary caregivers to a non-custodial or custodial grandparent who had dementia.

An Additional Finding of Empathy

The findings of the current study would be incomplete without addressing the empathy that each of the co-researchers described as they completed the various inherent roles within their primary caregiving role. Although there are many definitions of empathy, Krznaric's (2015) definition closely aligns with what the co-researchers experienced with their care recipients, "Empathy is the art of stepping imaginatively into the shoes of another person, understanding their feelings and perspectives, and using that understanding to guide your actions" (p. X).

Co-researchers frequently identified empathy as being a part of each of the identified roles in the current study. During the advocacy, decision-making, and liaison roles, the co-researchers appeared to wonder what the care recipient would have wanted and questioned how the care recipient, who could no longer voice their wants or needs, would feel about the co-researchers' actions. Edna identified how empathy played a part in her role as a decision-maker:

> Like I said, my father was a man of a few words, and I don't know how much he understood. He couldn't tell me what he wanted. I'd like…think about what it must be like to be him. So I'm thinking, even if there was a small piece of him that knew who he was, I wanted to respect that. Make decisions that he would make.

The co-researchers expressed trying to "be in her place" or "just trying to understand where he was" when explaining how they adapted care based on the care recipient's level of functioning. Joseph shared how his expectation for toileting his mother changed due to his feelings of empathy:

> When I first got her, I think it was the fourth day. You know, I don't understand this disease that much. She's like, "I got to go to the bathroom." "Look, Mama, it's a one-bedroom apartment. There's the door right there." Okay, and she's scared. I don't realize that she's afraid to go in there [bathroom]. She was looking at her pants. [Mother] "How do you take these off?" Would I be afraid to be alone if I didn't know how to take my pants off when I had to take a crap? I'd be terrified, and that's what she is. And I thought, How would you like to live like that? God,

> it's got to be horrible, you know. And I made sure, okay, I'll show ya, Mama, I'll show you again. I'll show you again and again and again.

Additionally, those co-researchers who expressed grieving for a parent/parent-in-law who was physically present also voiced empathy for their care recipients. Diane voiced empathy for her grandmother, who was physically present but was not emotionally or mentally present:

> You know, I would curl her hair, and I'd say, "Gram, look." And she'd say, "That's not me." She didn't even recognize herself in the mirror. Horrible. I would watch her and wonder what it must be like…to be gone. Like where was she?

Several research articles have explored the effects of empathy, cognitive and affective, on the well-being of dementia caregivers. Smith (2006) defined cognitive empathy as understanding another person's experiences, perspectives, and concerns, whereas affective empathy is sharing another's emotions. The co-researchers in this study appeared to voice cognitive empathy statements predominantly. Cognitive empathy is associated with less anxiety and stress, less depression, and higher life satisfaction in caregivers than affective empathy (Jütten, Marks, & Sitskoorn, 2019; Lee, Brennan, & Daly, 2004). Research findings suggested more negative outcomes for affective empathy, such as anxiety and depression (Jütten et al., 2019). Although the studies cited how cognitive and affective empathy may impact caregivers' well-being, questions remain as to how empathy may enhance or hinder the different roles adopted throughout the primary caregiving experience.

Implications

In the context of dementia caregiving, the primary caregiver is frequently conceptualized as a single role that functions to complete numerous tasks to assist the care recipient. The findings of this study suggest that the primary caregiver adopts five evolving roles (e.g., advocate/protector, liaison, decision-maker) in response to the changing needs and experiences of the caregiver and the care recipient. These roles are adjusted to fit various contexts of the caregiving experience. Furthermore, the roles appear to add structure, direction, and cohesiveness to the primary caregiver role.

Implications for Clinical Mental Health Counselors and Other Mental Health Providers

The primary source of support for individuals with dementia is family caregivers. Studies have shown that dementia caregivers are at a higher risk for chronic depression, anxiety, insomnia/sleep problems, and substance abuse and dependence than other care providers (Brodaty & Donkin, 2009; Ferrara et al., 2008; Fonareva & Oken, 2014). Schoenmakers, Buntinx, and Delepeleire (2010) found that one out of three dementia caregivers experiences depression and that depression is more prevalent in dementia caregivers than caregivers of other chronic illnesses. Despite the risk of increased mental health issues associated with caregiver burden, caregivers frequently do not utilize community supports. Robinson, Buckwalter, and Reed (2013) found that 73% of caregivers (*n*=241) did not attend support groups, and 78% did not use respite services. Generally, caregivers underutilize community services, such as clinical mental health counseling, although psychosocial interventions, psychoeducation, and cognitive behavior therapy are proven to reduce caregiver depression and stress (Cheng, Au, Lasoda, Thompson, & Gallagher-Thompson, 2019). Future researchers need to investigate the reasons why caregivers do not specifically seek mental health counseling.

Findings of the current study described roles, behaviors, and emotions associated with the primary caregiver role. For example, during one of the most arduous and time-consuming roles, the direct care provider for ADLs role, several co-researchers described the support they felt when loved ones completed tasks that were associated with the co-researchers' other life roles (e.g., parent, spouse/partner) so they could complete ADLs with the care recipient. Mental health interventions may assist the primary caregiver in identifying available supports and possibly renegotiating role expectations of the primary caregiver and their loved ones.

Co-researchers described the role of being a primary caregiver to a parent with dementia as emotionally, physically, and mentally draining; however, only three of the eight co-researchers reported engaging in self-care activities. Self-care activities discussed were exercising, prayer, a respite from caregiving, and attending church services. The co-researchers who reported no self-care activities identified denial, overeating, and substance use (marijuana and alcohol) as ways they coped with caregiving stressors. Counselors and other mental health professionals must understand the multiple roles adopted by a primary caregiver and the possible stressors associated with each to assist the primary caregiver in identifying and developing healthy, self-affirming coping skills and self-care activities to reduce caregiver burden.

The findings of the current study suggest the primary caregivers faced different challenges throughout the multiple roles and trajectory of their caregiving careers. The challenges for the co-researchers subsided with the death of the care recipient but did not end. In post-caregiving, the co-researchers described unresolved feelings of anger (e.g., toward the disease, poor nursing home care, other family members, God), grief, guilt, frustration, and sadness. Additionally, the co-researchers appeared to try to assimilate their caregiving experiences and make sense of their caregiving journey. Mental health professionals may help primary caregivers in processing the narrative of their caregiving career and author their next chapter of post-caregiving.

Co-researchers struggled with grief and loss throughout their caregiving careers. Several co-researchers reported that feelings of loss were exacerbated by the unknown. Physicians could not provide estimates of the care recipient's life expectancy, resulting in some co-researchers questioning if new symptoms were predictors of impending death (e.g., aphasia, incontinence). The grief associated with the impending death of the care recipient, anticipatory grief, occurred throughout the middle and late phases of caregiving and was compounded by ambiguous loss. Mental health professionals need to offer grief therapy for loss issues specifically related to dementia caregiving and to assess for post-caregiving complicated grief.

Five co-researchers reported their desire to participate in the current study was to help other dementia caregivers and, perhaps, resolve some of their unresolved caregiver issues. As emotionally painful as it was to tell their stories, these co-researchers wanted to share their experiences. Counselors and other mental health providers must understand that primary caregivers may not reflect on their caregiving career until its conclusion, and unresolved issues may exist from the inception of the primary caregiver role through post-caregiving.

Implications for Counselor Educators

The Council for Accreditation of Counseling and Related Educational Programs (CACREP), an accreditation body for graduate counselor education programs, does not currently have standards requiring counseling students to know areas of aging and gerontology. CACREP acknowledged the importance of geriatric care with the accreditation of the Gerontological Counseling specialization and eventually a 2001 standard; however, the gerontology standard was removed in 2009 (www.cacrep.org/counseling-specialties/, 2020). Although a counseling curriculum addresses human development across the lifespan, the primary focus is on developmental models. Caregiving, an aging parent, may be introduced as part of the discourse within the generativity versus stagnation stage of Erik Erikson's Eight Stages of Psychosocial Development. The generativity versus stagnation stage occurs during middle adulthood (approximate ages 45-60), and success in this stage results in the virtue of care (Bornstein, 2018; Erikson, & Erikson, 1998). Several of the co-researchers in the current study adopted the primary caregiver role during this stage and were part of the "sandwich generation." The metaphor of the sandwich describes how the caregiver is sandwiched between the competing demands of caring for children, an aging parent, and maintaining their role in the workforce (Spillman & Pezzin, 2000). The described experiences of the co-researchers in this study may promote a better understanding of the mental health needs of this population.

The experiences of the co-researchers in this study revealed the numerous challenges associated with the various roles adopted throughout a primary caregiving career. Competent counselors who are educated on topics of aging and issues specific to caregiving (e.g., ambiguous loss, anticipatory grieving, role overload) are needed to help primary caregivers navigate their way through times that the co-researchers identified as mentally, physically, and emotionally draining. Additionally, primary caregivers may benefit from counseling when transitioning to the primary caregiver role as well as role disengagement.

The primary caregiver role did not occur in a vacuum, and the effects of caregiving and the dementia process reverberated through the family. For some co-researchers, their primary caregiver role exacerbated pre-existing family tensions and fueled old grudges, whereas others found much-needed support and respite in family members. Co-researchers also described how family roles and role expectations were modified to accommodate the time-consuming demands of caregiving. The integration of these research findings in couples counseling and family therapy classes may assist future counselors in understanding the effects of primary caregiving on relationship dynamics and family systems.

Limitations of the Study

Qualitative data analysis requires the researcher to subjectively interpret the data, which may result in researcher bias. This researcher independently reviewed the data from the 16 interviews, selected and attributed meanings to the significant statements of the co-researchers, and developed themes and sub-themes. Although steps were taken to minimize researcher bias (e.g., bracketing in a reflexive journal, memos, member checking, and using a peer reviewer), other reviewers of the same data may not have determined the same findings.

The co-researchers were recalling and describing personal and intimate moments with their parent/parent-in-law during one of the most challenging times in their lives. Co-researchers may have minimized the hardships they experienced during their caregiving journey to be respectful of their deceased parent's memory. Additionally, it is impossible to assess the influence of the researcher on the co-researcher's responses during the face-to-face interviews. Although the researcher was careful not to ask leading questions, the researcher's presence and nonverbal communication may or may not have influenced the co-researchers' choices of which experiences were recounted.

The lack of diversity is another limitation of the current study. Although efforts were made to recruit and select co-researchers who represented diversity (e.g., race or ethnicity, relationship to care recipient, and types of dementia), more variation was needed. The eight co-researchers consisted of six White and two African-American individuals. The lack of variation also extended to the types of dementia. Five of the eight co-researchers were primary caregivers to care recipients diagnosed with Alzheimer's dementia. The other subtypes of dementia not represented in this study (e.g., vascular, frontotemporal, and Lewy body dementia) have different courses and clinical features; subsequently, other primary caregiving experiences based on symptomology may result in additional or different findings. It is noteworthy that the diagnosis of dementia occurred later in life for all of the care recipients. Primary caregivers who care for those individuals with early-onset Alzheimer's dementia or any subtype of dementia diagnosed before the age of 65 may have different experiences resulting in different findings.

Delimitations of the Study

During their first interview, seven of the eight co-researchers identified as being employed in the healthcare or social service sector (before or during their primary caregiving experience), whereas one co-researcher had been a skilled tradesman. The co-researchers' occupations and socioeconomic statuses were not part of the screening process resulting in a more homogenous sample. Co-researchers who represent different occupational sectors and socioeconomic statuses may have different experiences that shape their perspectives and experiences of being a primary caregiver to a parent with dementia. For example, a co-researcher with employment experience working as a nurse's aide in a nursing home may experience caregiving differently than a pottery worker who has never provided direct care.

Due to the sensitive nature of the caregiving journey, in person, face-to-face interviews were chosen for the method of data collection to build rapport with the co-researchers and to provide a personal and supportive environment to share their experiences. The choice to solely conduct in-person interviews limited the recruitment of possible co-researchers to five counties in Northeastern, Ohio. Findings may not reflect the experiences of adult children who were primary caregivers to a parent with dementia in other geographical regions.

Recommendations for Future Research

Researchers have been investigating dementia caregiving for approximately 40 years; however, more studies are needed that investigate the experiences of primary caregivers from the inception to the conclusion of their experiences. Additionally, more research is needed regarding disengaging from the caregiver role. Specifically, researchers need to identify factors that contribute to the healthy and productive re-engagement as well as factors that hinder progress past the primary caregiving experience, resulting in feelings of "being stuck" as three of the co-researchers described.

The small number of co-researchers (*N*=8) chosen was appropriate to answer the research question, but statistical inferences cannot be made about the total population. Future researchers may investigate these findings to determine if the results extrapolate to a broader population through a quantitative research design. Findings of the study identified five roles that comprised the primary caregiving role; however, the impact of these roles on caregiver burden is unknown. Research is needed to explore the possible correlation between each role and caregiver burden. If the caregiver roles are found to contribute to caregiver burden, it is essential to understand how much each role plays a part in caregiving stressors.

This study had two co-researchers who identified as part of the same ethnic minority culture. The replication of this study must include more ethnic diversity to capture different perspectives of the experiences of being a primary caregiver to a parent with dementia. A more diverse sampling may increase the richness of the data and discover if these findings extend across ethnicities or if additional roles emerge. Future research must also examine if the current research findings are congruent with experiences of partners and spousal caregivers or for caregivers to other types of dementia not represented in the sampling.

Additional research is needed that investigates stigma and dementia caregiving. Although studies have found a correlation between stigma and caregiver burden, researchers need to understand how caregivers resolve discredited stigma and feelings of embarrassment, humiliation, and shame. Findings of the current study suggest that co-researchers would, in part, share characteristics of their pre-dementia parent/parent-in-law to reduce discredited stigma. Future research may address this aspect of the liaison role to determine if it decreases the primary caregiver's feelings of embarrassment or if it serves other purposes.

Chapter IV Summary

The purpose of this descriptive phenomenological research study was to explore and understand the experiences of adult children who were primary caregivers to a parent with dementia. The research question addressed a paucity of investigations solely addressing the experiences of adult children who serve in the primary caregiving role from the inception to the conclusion of their caregiving careers. Each of the eight research participants had disengaged from their primary caregiver role and had opportunities to reflect upon the most remarkable experiences of their caregiving careers. Findings of the current study add to the scholarly literature on adult children who were primary caregivers to a parent with dementia and provide insights into the unique experiences of the adult children who adopted five roles as primary caregivers.

These roles comprised the primary caregiving experience from inception to disengagement: (a) advocate/protector, (b) liaison, (c) decision-maker, (d) direct care provider for ADLs, and (e) mourner/griever.

APPENDICES

APPENDIX A

IRB APPROVAL LETTER

APPENDIX A

IRB APPROVAL LETTER

18-039 entitled "The Caregiving Experiences of Adult Children Who Were Primary Caregivers to a Parent with Dementia: A Phenomenological Study"

Hello,
I am pleased to inform you that the Kent State University Institutional Review Board reviewed and approved your Application for Approval to Use Human Research Participants as a Level II/Expedited, category 6/7 project. **Approval is effective for a twelve-month period:**

February 27, 2018 through February 26, 2019

For compliance with:

DHHS regulations for the protection of human subjects (Title 45 part 46), subparts A, B, C, D & E

If applicable, a copy of the IRB approved consent form is attached to this email. This "stamped" copy is the consent form that you must use for your research participants. It is important for you to also keep an unstamped text copy (i.e., Microsoft Word version) of your consent form for subsequent submissions.

Federal regulations and Kent State University IRB policy require that research be reviewed at intervals appropriate to the degree of risk, but not less than once per year. The IRB has determined that this protocol requires an annual review and progress report. The IRB tries to send you an annual review reminder notice by email as a courtesy. **However, please note that it is the responsibility of the principal investigator to be aware of the study expiration date and submit the required materials.** Please submit review materials (annual review form and copy of the current consent form) one month prior to the expiration date. Visit our website for forms.

HHS regulations and Kent State University Institutional Review Board guidelines require that any changes in research methodology, protocol design, or principal investigator have the prior approval of the IRB before implementation and continuation of the protocol. The IRB must also be informed of any adverse events associated with the study. The IRB further requests a final report at the conclusion of the study.

Kent State University has a Federal Wide Assurance on file with the Office for Human Research Protections (OHRP); FWA Number 00001853.

Doug Delahanty | IRB Chair |330.672.2395 | ddelahan@kent.edu
Tricia Sloan | Coordinator |330.672.2181 | psloan1@kent.edu
Kevin McCreary | Assistant Director | 330.672.8058 | kmccrea1@kent.edu
Paulette Washko | Director |330.672.2704| pwashko@kent.edu

APPENDIX B

RECRUITMENT FLYER

APPENDIX B

RECRUITMENT FLYER

Adult Children Who Were Primary Caregivers to a Parent with Dementia Research Study

- **Are you 21 years or older?**
- **Were you a caregiver to a parent or parent-in-law who was diagnosed with dementia (Alzheimer's, Vascular, Lewy Body, or another dementia) by a medical provider?**
- **Were you the primary caregiver (provided the majority of care) for a minimum of 1 year?**

If you answered yes to these questions, you may be eligible to participate in a research project that is designed to explore the experiences of adult children who were primary caregivers to a parent with dementia.

You will be asked to complete 2 face-to-face interviews with the researcher and check the researcher's findings based on your interviews to ensure that your caregiving experiences were captured. Each interview will be approximately 60 minutes. The second interview will take place in approximately two weeks after your first interview. You can receive up to $30 for your participation ($15 gift card at the completion of each interview).

If you would like to be considered for the study, you may do one of the following:

1) Call Penny Minor [redacted]
2) Email Penny Minor at [redacted]
3) Visit the study's web page https://www.surveymonkey.com/r/KRXFHDQ
4) Scan the code at the top of the page with any smartphone to be taken directly to the study's website.

This study has been approved by the Kent State University Institutional Review Board (Approval # 18-039)

APPENDIX C

INTERNET WEBSITE RECRUITMENT POSTING

APPENDIX C

INTERNET WEBSITE RECRUITMENT POSTING

Adult Children Who Were Primary Caregivers to a Parent with Dementia Research Study

- **Are you 21 years or older?**
- **Were you a caregiver to a parent who was diagnosed with dementia (Alzheimer's, Vascular, Lewy Body, or another dementia) by a medical provider?**
- **Were you the primary caregiver (provided the majority of care) for a minimum of 1 year and no longer serve in this role?**
-

If you answered yes to these questions, you may be eligible to participate in a research project that is designed to explore the experiences of adult children who were primary caregivers to a parent with dementia. This is a research project being conducted by Penny Minor, a doctoral candidate in the Counselor Education and Supervision program at Kent State University.

You will be asked to complete 2 face-to-face interviews with the researcher and check the researcher's findings based on your interviews to ensure that your caregiving experiences were captured. Each interview will be approximately 60 minutes long. The second interview will take place in approximately two weeks after your first interview. You can receive up to $30 for your participation ($15 gift card at the completion of each interview).

If you would like additional information, you can contact Penny Minor at [redacted]

This study has been approved by the Kent State University Institutional Review Board (Approval #18-039)

APPENDIX D

INTRODUCTION TO THE STUDY LETTER

APPENDIX D

INTRODUCTION TO THE STUDY LETTER

KENT STATE
UNIVERSITY

Research Study: The Caregiving Experiences of Adult Children Who Were Primary Caregivers to a Parent with Dementia: A Phenomenological Study

I am writing to let you know about an opportunity to participate in a research study about the experiences of adult children who provided care to a parent with dementia. This study is being conducted by Penny Minor, a doctoral candidate in the Counselor Education and Supervision program at Kent State University.

For this study you will be asked to:

- Complete 2 audio-recorded interviews with the researcher, Penny Minor, with each interview lasting approximately 60 minutes each.
- Answer questions about your caregiving experiences for a parent with dementia.
- Review the researcher's findings and interpretations of your interviews to ensure that the researcher has captured your caregiving experiences.

To be considered for this study, you must have been at least 18 years of age at the time you were providing care to your parent who had a diagnosis of dementia (Alzheimer's, Vascular, Lewy Body or other type of dementia), a diagnosis issued by a medical doctor or other healthcare professional. You must no longer be in the caregiver role for this parent. You must be a son, daughter, daughter-in-law, son-in-law, partner to the son or partner to the daughter, and were the primary caregiver to the care recipient; however, you are not currently providing the majority of care for the parent. You must have been the primary caregiver for at least one year and provided assistance with things such as shopping, bill paying, meals, dressing, or bathing. If you're still assisting your parents, but they're currently residing in a care facility, or someone else is providing the majority of care, you may still qualify for the study.

If you're interested in being a research participant, you can contact me at [redacted] or visit www.surveymonkey.com/r/KRXFHDQ and complete the screening questions for the study.

Thank you for your consideration, and once again, please do not hesitate to contact me if you are interested in learning more about the research study.

Penny Minor, Kent State University Doctoral Candidate
This study has been approved by the Kent State University Institutional Review Board (Approval #18-039)

APPENDIX E

ONLINE SCREENING ASSESSMENT

APPENDIX E

ONLINE SCREENING ASSESSMENT

1. I was the primary caregiver to ____mother ____mother-in-law ____father ____father-in-law

2. What type of dementia was your parent diagnosed with by a healthcare professional?

   ___Alzheimer's ____Lewy Body _____Vascular ____Huntington's

   ___Frontotemporal Lobar Degeneration ___Prion Disease ___Traumatic Brain

   ___Substance/Medication-Induced ____HIV-Associated ____unknown

   ___Due to Medical Condition _____Multiple Etiologies (more than one type of dementia such as Alzheimer's and Vascular)

3. For how long were you a primary caregiver to a parent with dementia?
   _____years ______months

4. During the time that you were a primary caregiver, did you provide most of the care to your parent?
   _____yes _____no

5. What is your relationship to the parent with dementia?

   _____daughter _____daughter-in-law _____son-in-law
   _____son _____partner to the daughter _____partner to the son

6. Which of the following caregiving activities did you do for your parent?

   _____bathing
   _____dressing
   _____grooming
   _____toileting/maintaining continence
   _____feeding
   _____managing household tasks (such as cleaning, taking out the trash, etc.)
   _____managing finances
   _____shopping
   _____preparing meals
   _____managing medication
   _____transportation
   other (please list):

7. Your age at the time that you became a primary caregiver to a parent with dementia _____

8. Which of the following describes your relationship status while you were a primary caregiver?
   _____single, never married
   _____single, but cohabitating with significant other
   _____married
   _____divorced
   _____widowed
   _____in a domestic partnership or civil union
   _____separated

9. What is your race or ethnicity?
   _____Black or African American
   _____White
   _____American Native or Alaskan Native
   _____Asian American
   _____Native Hawaiian or other Pacific Islander
   _____from multiple races
   _____other race or ethnicity (please specify): _____________________________

10. Which of the following best describes your employment status when you were the primary caregiver to your parent with dementia?

    _____employed, working full-time
    _____employed, working part-time
    _____retired
    ____ disabled, not able to work
    _____not employed, looking for work
    _____not employed, not looking for work

If you would like to be considered to participate in the study, please complete the following contact information. Thank you for your time.
Name ____
Address ____
Phone Number ______________(Home) _________________________(Cell)
Email ____
Preferred to be contacted by: Phone ___home ___cell ___email _____
Best day to contact you: ___M ___T ___W ___TH ___F ___S ___Su
___Any day
Best time to contact you by phone: ______________ ___no preference

APPENDIX F

WEB SCREENING INFORMED CONSENT

APPENDIX F

WEB SCREENING CONSENT FORM

Study Title: The Caregiving Experiences of Adult Children Who Were Primary Caregivers to a Parent with Dementia: A Phenomenological Study

Principal Investigator: Cynthia Osborn

To determine your eligibility for the research study, I need to collect information about you. By clicking on the NEXT arrow at the bottom of the page, you are permitting me to collect this information. Clicking on the NEXT arrow and answering the questions does not commit you to participate in a study. Neither does it guarantee that you will participate. Before you participate in a study, I will give you a consent form with information about that study

SCREENING ACTIVITIES

I will ask you questions about your time as a caregiver to your parent with dementia (e.g., relationship to the parent, tasks that you completed as a caregiver, etc.) and questions about you (e.g., age, education, and race/ethnicity, etc.). You can choose not to respond to any question and may stop the screening by closing the web page.

RISKS

There are no anticipated risks beyond those encountered in everyday life.

BENEFITS

This research will not benefit you directly. However, your participation in this research will help to better understand the experiences of adult children who are primary caregivers to a parent with dementia. Also, the findings from this research may be helpful for healthcare professionals who provide services to caregivers and care recipients.

PAYMENT AND COSTS

You will receive no payment for the screening.

CONTACTS

If you have any questions about this screening you may contact:
Penny Minor [redacted] [redacted]

VOLUNTARY PARTICIPATION/WITHDRAWAL

Your participation in this screening is voluntary. At any time, you may change your mind and choose not to participate, without penalty or loss of benefit unrelated to the screening. You may withdraw from the screening at any time.

CONSENT

I have read this entire consent form. I have had a chance to ask questions, and my questions have all been answered to my satisfaction.

By clicking the NEXT arrow, I agree to participate in the screening. I give permission to use the resulting information to determine my eligibility for the research study.

Next

APPENDIX G

LETTER OF APPRECIATION FOR INTEREST IN THE STUDY FOR NON-SELECTED CO-RESEARCHERS

APPENDIX G

LETTER OF APPRECIATION FOR INTEREST IN STUDY FOR NON-SELECTED POTENTIAL CO-RESEARCHERS

Dear ____________________________

You recently expressed interest in participating in my research study regarding the experiences of adult children who were caregivers to a parent with dementia. I appreciate your willingness to share your experiences and assist me with the research; however, at this time, a sufficient number of participants have been selected to meet the needs of the study. Please be assured ha any information that you provided during the screening process of this study has been deleted or destroyed and will not be used for research purposes. If you have any questions, please feel free to contact me at [redacted] or [redacted].

Thanks again for your time and interest.

Sincerely,

Penny Minor, Kent State University Doctoral Candidate

APPENDIX H

PARTICIPATION STATUS LETTER

APPENDIX H

PARTICIPATION STATUS LETTER

KENT STATE
UNIVERSITY

Research Study: The Caregiving Experiences of Adult Children Who Were Primary Caregivers to a Parent with Dementia: A Phenomenological Study

Dear

Thank you for your interest in my study. I currently have a sufficient number of participants; however, should I need future participants, you may be contacted at a later date. I am saving your responses to the screening assessment and your contact information in a secure, password-protected computer file. Your information will not be used in any way in the study unless I contact you at a later date to request your participation. It is only being retained to contact you to be a future participant, if needed. At the end of the study, your screening assessment and contact information will be deleted.

Once again, thank you for your interest in the study. If you have any questions, please feel free to contact me at [redacted] or [redacted].

Sincerely,

Penny Minor

APPENDIX I

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

APPENDIX I

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: The Caregiving Experiences of Adult Children Who Were Primary Caregivers to a Parent with Dementia: A Phenomenological Study

Principal Investigator: Cynthia Osborn Co-Investigator: Penny Minor Key Personnel: Jane Cox

You are invited to participate in a research study. This consent form will provide you with information on the research project, what you will need to do, and the associated risks and benefits of the research. Your participation is voluntary. Please read this form carefully. It is important that you ask questions and fully understand the research in order to make an informed decision. You will receive a copy of this document from taking with you.

Purpose

The purpose of this study is to learn about the caregiving experiences of adult children who provided care to a parent diagnosed with dementia. Currently, the majority of research focuses on the present experiences of caregiving for a parent with dementia. This study endeavors to explore caregiving from the perspective of an adult child who has completed their journey as a primary caregiver (i.e., they no longer are in the role of primary caregiver to a parent diagnosed with dementia).

Procedures

You will complete two face-to-face interviews with Co-Investigator Penny Minor. These interviews will be audio-recorded, and you will review and, with your consent, sign a separate audio recording consent form. Each interview will be approximately 60 minutes in length. As the researcher, Co-Investigator Minor will review with you her findings or interpretation of your individual transcripts. You will be asked to provide feedback after both interviews on her preliminary findings regarding whether the interpretations accurately captured your caregiving experiences. After your first interview, we will email you the preliminary findings. Please be advised that email is not considered a secure form of communication, so there is a possibility that a third party may view your data.” The second interview will take place approximately two weeks after your first interview.

Audio and Video Recording and Photography

Each of the two interviews will be audio-recorded, and the recordings and subsequent transcript of the interviews will be stored in the researcher's password-protected computer. You will review and sign, with your consent, a separate audio recording consent form. The recordings will be used for research purposes only.

Benefits

This research will not benefit you directly. However, your participation in this research will help Co-Investigator Minor and other researchers to better understand the experiences of adult children who are primary caregivers to a parent with dementia. Also, the findings from this research may be helpful for healthcare professionals who provide services to caregivers and care recipients.

Risks and Discomforts

There are no anticipated risks beyond those encountered in everyday life. You will be provided with the interview questions before each scheduled interview. Should you feel uncomfortable answering a question, you may skip that question. You may stop participating in the study at any time without penalty. If you have experienced distress as a result of your participation in this study, you may contact Community Action Agency Behavioral Health, 7880 Lincole Place, Lisbon, OH, (330) 424-7721 or Coleman Professional Services, 3200 Johnson Road, Steubenville, OH, (740-996-7100). (Please remember that any cost in seeking medical assistance is at your own expense.)

Privacy and Confidentiality

A pseudonym, a fictitious name, will be used to identify your interview responses to maintain confidentiality. The transcripts of your interviews will be read by a peer reviewer and will be made available to Co-Investigator Minor's faculty advisors (Cynthia Osborn and Jane Cox). Quotes from the interviews will be used in the findings; however, your identity will not be revealed. Also, you will not be identified in any publication or presentation. Your signed informed consent, signed consent to audio record, screening form, contact form, and audio recordings will be kept in a locked file drawer and separated from your transcribed interviews, which will be stored in a password-protected computer. Also, the data analysis that Penny Minor will conduct will be stored on a password-protected computer. Research records will be retained for 3 years after the close of the study.

Compensation

You will be compensated at the end of each interview with a $15 gift card. The total amount of compensation for your two interviews is $30 (two $15 gift cards).

Voluntary Participation

Taking part in this research study is entirely up to you. You may choose not to participate, or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. You only will be compensated (the gift card mentioned), however, if you complete each of the two in-person interviews.

Contact Information

If you have any questions or concerns about this research, you may contact Penny Minor at [redacted] or Dr. Cynthia Osborn (330) 672-0695 or Dr. Jane Cox at (330-672-0698). This project has been approved by the Kent State University Institutional Review Board (Approval #). If you have any questions about your rights as a research participant or complaints about the research, you may call the IRB at 330-672-2704.

Consent Statement and Signature

I have read this consent form and have had the opportunity to have my questions answered to my satisfaction. I voluntarily agree to participate in this study. I understand that a copy of this consent will be provided to me for future reference.

Participant Signature	**Date**

"APPROVED"
February 27, 2018,
To
February 26, 2019

APPENDIX J

INTERVIEW GUIDE

APPENDIX J

INTERVIEW GUIDE

The following are the questions that you will be asked during the first and second interviews. Additional questions will be asked based on your answers to the question. You have the right to not answer any question(s) during our interview.

First Interview

1. Please tell me a little bit about yourself. Please describe how you became a primary caregiver to a parent with dementia.
2. What was your relationship like with your parent before you became their caregiver? Please describe your relationship with your parent during your caregiving experience.
3. Please describe a typical day of caregiving in the beginning of your caregiving career? In the middle of your caregiving career? In the last 3 months of your caregiving?
4. What are the feelings that you associate with being a caregiver?
5. Do you have any additional experiences or information that you would like to share about being a primary caregiver to a parent with dementia?

Second Interview

Member Checking Questions:

1. How do the themes or main points from my interpretation of your interview match your experiences as a caregiver?
2. How do the themes or main points from my interpretation of your interview differ from your experiences as a caregiver?

Subsequent Second Interview Questions:

1. How did being a caregiver affect your life?
2. How do you think your caregiving experiences would have been different if you were the secondary caregiver and your sibling or someone else provided the majority of care to your parent with dementia?
3. Can you tell me about the times when you felt supported in your caregiving role? What additional support(s) would you had wanted or needed during your caregiving experience?
4. How would you prepare others to be a caregiver to a parent with dementia?
5. What advice would you give to future caregivers to a parent with dementia?
6. What question or questions do you think that I should have asked but didn’t?

APPENDIX K

AUDIOTAPE CONSENT FORM

APPENDIX K

AUDIOTAPE CONSENT FORM

CELEBRATE CENTENNIAL
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AUDIOTAPE CONSENT FORM
THE CAREGIVING EXPERIENCES OF ADULT CHILDREN WHO WERE
PRIMARY CAREGIVERS TO A PARENT WITH DEMENTIA: A PHENOMENOLOGICAL STUDY
Researcher: Penny Minor

I agree to participate in two audio-taped interviews about adult children who were at one time, the primary caregivers to a parent with dementia. This is part of an approved research investigation. The purpose of audio recording these interviews is to make it possible for Penny Minor to analyze and interpret the possible meanings of the caregiver experiences. I understand she will be transcribing the audio recordings of both interviews and that I will be assigned a pseudonym. I have had my questions satisfactorily answered, and I agree that Penny Minor may audiotape/videotape these interviews.

Signature ____ Date ____________

I have been told that I have the right to listen to the recording of the interview before it is used. I have decided that I:

____want to listen to the recording ____do not want to listen to the recording

Sign now below if you do not want to listen to the recording. If you want to listen to the recording, you will be asked to sign after listening to them.

Signature ______________________________ Date ____________________

Penny Minor may / may not (circle one) use the audio-tapes/video tapes made of me. The original tapes or copies may be used for:

____this research project _____publication _____presentation at professional meetings

KENT • STATE • UNIVERSITY • INSTITUTIONAL • REVIEW • BOARD
"APPROVED"
February 27, 2018,
To
February 26, 2019

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REFERENCES

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