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African American Sibling Relationships when Caring for an Alzheimer's Parent

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Abstract

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By

Cynthia M Smith

MA, Webster University, 2014

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BA, Saint Louis University, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Alzheimer’s disease (AD) is the most commonly occurring form of dementia that affects African Americans at 2 to 3 times higher rate than other ethnic or racial groups in the United States. As the number of older African Americans with AD grows rapidly so will the need for daily supports; therefore, informal caregivers, such as an adult offspring, often assume the role of filial caregiver. Focusing on the unique patterns of caregiving among African Americans, this generic qualitative study may help explain the adult offspring’s perspective on sibling relationships as they function in the role of primary filial caregiver. Equity theory was the conceptual framework used to explore sibling relationships among African American adult filial caregivers. A purposeful sampling in conjunction with snowballing was used to recruit participants who provided filial caregiving to a home-bound parent with AD. For this generic qualitative study, 10 participants responded to 12 open-ended interview questions related to their sibling relationships and filial caregiving. After collecting and transcribing the data, thematic analysis approach was used, resulting in the following 5 emergent themes: (a) perception of equity, (b) continuing a close sibling relationship, (c) strategies of communication and collaborative decision-making, (d) varying siblings supports, and (e) attitudes towards caregiving and siblings. The results from this study may enhance culturally sensitive or responsive interventions/strategies and family-centered programs supporting African American adult filial caregivers and their siblings as they navigate the demands of elder care, thereby informing perceptions of fairness related to caregiving responsibilities.

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Dedication

I dedicate this work to my husband, Dwight, Sr., who has been my anchor since college. Thank you for your love, support, and being one of my biggest champions. I dedicate this work to my children, DJ and Nicholaus, who provided the wind, so I could keep sailing and soaring. I thank you for your love, patience, and ongoing words of encouragement. I also dedicate this work to my parents, Fred and Anne, who taught me to follow me dreams, always have faith, and believe in myself. I dedicate this work to my grandparents, Thomas Jackson, Willie Ann, R.B., and Daisy, who left an indelible mark on my life. Thank you for cultivating a familial atmosphere of love, strength, honor, faith, and charity. I have gained a wealth of knowledge and experiences throughout this journey that will guide me towards future goals. Thank you for your support and I love you all.

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me towards success. I would like to thank the ten participants who afforded me the opportunity to take a glimpse into their caregiving experiences. I would also like to thank the senior center that supported and helped me during this process. Finally, to the caregivers, who work tirelessly caring for their loved one, thank you for your effort, dedication, and commitment. Again, thank you for your support.

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Chapter 1: Introduction to the Study

Introduction

Cognitive disorders, such as Alzheimer’s disease (AD) and other related dementias, are significant health issues among the elderly population (Fredriksen-Goldsen, Jen, Bryan, & Goldsen, 2018). Researchers from the World Health Organization (WHO; n.d.) asserted that even though degenerative cognition is not deemed to be a natural dynamic in aging, as people age, the risk of developing AD and other forms of dementia are elevated. According to Karel, Gatz, and Smyer (2012), dementia and other related diseases are one of the challenges specific to the aging population. Approximately 60% to 80% of people experiencing cognitive loss ultimately receive a diagnosis of AD, while the rest are diagnosed with another form of dementia, such as frontal-temporal dementia, Lewy bodies, vascular dementia, and Parkinson’s disease (Leite, Camacho, Queiroz, & Feliciano, 2017; Macdonald, Martin-Misener, Helwig, Weeks, & MacLean, 2017). Wells et al. (2017) noted AD and related forms of dementia are disproportionately represented throughout the different racial groups. For instance, African Americans are 3 times more likely than Whites to experience AD (Barnes & Bennett, 2014).

Fingerman, VanderDrift, Dotterer, Birditt, and Zarit (2011) indicated that members of the African American community appear to deliver more support to an elderly parent than White Americans. Furthermore, African American caregivers provided the greatest number of supportive hours and were found to be engaged in more demanding caregiving tasks, such as bathing and lifting, than other racial or ethnic groups

(Wells et al., 2017). Additionally, African Americans appear to have more solid norms associated with family (Fingerman et al., 2011) and have stronger sibling relationships (Spitze & Trent, 2018) than White Americans. Samson, Parker, Dye, and Hepburn (2016) explained that given the strong sibling relationships among African Americans, this group typically react less negatively than White Americans as they function in their caregiving role. In other words, an African American assuming the role of an informal caregiver is driven by *familism,* which is characterized as a collection of powerful and significant cultural norms that encompasses a sense of duty, obligation, reciprocal support, and collaborative decision-making regarding care among family members (Fingerman et al., 2011; Potter, Roberto, Brossoie, & Blieszner, 2017; Sayegh & Knight, 2011).

Potter et al. (2017) proposed that distrust of non-kin providers or formal services and oppression and racism may explain why African Americans readily accept the role of an AD caregiver. In middle adulthood, African Americans are also receptive to caring for an elderly parent due to a feeling that the role may be rewarding (Fingerman et al., 2011). Although Amaro and Miller (2016) contended that sibling relationships are a long-lasting type of intimate relationship, providing care to an elderly parent can challenge that bond. In this chapter, I introduce some of the challenges and rewards that African American adult filial caregivers may experience within their sibling relationships during this period of caring for the parent. In Chapter 1, I discuss the significance of the study, the research question, methodology, conceptual framework, and definitions.

Background

A person may gradually advance from mild neurocognitive impairment to a major neurocognitive disorder within 20 years (Schaber, Blair, Jost, Schaffer, & Thurner, 2016). As the progression of AD impairs an aging parent's cognitive and physical abilities, there may be an increased need for informal caregivers, such as adult offspring, to provide home-based caregiving (Samson et al., 2016). When assuming caregiving responsibilities, family caregivers, such as a spouse or an adult offspring, may be affected in positive and negative manners (Broese van Groenou, de Boer, & Iedema, 2013). For instance, some caregivers expressed that caregiving can be a rewarding experience resulting in a closer relationship with family members, while other characterized their caregiving experience as stressful and intrusive in their personal lives (Broese van Groenou et al., 2013; Spigelmyer, Hupcey, Smith, Loeb, & Kitko, 2018).

In a 2015 report, Analysts from the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP, 2015) found that adult filial caregivers provide upwards of 28 hours per week of unpaid caregiver supports. Given this increased reliance on informal caregivers as their loved one ages in place, AD has become an urgent public health matter in need of attention for many scholar-practitioners and decision-makers (Bauer & Sousa-Poza, 2015; Hwang Rosenberg, Kontos, Cameron, Mihailidis, & Nygard, 2017). Frey (2010) identified the western and southern United States as having the largest and fastest growing older adult population (Frey, 2010). In metropolitan cities, such as Atlanta, Georgia, Austin, Texas, and Raleigh, North Carolina, the number of older adults has rapidly increased (Frey, 2010). For instance, in the state of Georgia, approximately 37% of individuals are over the age of 65 years (Administration on Aging, 2012). As the elderly population increases in numbers (Ngangana, Davis, Burns, McGee, & Montgomery, 2016), so will the number of various health diseases and disorders, such as AD, and the need for caregiving (Brodaty & Donkin, 2009). Gilsanz, Mayeda, Glymour, Quesenberry, and Whitmer (2017) noted that health conditions and diseases, such as diabetes, stroke, high blood pressure, and cognitive impairment, are higher for adults residing in the "Stroke Belt" or the Southern region when compared to other regions of the United States. The "Stroke Belt" includes North Carolina, South Carolina, Georgia, Alabama, Mississippi, Arkansas, Louisiana, and Tennessee because there is a 50% higher level of stroke mortality in these states (O'Neal et al., 2017; Wadley et al., 2011). Clark et al. (2018) and Gilsanz et al. also found that the geographical pattern between a stroke and AD is particularly high for individuals, especially African Americans, who were born or became adult residents in the "Stroke Belt" region of the United States. Additionally, the risk of developing dementia is quadrupled following a stroke (Clark et al. 2018).

Fundamentally, geriatric epidemiology is concerned with the lifespan of the aging population by studying physical health, functional status, and quality of life (Ferrucci, Giallauria, & Guralnik, 2008). Therefore, my goal with this study was to foster in-depth insights into the experiences of the caregiving phenomenon from the perspective of an African American adult offspring. In an attempt to understand the caregiving experiences of the African American adult offspring, special consideration was paid to the layers of familial obligation and sibling ties that may be informed by cultural beliefs.

Clay et al. (2013) discussed that unlike other ethnic or racial groups, African American caregivers functioning in similar caregiving tasks experience poorer health outcomes, have more positive coping styles and interactions, and experience less distress and strain. Although there is a large body of literature on caregiving among various ethnic or racial groups, my search for current, scholarly works on AD caregivers and sibling relationships, specifically from the perspective of African American offspring, yielded limited results. Despite there being a limited body of work on the issue of sibling caregivers and the unique caregiving challenges they may encounter, Namkung, Greenberg, and Mailick (2017) noted that findings on sibling caregivers may have significant implications for the field of gerontology. Therefore, there is a push to further gerontologists' awareness on this matter to extend outreach (Namkung et al., 2017).

Given the expansion of community and home-based dwelling older adults with AD and the increasing need for caregiving within the African American community within a southeastern U.S. metropolitan area and across the United States, I reviewed pertinent literature related to adult caregivers and their sibling relationships for this study. My aim for this study was to add to existing literature and to gain an understanding of caregiving by an adult offspring who served as the primary informal caregiver and how those caregiving experiences may have affected his or her sibling relationships. For this generic qualitative study, I explored African American adult caregiver perceptions of sibling relationships during the time of providing care to a parent with AD.

Statement of the Problem

The U.S. Census Bureau (2014) estimated that the population of adults 65 years and older would increase from 43 million to over 83 million between 2012 and 2050 in the United States. Additionally, by 2050, the population of adults 85 years and older is anticipated to increase by 4% or 18 million people (U.S. Census Bureau, 2014). Amaro (2017) attested that although an aging adult can live a healthy and satisfying lifestyle, there is a higher chance of them becoming ill or disabled. As the aging population increases in quantity so will the number of chronic health diseases and conditions such as AD (Barnes & Bennett, 2014; Bekhet, 2015).

Furthermore, Barnes and Bennett (2014) noted that the racial and ethnic composition among this population would also become more diverse. Additionally, with the expansion of the ethnic minority aging population and their high health demands, the need for family caregivers will also increase (Goren, Montgomery, Kahle-Wrobleski, Nakamura, & Ueda, 2016; Pharr, Dodge Francis, Terry, & Clark, 2014). Therefore, family members will increasingly become critical to informal caregiving of an elderly parent with dementia (Doris, Cheng, & Wang, 2018). Tolkacheva, Broese van Groenou, and Van Tilburg (2010) asserted that the aging person's spouse, partner, or adult children are usually the family members who provide the most support. Family caregivers deliver nearly 80% of supports to older adults (Alzheimer's Association, 2017; Varela, Varona, Anderson, & Sansoni, 2011; Williams et al., 2016).

Pillemer and Suitor (2013) found that adult children of a care recipient viewed the role of caring for a parent as a shared responsibility between siblings. Although Volkom

(2006) posited that siblings may lean on each other for physical and emotional support as well as moral encouragement, Amaro (2017) noted that parental caregivers may also encounter considerable strife and strain among their siblings due to concerns over parent care. Additionally, Kwak, Ingersoll-Dayton, and Kim (2012) agreed that elderly caregiving may expose adult children to family strife and arguments. Despite some literature on the effects of caring for a loved one regarding race and ethnicity, there is limited understanding of racial differences regarding family caregivers (e.g., adult child and spouse) and family tension (Suitor et al., 2017).

Pharr et al. (2014) also noted that due to the expansion of the ethnic minority population, researchers are anticipating that this group will experience greater demand for a family caregiver when compared to White family members. According to Fingerman et al. (2011), African Americans deliver more filial or informal caregiving than any other ethnic or racial group. Although I encountered difficulty in finding existing scholarship on understanding the experiences of caregiving among African American family members (see White, Townsend, & Stephens, 2000), I found limited research on sibling relationships (i.e., Fingerman et al., 2011; Halliweel, Wenzel-Egan, & Howard, 2017; Namkung et al., 2017; Ngangana et al., 2016; Lashewicz & Keating, 2009; Willyard, Miller, Shoemaker, & Addison, 2008) among African American adult children when caring for a parent with AD. Considering the gap in existing scholarship on sibling relationships and caregiving among African American adult filial caregivers, further research was warranted.

Purpose of the Study

The purpose of this qualitative study was to explore sibling relationships experienced by an adult offspring of a parent with AD. For this research, I used a generic qualitative approach to gain narratives from African American adult filial caregivers regarding their experiences and attitudes of their sibling relationships as it relates to filial caregiving. Although I found prior studies on the relationship between care recipients and their informal or formal caregivers, there were a limited number of existing studies related to the effects of parental caregiving on adult sibling relationships (see Namkung et al., 2017; Ngangana et al., 2016; Willyard et al., 2008). Through in-depth interviews with adult filial caregivers, I addressed the gap in the existing literature on caregiving and sibling relationships among African Americans. The implications for positive social change may assist gerontologists, medical practitioners, mental health therapists, and community-based social service organizers in developing and implementing culturally responsive strategies and supports for African American adult filial caregivers of AD parents and their siblings.

Research Question

This study was guided by the following research question: How does an African American adult offspring who assumed the primary family caregiving role and responsibilities for their parent with AD perceive his or her relationship with a sibling?

Conceptual Framework

For this research study, I utilized equity theory as the conceptual framework for examining sibling relationships during the period of parental caregiving. Ingersoll-

Drayton et al. (2003) and Sechrist, Suitor, Howard, and Pillemer (2014) posited that equity theory is a useful framework for gaining an understanding of intimate, interpersonal relationships of social exchange. Therefore, I used this framework as a map that guided my exploration of each interviewee's experiences to illuminate his or her perceptions of sibling relationships during the time of caring for a parent with AD (see Green, 2014).

Nature of the Study

Qualitative researchers are active instruments who observe, interact, and attempt to make sense of the essence of participants' lived experiences with a phenomenon (Matua & Van Der Wall, 2015). A qualitative study is an in-depth research approach in which scholar-practitioners gather detailed information about a complex phenomenon (Houghton, Murphy, Shaw, & Casey, 2015). The basis of qualitative research encompasses the utilization of subjective data to gain further insight to provide clarification of an event rather than to establish an exact causal relationship (Sutton & Austin, 2015). Moreover, qualitative research is not about empirical evidence; instead, qualitative research is about digging deeper, describing, or interpreting a phenomenon (Baker & Edwards, 2012).

Anderson (2010) advised researchers to choose an appropriate approach for a study and to be mindful of their objectives. Following this suggestion, I employed a generic qualitative approach for this study. Scholar-practitioners employing a generic qualitative study considers people's account of their subjective thoughts, viewpoints, beliefs, or reflections on their encounters of the outward environment (Percy, Kostere, &

Kostere, 2015). Furthermore, generic qualitative researchers are epistemological, social constructivists whose focus is to make sense of people's interpretations, how individuals construct their environment, and the meaning ascribed to the experienced phenomenon (Kahlke, 2014). . To address the research question, I used a purposeful sampling strategy in conjunction with snowball sampling to identify and recruit adult filial caregivers of an elderly parent with AD.

For this study, I sampled African Americans who were between 45 and 65 years of age, had at least one sibling, functioned as an unpaid primary caregiver in either a full- or part-time capacity to a home-based elderly parent with AD. Boland et al. (2017) explained that location of care options include two types of setting: home care or institutional care. The authors viewed home-based care as someone living with supports or home accessibility modifications for promoting independence and well-being (Boland et al., 2017).

I conducted this study in an urban area in the southeastern United States. For this qualitative research study, I interviewed a sample of 10 participants. Although there is not a universal consensus as to what is an appropriate sampling size for saturation, Boddy (2016), Fugard and Potts (2015), and Hagaman and Wutich (2017) recommended six to 10 interviewees for a smaller study, two to four interviewees for a focus group, and 10 to 100 for secondary sources. Therefore, I sought rich, quality information rather than being focused on the number of participants (see Hennink, Kaiser, & Marconi, 2017).

Operational Definitions

Alzheimer's disease (AD): A slowly progressive neurodegenerative disorder on the continuum of dementia that impairs mental and behavioral functioning (Adler, Marczak, & Binder, 2018; Kumar & Singh, 2015). The progression of the disease impairs memory, recognition, speech, and the ability to complete daily tasks ultimately ending in death (Kumar & Singh, 2015).

Care recipient: An individual who receives caregiving supports on a temporary, short-term, or ongoing basis. A person with AD may receive informal or formal care supports through a skilled facility, a home-based, or community-based setting (Alzheimer's Association, 2015).

Caregiver: A paid or unpaid person who assumes responsibility for the daily care of an elderly person with AD (Alzheimer's Association, 2015) or someone who provides supports at least one activities of daily living (ADLs) or instrumental activities of daily living (IADLs; Roth, Fredman, & Haley, 2015).

Caregiver burden: When the task of caregiving places a strain on the caregiver's personal relationships, social relationships, finances, physical and emotional well-being, or employment (Broese van Groenou et al., 2013).

Caregiving: Attending to the needs of an individual with cognitive impairment or some form of dementia such as AD (Alzheimer's Association, 2015). Formal or informal caregivers may assist individuals with food preparation, grocery shopping, toileting, companionship, mobility, financial management, transportation, medication management, or scheduling medical appointments on a part- or full-time basis (Alzheimer's Association, 2015).

Dementia: Broadly described as a decline in brain functioning affecting a person's ability to think, remember, communicate, and use judgment (Alzheimer's Association, 2017). There are many forms of dementia that include AD, vascular, or Lewy body (Alzheimer's Association, 2015). Furthermore, an individual can experience a range of symptoms, such as mild impairment like forgetfulness to more severe symptoms such as an inability in recognizing loved ones like family members or friends, self-care, swallowing, or continence (Alzheimer's Association, 2015).

Home-based care receiver: Someone living with supports or with home accessible modifications for the promotion of independent living and well-being (Boland et al., 2017).

Informal caregivers: Unpaid caregivers, such as a spouse, children, other family members, neighbors, or friends, who provide care or support to a person. Informal caregivers may support the care recipient by providing companionship, running errands, cleaning the home, or scheduling and maintaining professional healthcare appointments (Broese van Groenou & de Boer, 2016).

Siblings: Individuals who share genetics through one or both parents or become family through marriage, adoption, or by foster care (Child Welfare Information Gateway, 2013).

Sibling relationships: The most enduring type of kin relationship involving individuals within a family structure that outlast other types of relationships, such as a parental, spousal, or offspring relationship (Suitor et al., 2017; Whiteman, McHale, & Soli, 2011).

Assumptions

In this study, I assumed that the sampling population was willing to discuss their sibling relationships. I further assumed that participants provided honest and candid accounts of their sibling relationships as they have experienced in their role as a caregiver to an elderly parent with AD.

Scope and Delimitations

For this research, I focused on African American adult filial caregivers of a parent with AD as participants. I defined a caregiver as an African American adult offspring, between 45 years to 65 years of age, male or female, who had at least one sibling, and currently functioned or had functioned in an unpaid capacity either part-time or full-time. Additionally, the adult filial caregiver was to provide home-based supports to an AD parent. Given these participant parameters, the findings from this study may not be transferable to all African American adult filial caregivers or caregivers outside this demographic characteristic or geographical location. Another delimitation was that the sampling population was solely drawn from an urban area in the southeastern United States.

Limitations

This research was limited to African American adult filial caregivers who provided home-based supports to a parent with AD and had at least one sibling. The participants resided in an urban area in the southeastern United States. Furthermore, caregivers of other racial or ethnic groups were not considered for this study; therefore, the results from this qualitative study may not be transferable or generalizable to other African American caregiver groups or other types of caregiver groups concerning race or ethnicity.

Another limitation of this study was the small sample size. Although I accepted a minimum sample size of eight participants for this generic qualitative research, I ended up with 10 participants. The sample size should be large enough to address the research question and small enough to reach saturation (Burmeister & Atiken, 2012). Additionally, Clearly, Horsfall, and Hayter (2014) noted that researchers may extract relevant information from a small, carefully selected, homogeneous participant group with expert knowledge related to the research topic.

Significance of the Study

The results from this study add to the existing body of literature in the field of gerontology, family studies, and AD support networks by providing an in-depth analysis of sibling relationships from the perspective of the primary adult sibling caregiver of an AD parent. Furthermore, these findings, when combined with existing literature, may contribute to policy development within the above-stated fields. Moreover, human service providers may utilize the results from this study as a useful tool in developing culturally relevant strategies and family-centered psychoeducation programs and supports. The possibility of promoting positive social change was grounded by the results from this research, which included insights into sibling relationships from the perspective of the adult primary filial caregiver. Further implications may include mental and medical clinicians being able to identify caregiver stress and sibling strain, offer meaningful community-based interventions to alleviate caregiver stress, or offer guidance in maintaining positive outcomes related to the task of filial care.

Summary

In Chapter 1, I introduced the primary direction and purpose of the research and provided a brief overview justifying the need for a study focused on the sibling relationships of African American adult filial caregivers of an AD parent. I concluded Chapter 1 with a description of the significance of the study and the implications for positive social change. Chapter 2 will include a detailed review of pertinent literature exploring AD, African American adult filial caregivers, and the impact that AD caregiving has on sibling relationships among African Americans caring for an elderly parent.

Chapter 2: Literature Review

Introduction

Chapter 2 contains a review of extant literature related to sibling relationships among African American adult filial caregivers of parents with AD. After an extensive literature review, I concluded that the perspectives of African American filial child caregivers on their sibling relationships during the period of caregiving of parent with AD are lacking, despite Wermuth (2011) noting an increase since the 1990s on dementia caregiving research. Pinto, Barham, and Prette (2016) stated that caring for an aging family member is a complicated responsibility that can disturb the caregiver’s life course. For many family members, caring for an ill or disabled parent or grandparent can become a central challenge in their midlife (Kim et al., 2017). AD is a disease that can affect a caregiver due to the required daily demands (Alzheimer’s Association, 2018). According to Macdonald et al. (2017), AD is a common and well-known type of fatal degenerative neurocognitive disorder that affects millions of older individuals. Due to the enormous ramifications that befall the care recipient’s support network, AD is frequently touted as the *family disease* (DeFina, Moser, Glenn, Lichtenstein, & Fellus, 2013). Providing support to an ailing parent may result in significant changes to the emotional, physical, and social well-being of the caregiver.

In this chapter, I identify and discuss relevant existing scholarship as well as support the significance of this study. I begin by outlining the literature search strategy and subsequently present an overview of equity theory as the theoretical foundation guiding this study. Following the theoretical framework section, I provide a review of existing scholarship related to the experience of caregiving, sibling relationships, and African American caregivers.

Literature Search Strategy

I conducted a review of the extant literature using several different resource sites that included, but were not limited to, the following fields: social work, nursing, and psychology. I also conferred with the librarians from Walden University in searching for peer-reviewed journal articles. In the search for peer-reviewed journal articles, books, and doctoral research, I accessed the following databases, websites, and search engines: Walden University Library EbscoHost, ERIC, ProQuest Central, Thoreau, MEDLINE, PsycARTICLES, American Psychological Association Articles, Google Scholar, SAGE Journal, ResearchGate, Cumulative Index to Nursing and Allied Health Literature, the Centers for Disease Control and Prevention, Alzheimer's Association, PubMed, Google Scholar, SAGE full-text collection, and the National Institute on Aging. To extract pertinent literature related to this study, I used the following keyword terms, either in combination or by themselves: *family caregiver, parental caregiver, African American caregivers, sibling conflict and adult child caregiver, informal caregiver, formal caregivers, sibling relationships and caregiving, sibling strain, Alzheimer's disease,* and *Alzheimer's and caregiving.* I collected and reviewed over 200 studies and peer-reviewed scholarship related to AD, caregiving, African American caregivers, and adult filial caregivers. Apart from seminal scholarship dating back to 1965, I focused on peer-reviewed journal articles published from 2003 to 2018 for this literature review.

Conceptual Framework

Equity theory is a social psychological theory of comparison that was developed by Adams in the early 1960s (Tam, 2017). Adams formulated equity theory to explain workplace behaviors and employee performance (Arvanitis & Hantzi, 2016). The basis of Adams's equity theory is the difference between inequality and equality and the perceived value of the input put forth (Mutuma, Iravo, Waiganjo, & Kihoro, 2017). According to Adams (1965), the overarching premise of equity theory is a social comparison of fairness, exchange, and reciprocity. Adams found that when a person senses increased equity their motivation to perform will increase. However, when an employee perceives an inequitable workplace environment, he or she may become an unmotivated performer (Adams, 1965). The perception of imbalance occurs when the ratio of outcomes is believed to be insufficient when weighed against the input (Adams & Jacobsen, 1964). Therefore, input should be proportional to the output and the reward generated from the action of input (Adams, 1965).

Adams and Jacobsen (1964) explained that whenever there is an exchange between two people, there is always a possibility that either party will deem the exchange inequitable. Adams (1965) posited that individuals compare inputs and outcomes to that of others to assess an existence of unfairness. An input is what a person gives, and an outcome is what the person on the other side of exchange receives (Al-Zawahreh & Al-Madi, 2012). Consequently, people in an over benefitted or under benefitted relationship may become distressed, showing signs of anger, depression, sadness, or guilty feelings because they have received more than others, while individuals in an equitable or balanced relationship are less likely to experience negative outcomes (Al-Zawahreh & Al-Madi, 2012; Yum & Canary, 2009). Cook and Hegtvedt (1983) highlighted that equity in a relationship entailed a party of two or more individuals exchanging resources, services, monetary capital, love, or regard.

Social scientists, such as Adams (1965) and Adams and Jacobsen (1964), noted that equity theory was an extension of social exchange theory that has mainly been used to explore perceptions of proportional fairness in a workplace environment; however, Al-Zawahreh and Al-Madi (2012) stated the theory is now commonly applied to social conditions, such as romantic relationships, friendships, and family relationships. Individuals in an imbalanced relationship are motivated to reduce inequity by engaging in acts to rebalance or restore the relationship (Al-Zawahreh & Al-Madi, 2012). Ingersoll-Drayton et al. (2003) outlined equity theory as a valuable framework for gaining insight into relationships of social exchange since the tenets of this theory feature the observation of contributions, outgoing costs, and compensations or rewards. Theorists proposed that relationships were more congenial when vested members deemed transactions or exchanges as equitable (Sechrist et al., 2014). Equity theorists contended that resources should be utilized in a manner where the ratio of inputs and outcomes of an exchange are proportionate (Al-Zawahreh & Al-Madi, 2012). Researchers may find that equity framework be significant in examining perception of fairness between the adult filial primary caregiver’s siblings (Ingersoll-Drayton et al., 2003).

Lashewicz and Keating (2009) conducted a qualitative study guided by equity theory that explored tension among sibling caregivers. According to Lashewicz and

Keating, a sibling makes up a collection of people who are not only mindful of cost and benefit but also tends to make comparisons. For members in the relationship, an unequal or unbalanced support or contribution can be distressing (Lashewicz & Keating, 2009). Hence, adult caregivers who perceive that they are providing more caregiving than siblings may harbor bitterness and antipathy (Ingersoll-Dayton et al., 2003b). On the contrary, the other siblings may deem contributions as a minimal exchange, and in trying to alleviate guilt-ridden thoughts, the siblings may pursue restoring equity (Ingersoll-Dayton et al., 2003b). Additionally, Ingersoll-Dayton et al. (2003b) examined two ways that siblings providing less care may try to restore equity. First, siblings can adjust behaviors (Ingersoll-Dayton et al., 2003b). Second, siblings providing less care may seek to reestablish equity or fairness by revising their viewpoints of events over actual and psychological equity (Ingersoll-Dayton et al., 2003b). Ingersoll-Drayton et al. (2003a) conducted a qualitative study where researchers gained accounts of 43 focus group members who provided care to a fragile parent; of the 43 adult child caregivers, 28 had an inequitable distribution of parental caregiving among siblings, while 15 expressed responsibilities as equitable.

Ingersoll-Drayton et al. (2003a) found some siblings distributed parental care by assigning different tasks based on abilities or capabilities or taking turns either through an equally distributed timeframe, such as a shift, or by switching roles from primary to secondary caregiver throughout the caregiving process. Ingersoll-Drayton et al. also found that participants made deliberate attempts to integrate a collaborative approach to parental caregiving where siblings were part of a system that not only worked in an autonomous nature but often sought guidance from others. Another key finding related to the perception of equity was the parent's role during the caregiving process (Ingersoll-Drayton et al., 2003a). According to Ingersoll-Drayton et al., the adult child caregiver reported that the care-recipient parent helped in facilitating a balance between siblings by preplanning their care and providing the same instructions of that plan to family members.

The Aging Population

Researchers projected that by the year 2050, 1 in 4 people will be over 65 years of age and close to 10% will be over 80 years old in the United States (Alzheimer's Association, 2018). The fastest increasing population in the United States are also the oldest old who are individuals 90 years and older (Corrada et al., 2017). Bicket and Mitra (2009) asserted that adults 65 years old and over represent a significant portion of the total population of the United States. According to Frey (2010), Hrostowski (2010), and Wolf and Amirkhanyan (2010), the baby boomer generation are individuals who were born between 1946 and 1964 who are recognized not just for their size but also their social and demographic traits. Furthermore, researchers projected that the population consisting of individuals age 65 years and over will continue to expand well into the year 2030, eventually representing nearly 20% of the total population (Centers for Disease Control and Prevention, 2013).

Dementia and Alzheimer's Disease

Dementia is a gradual progression of cognitive impairment of the brain that affects memory, attention, and functioning (Abraha et al., 2017; Qiu & Fratiglioni, 2018);

it is the fifth most common factor of mortality among more wealthier countries (Dolgin, 2016). To meet the qualifications of a dementia or a major or mild neurocognitive disorder, the following symptoms should be present: moderate or significant decline in cognitive ability, poor language and social cognition, poor emotional regulation, mood swings, agitation or aggressive behaviors, and inability to independently complete ADLs and IADLs (Leite et al., 2017; Subramanian, Selvamani, & Natarajan, 2018). Tewari et al. (2018) and Pohontsch, Scherer, and Eisele (2017) acknowledged that dementia could be reversible and irreversible. For instance, reversible dementia is characterized as a cognitive impairment since it can stem from a reaction related to medications, substance misuse or abuse, a removable brain tumor, environmental toxins, or a nutritional deficiency (Feast Orrell, Charlesworth, Melunsky, Poland, & Moniz-Cook, 2016; Tewari et al., 2018), while irreversible dementia can be caused by degenerative brain diseases, such as AD, Huntington's disease, and neurological diseases such as Parkinson's disease (Tewari et al., 2018).

AD was first described by a German neuroanatomist and psychiatrist, Dr. Alzheimer (Kumar & Singh, 2015). Dr. Alzheimer first made observations at the Frankfurt Psychiatric Hospital of a 51-year-old woman exhibiting bouts of paranoia, sleep, personality disturbances, difficulty speaking, behavior disturbances, memory changes, and periods of aggressiveness (Coenen, 2016). The doctor later described this patient as having an aggressive form of dementia, manifesting in memory, language, and behavioral deficits (Coenen, 2016). Dr. Alzheimer cared for this patient until her death (Coenen, 2016). Subsequently, an autopsy was performed in 1906, showing fatty deposits in her blood vessels, atrophied brain cells, and shrinkage of her cerebral cortex (Coenen, 2016).

Abraha et al. (2017) and Qiu and Fratiglioni, (2018) found that AD is not only the most common type of dementia, but it is also the leading cause of dementia among the aging population, accounting for over 60% of dementias. Although modern advances in medical technology have resulted in longer life expectancy (Eldh & Carlsson, 2011), researchers suggested that the risk of experiencing a degenerative cognitive impairment exponentially increases with progressing age (Qiu & Fratiglioni, 2018; Thomas & Bai, 2017). Although the exact cause of AD has yet to be fully realized, geriatric practitioners suggested that age is a high-risk factor (Barnes & Bennett, 2014; DeFina et al., 2013; Qiu & Fratiglioni, 2018). Additionally, Thomas and Bai (2017) found the rate of occurrence is between 2% to 3% at age 65 years old and elevates over 40% after 85 years of age. Other risk factors include gender, genetics, high blood pressure, heart disease, lower education levels, inflammation, and head injuries (DeFina et al., 2013; Macdonald et al., 2017). Although symptoms are different from one person to the next, those affected by AD commonly experience memory problems and other behavioral and psychological degeneration; impaired speech; and difficulty with identifying objects, thinking abstractly, and executing daily motor activities (Alzheimer's Association, 2016; Varela et al., 2011).

DeFina et al. (2013) posited that a true diagnosis of AD is confirmed post mortem. However, until a confirmation is determined, medical practitioners may rely on family caregivers or other types of caregivers as informants in providing historical information on any cognitive or functional changes expressed by the care recipient (DeFina et al., 2013). Medical practitioners will also conduct an exhaustive examination that may account for memory loss through a battery of physical and neurological examinations and neuro-imaging (Neugroschl & Wang, 2011). Additionally, the diagnosis of AD may involve a battery of cognitive and memory tests such as The Mini-Mental State Examination or the Montreal Cognitive Assessment (Neugroschl & Wang, 2011). Furthermore, a postmortem brain investigation includes measurement and magnetic resonance imaging of beta-amyloid plaques and tangles brain lesions (DeFina et al., 2013).

Despite not being able to find a cure for AD, many medical providers utilize prescription drug therapy as a course of treatment for some relief (Macdonald et al., 2017). Although many medical experts understand that currently there is no cure for AD, they still recommend incorporating alternative approaches such as an exercise routine for the promotion of cognitive and noncognitive performance (Lamotte, Shah, Lazarov, & Corcos, 2017). Accordingly, family caregivers of AD individuals may find management of the disease a challenge and time consuming (Kim, Ullrich-French, Bolkan, & Hill, 2018).

Alzheimer’s Disease and Caregiving

AD is a degenerative neurocognitive disorder affecting roughly 5.7 million people in the United States (Alzheimer’s Association, 2018). Furthermore, someone is diagnosed with AD every 3 seconds (Thomas & Bai, 2017). According to WHO (WHO, 2012), even though degenerative cognition is not deemed to be a natural dynamic in the aging process, WHO scholars and other researchers acknowledged that as a person ages the risk of developing AD and other forms of dementia is elevated (Clark et al., 2018; WHO, 2012).

Analysts projected that the human resources and economic expenses it will take to care for AD sufferers will be astounding (Macdonald et al., 2017). Faria, da Cruz Scardoelli, de Castro, and Nishida (2017) acknowledged that AD and other forms of dementia may leave an economic and emotional effect on families. In 2010, research scholars composed a report in which they tabulated the economic cost of treating AD at $109 billion which included institutionalized supports, Medicare, and out-of-pocket expenses (National Institute on Aging, 2013). Also, informal caregiving increased from 2010 to 2013 by $15 billion which translates to nearly 18 billion hours of unpaid caregiving supports (Alzheimer's Association, 2014a; National Institute on Aging, 2013). Further, AD and dementia caregivers spend on average 28 hours a week providing care which often leads to employment issues (National Alliance for Caregiving and AARP, 2015). Therefore, da Silva Falcão, Teodoro, and Bucher-Maluschke, (2016); Goren et al. (2016) affirmed an increasing reliance on the family caregivers in supporting an elderly parent with AD. Hence, middle-aged adult children must decide on how best to provide care supports to parents (Namkung et al., 2017).

In their work, Roth et al. (2015) characterized caregiving as the delivery of supports to someone with a disability which can be done in either an informal and formal manner. Broese van Groenou and de Boer (2016) defined informal caregivers as unpaid individuals such as a spouse, children, other family members, neighbors, or friends who provided care or support to a person with a disability. Informal caregivers may support the care recipient by providing companionship, running errands, cleaning the home, or scheduling and maintaining professional healthcare appointments. According to Namkung et al. (2017) deciding how to best support an ailing parent is usually a conversation that involves multiple members of the family.

Moreover, family members providing care to an elderly parent in the early stages of AD and throughout may assume management of IADL such as domestic tasks, preparing meals, managing finances, and scheduling medical or mental health appointments (Giebel, Sutcliffe, & Challis, 2015; Pocnet, Rossier, Antonietti, & von Gunten, 2013). Caregivers may also be tasked with assisting the care-recipient with ADL which consist of a litany of basic personal needs such as toileting, dressing, bathing, transferring from chair to bed, and feeding (Fujita, Notoya, Sunahara, Nakatani, & Kimura, 2018; Giebel et al., 2015; Pocnet et al., 2013). McInnis-Dittrich (2014) asserted that in the second stage of AD, a person may wander off, become disorientated, be unable to recognize family members and friends, and show signs of physical deterioration. The authors characterized that in the final stage of AD there is an increased demand for caregiving supports since the individual will experience incontinence, limited mobility, and a diminished ability to verbally communicate (McInnis-Dittrich, 2014).

Consequences of Dementia or Alzheimer’s Disease Caregiving

Although the course for AD and other forms of dementia differs from person to person ranging from 5 to 20 years (The Alzheimer’s Association, 2016). Simpson, Stansbury, Wilks, Pressley, Parker, and McDougall (2018) noted that for most dementia caregivers they may face 3 to 15 years of exposure to the physical and psychosocial demands from the care recipient. For instance, as dementia or AD progresses, the caregiver may endure countless hours of monitoring and managing AD care such as household chores, addressing any breakdown of mental and emotional such as agitation, wandering, sleep disorders, paranoia, bouts of anger, or sadness (Faria et al., 2017). Taking into consideration the responsibilities and roles associated with caregiving, Schulz and Sherwood (2008) noted that despite dementia caregivers experiencing chronic physical and psychological stressors, dementia caregivers frequently express positive sides of the caregiving experience.

Given the span and the amount of care being provided, researchers such as Simpson et al. (2018) affirmed that caregiving is a difficult undertaking that may bring about several risks for the person functioning in that role. Furthermore, stress during the timeframe of AD caregiving may compromise the mental and physical well-being of family caregivers (Simpson et al., 2018; Suitor et al., 2013). For instance, caregivers may become more susceptible to physical and emotional illnesses, be at an increased risk for hypertension or coronary heart disease, may engage in risky behaviors such as substance and chemical abuse, become sleep deprived, and may have poorer social relationships such with other family member or friends (Amaro & Miller, 2016; da Silva Falcao et al., 2016; Leite et al., 2017).

Although caregiving is experienced through the subjective lens of the caregiver (Hodge & Sun, 2012), representation of the positive and negative consequences of caregiving are not equally examined by researchers. For instance, there is seminal and recent scholarship focusing on negative outcomes of dementia and AD caregiving (Charles, Brémault-Phillips, Parmar, Johnson, & Sacrey, 2017; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Liu, Kim, Almeida, & Zarit, 2015; Vitaliano, Zhang, & Scanlan, 2003), yet research on positive aspects of caregiving is scarce (Doris et al., 2018; Hodge & Sun, 2012; Semiatin & O'Connor, 2012).

Grover, Nehra, Malhotra, and Kate (2017) suggested that positive and negative appraisals can be experienced at the same time. Researchers noted that studies exploring positive aspects of caregiving are just as significant as studies on negative aspects of caregiving (Abdollahpour, Nedjat, & Salimi, 2018). These scholars defined positive aspects of caregiving as positive feelings gained through the caregiving experience (Abdollahpour et al., 2018). By ignoring the other dynamic in the caregiving experience, Doris et al. (2018) argued that setting perimeters limit understanding and implementation of interventions for caregivers of individuals with dementia. Through a systematic review the authors noted the following key results on positive outcomes related to caregiving: higher self-worth, life satisfaction, reduction of anxiety and depression, a sense of fulfillment, and family cohesion (Doris et al., 2018).

A descriptive, cross-sectional study conducted by Bekhet (2013) compared 28 African American females and 45 White American female caregivers on caregiver's burden, well-being, personal and social resourcefulness, and depression. The average age of participants in this study was 57.46 years with 47.39 years being the mean age among African American female caregivers and 64.6 years being the mean age for Whites (Bekhet, 2013). Although the authors found that the differences between African

American female caregivers and White female caregivers were not statistically significant, they noted African American female caregivers had higher mean scores related to resourcefulness, positive thinking, and psychological well-being (Bekhet, 2013). In other words, African American female caregivers had a much more positive outlook on their caregiving experiences, they were generally in good mental health, and had lower distress (Bekhet, 2013). The authors suggested that resourcefulness and the positive outlook on caregiving among the African American female caregivers may function as a safeguard against angst, despair, and feelings of resentment (Bekhet, 2013).

Alzheimer’s Disease and African Americans

Due to a rise of AD and other forms of dementia in the African American community, more adult children are assuming the role of caregiver (Samson et al., 2016). For this study, the U.S. Census Bureau (2011) characterization of African Americans will be utilized. U.S. Census Bureau (2011) noted that African Americans are a group of people identified as having African ancestry. Currently, there are approximately 35 million African Americans who represent 13% of the general population (U.S. Census, 2011) but by the year 2050, over 10 million African Americans aged 65 and over may be at risk for AD (Alzheimer’s Association, 2016).

Matthews et al. (2018) found that African Americans and Hispanics are disproportionately more likely than Whites to have AD or related forms of dementia. Zhou et al., (2017); Mayeda et al. (2016); Barnes and Bennett (2014) stressed that African Americans are at a 2 to 3 times higher risk of experiencing AD. The reason for higher representation may be related to a higher incidence of diabetes, high blood pressure, lack of physical activity, poor diet, and stroke among the African American and Hispanic communities (Alzheimer's Association, 2014; Hughes, Tyler, Danner, & Carter, 2009). For modifiable risk factors, researchers emphasized that implementing pro healthy lifestyle behaviors such as keeping socially connected, maintaining physical activity and healthy eating habits, and remaining mentally active may reduce the possibility of AD or related dementias (Matthews et al., 2018). Matthews et al. (2018) also recommended genetic testing and guidance for nonmodifiable risk factors such as age, family history, and heredity to increase knowledge as a precautionary measure.

Although the use of antihypertensive and statin medications has been effective in reducing strokes and heart attacks over the last 20 years, African Americans continue to suffer from these types of medical conditions at a higher incident than other ethnic groups (Gilsanz et al., 2017). Mayeda et al. (2016) noted that there are social and behavioral influences serving as a catalyst in the racial and ethnic inequalities regarding AD and related dementias. In their study, these scholars extracted 14 years of data from Kaiser Permanente Northern California which included African Americans, Whites, American Indians and Alaska Natives Latinos, Asian Americans, and Pacific Islanders. The authors found that when compared to other racial or ethnic groups, the rate of dementia was highest among Blacks, regardless of gender and age (Mayeda et al., 2016). Other scholars (Williams, Park, Tsang, Sperling, & Manning, 2018) illuminated that education level, socioeconomic status, literacy disparities, discrimination, and behavioral norms may offer an explanation regarding an increased link to cognitive decline and AD among African Americans (Kalaria et al., 2008; Mayeda et al., 2016; Sharp & Gatz, 2011). The

Alzheimer’s Association (2016) also affirmed that factors such as late diagnosis, culturally biased instruments, and failure to report a decline of cognitive abilities to practitioners resulting in poor management of care among African Americans may contribute to the over-representation of AD. Therefore, it is necessary to understand caregiving characteristics such as the steady growth rate, higher prevalence rate of AD, and the increased need for family caregivers in the African American community (Cothran et al., 2015).

The African American Caregiver

In Western societies, adult offspring frequently find themselves in the position of supporting aging parents (Fingerman et al., 2011). Dilworth-Anderson et al. (2005) asserted that African American caregivers typically deliver more support to an elderly parent than White Americans. However, these family norms may deviate by age groups (Fingerman et al., 2011). For instance, there are differences among generations concerning family and community cohesion where older individuals express feelings of reciprocity towards neighbors and family members than those in the younger generation (Fingerman et al., 2011). Also, African Americans were found to have stronger communal beliefs on caregiving than other racial groups (Friedemann & Buckwalter, 2014). In other words, African Americans experienced shared care assistance from family members (Friedemann & Buckwalter, 2014).

Culture and Filial Attitudes Towards Caregiving

Rozario and DeRienzis (2008) relied on stress and coping, contextual, and sociocultural models to frame their research on familial beliefs in caregiving among

African American women. Rozario and DeRienzis (2008) noted that if there is a strong relationship between the caregiver and care-recipient; then the caregivers will more than likely perceive responsibilities as positive and rewarding, thereby experiencing lower levels of perceived distress. This cross-sectional study involved 521 African American female caregivers with daughters, representing close to 50% of the sampling population (Rozario & DeRienzis, 2008). The mean age was 53.8 years old with more than half of the sample unemployed (Rozario & DeRienzis, 2008).

The scholars found different scales of familial beliefs, and although this study offers insight cultural and filial obligation of care, there are some limitations of this study. First, the authors were unable to investigate a causal association between the caregiver's sociocultural attitudes and psychological distress (Rozario & DeRienzis, 2008). Second, since the focus of the study was aimed at African American female caregivers, it may not be generalizable to male caregivers (Rozario & DeRienzis, 2008). Third, participants were from rural and urban areas in the Saint Louis, Missouri region and findings may not be generalized to other regions across the United States (Rozario & DeRienzis, 2008). Despite these limitations, Rozario and DeRienzis (2008) study is congruent with some of the earlier findings from Dilworth-Anderson et al. (2005) in which these scholars highlighted a link between a caregiver's education level and cultural caregiving beliefs. Other researchers such as Heo and Koeske (2013) and Sterba et al. (2014) noted that unlike the White counterparts, the strong sense of filial obligation and prayer that many in the African American community embrace may also mitigate experiencing the caregiving relationship as a burden.

Napoles, Chadiha, Eversley, and Moreno-John (2010) explained that minority family caregivers are less likely to institutionalize an older adult who has dementia when compared to White Americans. African Americans are more likely to deliver home care supports (Intrieri & Kurth, 2018). Also, racial variances associated with filial caregiving may be a result of limited financial resources, religious beliefs, cultural mores, and perceptions related to aging (Intrieri & Kurth, 2018). Analysts from the NAC and AARP (2015) released a survey highlighting close to 40 million people in the United States assumed the role of an informal caregiver and of that close to 21% were African Americans. Scholars such as Wells et al. (2017) not only asserted that the need for care supports is elevated throughout the different ethnic and racial groups, but they also acknowledged that African Americans provide more hours in care, perform more physically taxing supportive duties, and are less likely to be able to access adequate supportive resources. Despite the high demand and other barriers noted by these scholars, African American caregivers reported higher levels of rewards and lower levels of depression (Wells et al., 2017). However, Wells et al. (2017) cautioned readers to not disregard that African American caregivers are at great risk of experiencing heart-related conditions and high blood pressure, may over consume alcohol, have a poorer diet, lack an exercise regime, and become financially strained due to out of pocket medical cost (Intrieri & Kurth, 2018).

According to Lincoln, Taylor, and Chatters (2013), African Americans often utilize informal support such as family or other types of kinship networks, and their community to cope with daily life occurrences or stressful life events related to homelessness, financial issues, chronic health conditions, death, or an ailing family member. Moreover, these social networks may be useful in providing information, physical or financial aid, or emotional support (Lincoln et al., 2013). However, too much reliance on family coupled with excessive requests for help may exhaust these resources (Lincoln et al., 2013). Lincoln et al. added that inadequate reciprocity related to social exchange could also strain a relationship.

Additionally, Beard, Knauss, and Moyer (2009) acknowledged that the responsibility of caring for a loved with AD will continue to rise significantly especially when the care recipient is in his or her final stages of life. Pharr et al. (2014) offered insight into why there is a greater need for care supports of older adults. According to these authors, families are assuming the role of caregiver due to the high cost of health resources, the steady expansion of the aging population, longer life expectancy, an overwrought healthcare system, and an increased prevalence of chronic health condition and diseases. While ethnic and racial customs may influence family devotedness and bring about more positive feelings towards caregiving than other groups; DeForge (2013) maintained that stress levels may remain elevated. Two reasons that may explain a more positive caregiving experience among African Americans are coping styles and resilience, which can safeguard against negative life encounters (Roth et al., 2015).

Other reasons why minority ethnic or racial groups are assuming the caregiver role more often than their White counterparts is attributed to cultural beliefs and norms (Pharr et al., 2014). For their interpretive phenomenological qualitative study, Pharr et al. conducted a focus group consisting of 35 participants who provided caregiving. These participants were divided into four groups: 11 African Americans, nine White Americans, seven Asian Americans, and eight Hispanic Americans with the average age of the caregiver at 52 years old (Pharr et al., 2014). A common theme among the different racial groups was the challenges they faced while providing supports (Pharr et al., 2014).

Pharr et al. also noted the White participants did not convey caregiving as being culturally embedded within their family network. Further, the three minorities groups offered historical examples highlighting acts of family caregiving with African Americans expressing caregiving as a natural part of life that was done throughout the different generations (Pharr et al., 2014). Moreover, Asian Americans, African Americans, and Hispanics Americans encouraged by familism possessed a strong sense of duty and obligation and subsequently believed that care supports were not to be provided by a long-term care institution or by formal caregivers (Pharr et al., 2014). Essentially, members from these ethnic or racial minority groups believed that family takes care of each other (Pharr et al., 2014).

Another difference Pharr et al. (2014) highlighted in the caregiver experience was the adoption of cultural ideologies such as collectivism and individualism. For instance, family members from a collectivist culture appeared to be more motived to take care of each of other than those from an individualistic culture (Pharr et al., 2012; Willis, 2012). Willis (2012) conducted a comparative qualitative study in London, England using a purposive sampling with six men and 13 women from different ethnic groups. The purpose of the study was to explore the way these different ethnic groups received or provided informal care (Willis, 2012). Participants included one Black British, six White

Irish, five White British, five South Asians, and two Mauritian (Willis, 2012). Willis concluded that members of the ethnic minority groups experienced stronger pro-caregiving behaviors due to their collectivist orientation than those leaning toward an individualist orientation (Willis, 2012). Although the sample size was small rendering generalizability a challenge; the findings from the study may serve to be significant due to the exploration into cultural influences as a motivating factor for ethnic minorities assuming the role of caregiver.

Dilworth-Anderson et al. (2005) noted that when race is discussed, it is classically but not universally defined as physical, social, and biochemical traits accounting for the groups of people's experiences. Braun, Wolfgang, and Dickersin (2013) referred to race or ethnicity as a cluster of people who are connected by skin color, birthplace, language, or country. Culture is defined here as a set of shared symbols, beliefs, and customs that influences individual and group actions which may address why groups from different cultures and races decide to provide caregiving to an elderly family member (Dilworth-Anderson et al., 2005). Also, culture is increasingly accepted by psychologists as a dynamic that informs many facets of human social life (Campos & Kim, 2017). Although the U.S. Census (2011) indicated that African Americans generally have a lower socioeconomic and educational status than other racial and ethnic groups; despite these poorer living conditions this community of people tends to be more resilient and are more likely to possess stronger cultural bonds when compared to the larger general population. Hence, cultural practices and beliefs, as well as a social network, may affect the informal caregiver's role (Hinojosa, Zsembik, & Rittman, 2009).

Family and Adult Filial Caregivers

The occurrence of dementia has increased significantly and given this expansion as well as the frequency of other age-related illnesses; family members are often assuming the management of care for aging older adult (Vainganker et al., 2016). Family caregiving is a defined as a family member or friend who assumes an unpaid role as a caregiver to a loved one experiencing a functional impairment or chronic condition (Sharma, Chakrabarti, & Grover, 2016). Family members assuming the role as a primary caregiver typically provide home-based care (Faria et al., 2017). Sharma et al. (2016) noted that upwards of 80% of the elderly population are cared for at home. Individuals receiving home-based care are people who typically reside in a modified home and receive personal care supports for the benefit of promoting independence and well-being (Boland et al., 2017). Regardless of age or culture, home typically symbolizes a significant and special place of dwelling for an older individual (Soilemezi, Drahota, Crossland, Stores, & Costall, 2017). For instance, home for many older adults, represents a sense of independence, respite, safety, and security especially when they face spending much of their time indoors due to limited mobility and chronic health issues (Soilemezi et al., 2017).

Characteristics of a Caregiver

Classically, the role of caregiver typically falls on the spouse, then adult children (mainly the daughter) with an in-law serving a minor supportive role (da Silva Falcão et al., 2016). Moreover, adult child caregivers were found to have supplied close to 80 % of supports to older community-dwelling adults (Williams, Sethi, Duggleby, Ploeg, Markle-

Reid, Peacock, & Ghosh, 2016). Elnasseh et al. (2016) found that the common characteristics of a parental caregiver or filial caregiver are single, Black, or a woman (Fingerman et al., 2011). Although the typical age of a caregiver in the United States is 49 years old; older caregivers aged 65 years and older provided the most hours of weekly care than younger caregivers between the ages of 18 and 64 (NAC & AARP, 2015). Therefore, many in the health community believe that family caregivers are instrumental resources of care often serving as surrogate to medical practitioners (Grant & Ferrell, 2012; Spigelmyer et al., 2018). For this reason, these family caregivers are typically the ones managing and administering medications, coordinating health services, and providing home-based supportive care (Grant & Ferrell, 2012; Spigelmyer et al., 2018).

Miller (1981) coined the phrase "sandwich generation" to describe adult middle-aged children who are responsible for the care of their maturing children and aging parents as they juggle additional roles such as an employee or spouse. Adult, middle-aged children must decide on how to best provide care to their parents, which usually involves a conversation among multiple members of the family (Namkung et al., 2017). Researchers acknowledged that adult child caregivers experience their roles differently than other types of caregivers (Hwang et al., 2017). For instance, competing tasks such as employment, child care responsibilities, and caregiving duties may make the adult child caregiver more vulnerable in experiencing numerous stressors and strains (Liu et al., 2017). Moreover, Straus (2012) discussed that imbalanced roles may manifest in poorer mental and physical health, and increased family conflict. Stone and Clements (2009) posited that providing parental caregiving may also affect relationships with a spouse or other family members. For instance, during the period of caregiving tension may arise between adult child caregivers and their siblings (Suitor, Gilligan, Johnson, & Pillemer, 2013). The tension between caregivers and siblings may arise due to the disapproval of care or decision-making, extraordinary demands, unfulfilled needs for support, or unsolicited or unconstructive advice (Suitor et al., 2013). Furthermore, adult child caregivers may also experience financial strain and difficulties with managing employment responsibilities (Eldh & Carlsson, 2011). Also, parental caregiving can be a source for tension between siblings when supports are viewed as insufficiently contributing to parent care (Ingersoll-Dayton et al., 2003).

Descartes (2007) contended that support delivered and received between siblings is affected by age. For instance, siblings in mid to late adulthood stage are more inclined to provide emotional and instrumental supports as well as offering small services (Descartes, 2007). Descartes (2007) further acknowledged that although there is an existing body of literature focused on sibling research, issues on race and ethnicity related to sibling relationships and exchange has largely been ignored. Nevertheless, what was been uncovered were mixed findings on culture and race with respect to siblings' exchange supports to one another (Descartes, 2007); the quality of sibling relationships, and the caregiving experience (Cothran et al., 2015; Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015).

Researchers estimated that daughters provided approximately 70% to 80% of filial caregiving supports (Willyard et al., 2008). The higher caregiver representation may be attributed to societal norms that dictate gender roles and daughters who experience a strong sense of duty and obligation to an elderly parent (Friedemann & Buckwalter, 2014). For instance, Tao and McRoy (2015) noted that family caregivers often assist an ailing older individual with ADLs and IADLs. However, daughters were found to be more consistent with their caregiving, provide more caregiving hours, and deliver a wider range of supportive care which included ADLs and IADLs (da Silva Falcão et al., 2016). To mitigate stressors, a daughter serving as the primary caregiver may distribute caregiving tasks among her siblings (da Silva Falcão et al., 2016).

Caregiving and Sibling Relationships

Sibling relationships are typically the longest and unique type of intimate relationship an individual will endure during his or her lifetime (Shalash, Wood, & Parker, 2013; Thomas, Liu, Umberson, & Suitor, 2017). Close to 90% of people in the Western part of the world may have either a sibling who is biologically related through both sets of parents or one, have a step-sibling, or an adoptive sibling or (WHO, 2012). Hall and McNallie (2016) discussed kinship, support, comradery, love, a feeling of closeness, proximity, and shared background as the seven reasons that may draw and maintain sibling connectedness throughout adulthood. According to Hindman, Riggs, and Hook (2013); McHale, Updegraff, and Whiteman (2012), in childhood, siblings may function as role models or teachers, but as they transition into early and late adulthood, siblings become a source of support and emotional exchange. Furthermore, Myers and Goodboy (2010) noted that some adult children expressed their sibling relationships in a positive manner. This favorable assessment of a sibling relationship typically occurs when exchanges are deemed equitable (Myers & Goodboy, 2013).

A sibling relationship is a multifaceted bond that fluctuates between conflict and partnership (Amaro & Miller, 2016). Nevertheless, adult siblings will need to coordinate care supports of their aging parents (Ingersoll et al., 2003a). Also, this type of kinship plays a significant role in the emotional health for siblings in adulthood (Gilligan et al., 2017) since the nucleus of the sibling relationship extends to a mutual feeling of obligation of care towards elderly parents (Lashewicz & Keating, 2009). Moreover, Esandi, Nolan, Alfaro, and Canga-Armayor (2017) noted that this may be the case when redefining daily family roles. Although adult siblings are not required to work together, an emerging family crisis may promote reliance between siblings (Tolkacheva et al., 2010). For instance, when a life event such as becoming an AD caregiver affects one sibling then other family members are affected (Amaro & Miller, 2016). Furthermore, opportunities of caregiving may encourage adult children toward providing supports to a parent (Tolkacheva et al., 2010).

Matthews and Rosner (1988) outlined five principal types of sibling caregiving: (a) routine care-when an adult child provides ongoing care to the care recipient, (b) back up care-when the primary adult child caregiver may request help from a sibling with managing routine care assistance, (c) circumscribed care-limited caregiving on the part of siblings, (d) sporadic care-occurs on an inconsistent basis or whenever the sibling or adult child becomes available, and (e) dissociation care-when siblings are no longer involved and cannot be counted on to provide supportive care. In a study on caregiver burden, social network, and the adult child caregiver; Tolkacheva, van Groenou, de Boer, and van Tilburg (2011) posited that an adult child serving in the role of the primary caregiver may experience lower stress levels when responsibilities are distributed among other family members for an extended period and can be accomplished without conflicts. However, McGrew, Heston, Kelly, and Hicks (2018) asserted that filial caregiving should not be weighted as an always equally distributed task. Nevertheless, for Tolkacheva et al. (2011), the actual contribution of care is crucial in determining if the adult child caregiver's social network is helpful.

Furthermore, siblings can express their cooperation by offering instrumental and emotional aid to the caregiver (Tolkacheva et al., 2011) added that the extension of support to the adult child caregiver could be executed through instrumental and emotional support. In other words, a supportive network not only helps in alleviating some caregiving hours from the adult child caregiver but also can aid in reaching an understanding of shared responsibilities so that he or she does not have to assume sole responsibility (Tolkacheva et al., 2011). Szinovacz and Davey (2013) conducted a two-year study investigating the involvement of care and the occurrence of adult offspring switching their role as a primary caregiver. They found that nearly 25% of adult offspring continued to provide ongoing primary care supports, 15% changed roles, while many adult children never assumed the role of caregiver (Szinovacz & Davey, 2013). Szinovacz and Davey (2013), also indicated that the more offspring the care-recipient had, the less likely there were going to be changes with a primary caregiver. Additionally, daughters and adult offspring living in close proximity often assumed the role as primary caregiver (Szinovacz & Davey, 2013).

In gathering data from a longitudinal study, Pillemer and Suitor (2013) found that adults viewed the role of caring for a parent as a shared responsibility between his or her siblings. Keeping that in mind, Grigoryev (2017) postulated that daughters are of the belief that caregiving tasks are to be divided amongst other female siblings, while sons anticipate his sisters will assume the role a lead caregiver. In essence, male and female siblings possess divergent beliefs relating to the way in which parents are supported (Grigoryev, 2017). When the family structure consists of both male and female offspring, daughters are expected to naturally accept the role of caregiver (Grigoryev, 2017). Furthermore, daughters functioning in the role of parental caregiver rarely relied on support from other siblings, especially a brother (Grigoryev, 2017). However, when a son assumes this responsibility, they tend to seek their female siblings for primary assistance (Grigoryev, 2017). As a consequence of being the primary supplier of parental care, female siblings are more vulnerable to experiencing unfavorable outcomes than their brothers (Grigoryev, 2017).

Despite this trend of daughters rarely seeking supports from other siblings, the lack of request for support does not nullify their siblings from filial responsibilities (Turcic & Hughes, 2004). According to Turcic and Hughes (2004), siblings are designated as secondary caregivers. Therefore, the primary caregiver has to negotiate the distribution of tasks among family members which according to (Kwak et al., 2012) may bring about conflicts and discord. The purpose of their study was to investigate the effect of caregiving has on couples who are competing with other responsibilities such as work life, parenthood, responsibilities to a spouse or partner, and caregiving to an elderly parent (Ingersoll-Drayton et al., 2003b). Initially, there was no particular interview questions related to caregiving and sibling relationships or the distribution of care supports (Ingersoll-Drayton et al., 2003b). However, a total of 45 interviewees from the focus groups spontaneously began discussing the issue of caregiving, sibling relationship, and equity (Ingersoll-Drayton et al., 2003b). There were six emerging themes highlighted from the transcripts: (a) equality and inequality, (b) negotiating of caregiving, (c) previous changes in duties, (d) anticipated changes in duties, (e) siblings engaging in support exchanges, and (f) and overall feelings related to his or her siblings (Ingersoll-Drayton et al., 2003b).

Framed by the equity theory, the authors used two components such as actual and psychological equity to inform the purpose of the study (Ingersoll-Drayton et al., 2003b). They uncovered that nearly two thirds of caregivers believed caregiving with a sibling was inequitable or unfair while one third believed care was equitable (Ingersoll-Drayton et al., 2003b). Participants expressed a variety of emotions that included anger over the imbalance of care and guilty that they even experienced negative thoughts regarding their siblings (Ingersoll-Drayton et al., 2003b). The authors were able to highlight how the perception of unfairness, inequality or unfairness may lead to distress and how the adult child caregivers will seek redress (Ingersoll-Drayton et al., 2003b). To restore balance, the adult child caregiver may employ negotiation of actual equity to mitigate negative emotions or conflict with siblings (Ingersoll-Drayton et al., 2003b). The act of balancing actual equity may include behavioral changes such as siblings making more visits to the parents or offering monetary assistance (Ingersoll-Drayton et al., 2003b). Another way

Ingersoll-Drayton et al. (2003b) noted that caregivers could frame psychological equity was to modify his or her perception of what constitute fair-share responsibilities (Ingersoll-Drayton et al., 2003b). In other words, changing the way one perceives equity may be steered by a self-awareness evaluation (Ingersoll-Drayton et al., 2003b). Although this study added to the body of existing knowledge on caregiving, there are some notable limitations. First, the study lacked diversity where the sampling universe consisted of White caregivers (Ingersoll-Drayton et al., 2003b). Second, sibling caregivers and equitable care of an aging parent were not the original purpose of the study. Therefore, further research should be intentional in designing a study addressing sibling care supports and equity (Ingersoll-Drayton et al., 2003b). Third, there is a need to expand research that includes the perception of equity among siblings or sibling serving as secondary caregivers (Ingersoll-Drayton et al., 2003b). Fourth, the authors recommended a need to incorporate a different type of instrumentation approach as an in-depth interview rather than a focus group (Ingersoll-Drayton et al., 2003b).

Extending on earlier work by Ingersoll-Dayton et al. (2003b); Amaro and Miller (2016) presented a qualitative study exploring the perception of the caregiving experience from the perspective of the primary adult sibling caregiver. Twenty participants were recruited to provide their perspective as a primary caregiver. Through open-ended questions, the participants’ responses included division of caregiving duties among siblings, how they assumed the role of caregiver, and feelings of gratitude or ingratitude towards and from siblings. The researchers found that accepting the role of a primary caregiver required a considerable amount of time, energy, and financial responsibility that could profoundly affect the caregiver’s relationship with his or her own family. Furthermore, caregiving of an aging parent is a responsibility that should not be assumed by one person (Amaro, 2016).

Subsequent research by Amaro (2017) found that the challenge of decision-making coupled with the pressures of various parental caregiving tasks may impede the sibling relationship. Some siblings may find that forging a cohesive bond on how to best manage parental care may be challenging given the contentious environment (Amaro, 2017; Amaro & Miller, 2016; Halliweel et al., 2017). On the other hand, siblings may offer support and gratitude throughout the transition which may result in a more cooperative caregiving atmosphere (Amaro, 2017; Amaro & Miller, 2016; Halliweel et al., 2017). Halliweel et al. (2017) conducted a narrative research by employing the Communicated Narrative Sense-Making conceptual framework. Using the Communicated Narrative Sense-Making conceptual framework, the authors were able to explore narratives of caregiving experiences expressed by the adult child parental caregiver (Halliweel et al., 2017).

Participants consisted of 20 adult-filial caregivers who provides or has provided supports to an elderly parent (Halliweel et al., 2017). Participants were between 41 and 66 years of age and had one to six siblings (Halliweel et al., 2017). The participant’s care-recipient parents ranged in age between 70 and 99 years (Halliweel et al., 2017). Over half the participants noted their siblings were somewhat engaged in caregiving duties, 15 participants reported to shared caregiving duties with their siblings, while five reflected on their caregiving experiences when there their parents were alive (Halliweel et al., 2017). Data collection was conducted by using in-depth interviews with siblings face-to-face or by telephone (Halliweel et al., 2017). Siblings were able to reflect and narrate their experiences related to caregiving such as the need to provide care to one parent or both, dividing caregiving duties among siblings, decision-making, and how parental caregiving has affected their sibling bond (Halliweel et al., 2017). Responses were audio recorded and transcribed verbatim, and a thematic analysis was used to identify codes and categorize themes (Halliweel et al., 2017). The researchers uncovered three overarching themes: (a) narrative of inequality or unequal involvement of care, (b) narrative of ideal care versus real care-related issues, and (c) narratives of relational growth and challenges (Halliweel et al., 2017).

The authors revealed that through narration or storytelling, the adult offspring was able to make sense of the many challenges faced in parental caregiving with their siblings who furthered the need to perform equitably, express gratitude for contributions that other siblings may perform, and the need to express empathy (Halliweel et al., 2017). Although the findings from this research have strong implications underscoring the need for family systems support to guide family caregivers towards an equitable and communicative relationship; additional research is warranted to incorporate diverse ethnic groups. Halliweel et al.'s (2017) research share some similarities with McGrew et al. (2018) particularly in communication within the family system. In the mixed methods research by McGrew et al.'s the aim was to investigate communication and care arrangements of older individuals with care needs due to a disability. They contended that planning care is ultimately a result of family members mutually relying on each other to reach a resolution (McGrew et al., 2018). Additionally, it was their position that poor communication and decision-making among family members are consequences of an unbalanced dependence on the adult child functioning as the primary caregiver (McGrew et al., 2018).

The authors further posited the following: (a) perceptual incongruence related to who, what, and how care is to be provided; (b) objectives and predilections towards care; (c) decision-making that fails to include input from some members during the process; and (d) failure to discuss or acknowledge transactions, costs, benefits, and exchanges are four types of communication issues that may steer towards an dereliction of normative care expectancies as well as an imbalance of care and support planning (McGrew et al., 2018). McGrew et al. (2018) noted these four issues were critical in their strategy of correcting communication challenges to address more balance or fair care and support planning. In examining perceived and actual equity, the authors' delineated distress regarding equity is a feeling of resentment, hostility, or frustration when an individual perceives he or she is over-benefited or under-benefited (McGrew et al., 2018). To mitigate feelings of distress, McGrew et al. suggested that a small gesture of exchange such as socioemotional support or financial assistance may help in redressing fairness.

Namkung et al. (2017) conducted a study among sibling caregivers examining if mental health and positive attitude were affected by caregiving and if race was a moderator. The authors identified sibling caregivers as individuals who supported a brother, sister, sister-in-law, or a brother-in-law (Namkung et al., 2017). Namkung et al. examined the well-being of this group in comparison to non-caregivers, and other types of caregivers such as adult child caregivers, spousal caregivers, and parental caregivers. From their research, they found significant differences among the five groups concerning life satisfaction, depressive symptoms, reported physical health, and perceived control.

Summary

Although there is existing literature on AD caregivers, there is a paucity of available information on African American adult filial caregivers and sibling relationships. Therefore, this current study may fill a gap in existing literature by offering information about how sibling relationships may be affected among African American adult filial caregivers of a parent with AD. Although the physical and emotional well-being of caregivers are areas of concern; caregivers have expressed difficulty with their social and intimate relationships (Amaro, 2017).

For instance, sibling relationships may also be a source of conflict (Amaro, 2017). However, siblings can also be a supplier of support, affection, and they can safeguard against risk factors often associated with caregiving (Amaro, 2017). I used a generic qualitative methodology to explore and offer some insight into the experiences and challenges that African American adult filial caregivers may encounter among their sibling relationships. Chapter 3 contains a description of the research methodology, a discussion of data collection, analysis, issues of trustworthiness, and ethical consideration.

Chapter 3: Research Method

Introduction

The purpose of this study was to explore the sibling relationships of African American adults who assumed the role of primary caregiver of a parent with AD. the results of this study may provide evidence that may assist geriatricians, gerontologists, hospital administrators, local policy-makers, and other invested healthcare stakeholders in developing and implementing effective tools meeting the demands of adult-child caregivers who have assumed the role of caregiving and other members within the family network. In Chapter 3, I present the research design and rationale, the research question, my role as the researcher, methodology, procedures used to collect and analyze data, ethical considerations, and informed consent.

Research Design and Rationale

Quantitative and qualitative research are two types of designs used in various fields, such as education, social science, physical science, and health science (Anderson, 2010; Antwi & Hamza, 2015). Antwi and Hamza (2015) indicated these two research methodologies are long considered to possess fundamentally different worldviews views. Leung (2015) noted that establishing rigor is an essential element for quantitative and qualitative research designs. Malagon-Maldonado (2014) postulated that while the objectives in a quantitative study are to determine sampling size, measure or quantify data, and generalize to a larger population, the qualitative method is used when there is limited scholarship about a topic, there are not many instruments to quantify the phenomena under exploration, or when the purpose of the study is to grasp the participants' viewpoint.

In the healthcare field, a qualitative research approach may be a useful method to explore how healthcare environments can be augmented to promote better outcomes for individuals receiving and delivering care and to advance knowledge of research-based interventions (Malagon-Maldonado, 2014). Researchers employing a qualitative methodology embrace how knowledge is intersubjectively formed through culture and historical background (Davidsen, 2013). Furthermore, qualitative studies may provide a depth of understanding that may not be addressed from a quantitative study when addressing the *how* and *why* of a phenomenon (Ramadhan, 2015). This may be the case when exploring symbols, a set of principles, exploring interpretations, or characteristics (Ramadhan, 2015). Anderson (2010) argued that it is imperative that researchers decide on the most suitable method for inquiry. Keeping that in mind, qualitative research may not be the most appropriate design to address every research question; hence, researchers should first consider the objectives of the inquiry (Anderson, 2010).

I found the qualitative method to be appropriate for this topic of inquiry on caregiving and sibling relationships because of its person-centered approach (see Malagon-Maldonado, 2014). Additionally, qualitative researchers are active instruments who observe, interact, and attempt to make sense of the essence of a participant's lived experiences with a phenomenon (Matua & Van Der Wall, 2015; Patton, 2015). Qualitative research encompasses the utilization of subjective data to gain further insight to provide clarification of an event rather than to establish an exact causal relationship (Sutton & Austin, 2015).

I selected a generic qualitative research design since prior knowledge about this topic of inquiry may be increasingly informed by the participants' viewpoint (see Percy et al., 2015). Generic qualitative researchers are epistemological, social constructivists whose focus is to make sense of: (a) how individuals understand personal experiences, (b) how individuals form their environment, and (c) what meaning individuals assign to the experienced phenomenon (Kahlke, 2014). Generic qualitative research is not bound by a collection of philosophical suppositions or procedures that the more commonly used methodologies such as grounded theory, phenomenological, narrative, or case study are (Kahlke, 2014). In other words, a generic qualitative study is not committed to one conventional methodology (Kahlke, 2014).

Research Question

For this current study, the research question was: How does an African American adult offspring who assumed the primary family caregiving role and responsibilities for their parent with AD perceive his or her relationship with a sibling?

Role of the Researcher

Researchers employing a generic qualitative design are seeking to gain an understanding of a person's worldview or perspectives, an event, or a process by employing congruent techniques and designs (Cooper & Endacott, 2007). Therefore, I collected data through one-on-one interviews with research participants in this study. I methodically collected and structured information based on the approach selected for this study. I also maintained a record of the data and upheld a neutral position throughout this process. I conducted periodically self-evaluations to monitor and alleviate any presence of personal bias.

For this study, my role was that of an active interviewer, gathering data from participants about their life experiences. I used open-ended questions and made use of prompts to extract the data-rich information from the participants. I embraced my subjectivity by recognizing and admitting my past and current personal experiences with the topic under exploration. To mitigate affecting the research, I was routinely reflexive by examining personal beliefs, social background, characteristics, and experiences (see Palaganas, Sanchez, Molintas, & Caricativo, 2017).

I currently live within the greater metropolitan area in the southeastern United States where the study was located. During the duration of this study, I did not function as a mental health provider or a gerontologist; instead, participants came to know my capacity as a doctoral student. Several years ago, my paternal grandfather received an initial diagnosis of AD at 88 years old. As a distant observer, I was able to see how he was cared for in a home-based setting by his children. Given the prior history that I have to this topic of inquiry, my personal experience may have had the potential to bias the research process; however, to alleviate researcher bias, I employed a reflexive journal to aid in managing any personal biases related to AD and caregiving throughout the various stages of the research process.

Methodology

In this section, I used generic qualitative approach to explore the perspectives of African American adult filial caregivers. This generic qualitative study was an exploration of the primary caregivers' perspective on sibling relationships during their caregiving experience of a parent diagnosed with AD among African Americans. I used semistructured interviews with African American adult filial caregivers where they retrospectively reflected on their experiences. A generic qualitative study considers people's account of their subjective thoughts, worldviews, beliefs, or reflections on their encounters of their outward environment (Percy et al., 2015).

Instrumentation

Instrumentation for this study included an audio recorder for each interview as well as observation notes taken by me. I prepared interview questions (see Appendix A) seeking to elicit the perspectives of African American adult filial caregivers. The interview questions addressed how African American adult filial caregivers experienced sibling relationships as they provided primary care to an elderly parent with AD.

Sampling Size

In this study, the sampling included recruitment of African American adult filial caregiver population. When determining a sampling size, qualitative researchers should think about the following factors: (a) the scope and nature of the research, (b) whether the topic under exploration is clearly stated, (c) the quality of the information, (d) the research design, and (e) timeframe (Mason, 2010). Although Dworkin (2012) suggested that sample size could be small or large, Clearly et al. (2014) and Malterud, Siersma, and

Guassora (2015) advised that with a clear and concise research topic and a small, purposefully chosen, homogeneous participant pool, a researcher may extract relevant data for analysis. Bowen (2008) and Marshall, Cardon, Poddar, and Fontenot (2013) advised that data saturation is difficult to express as an element in a qualitative study given the absence of universal methods. Furthermore, they noted a scarcity of published, universal practices for assessing the sampling size needed to promote saturation (Bowen, 2008; Marshall et al., 2013). In this study, I accepted a minimum sample size of eight participants and interviewed a total of 10 persons. The process of collecting and analyzing data concluded when no new information, new themes, or codes could be gained, and data became redundant (see Bowen, 2008; Guest, Namey, & McKenna, 2017; Mason, 2010).

Selection of Participants

Bradshaw, Atkinson, and Doody (2017); Etikan, Musa, and Alkassim (2016); and Rudestam and Newton (2015) noted purposive sampling is a predetermined, nonrandom identification of shared characteristics among potential participants who possess a unique experience or perspective on a topic. In addition, purposive sampling is also used to gain information-rich data (Etikan et al., 2016) where recruiting participants can be promoted through shared social networks (Rubin & Rubin, 2012). Palinkas et al. (2015) acknowledged that merging sampling approaches may be suitable for addressing the goals of a study. In this study, I used a purposive sample in conjunction with snowball sampling to recruit potential participants. The goal was to recruit participants who possessed relevant information given their experiences related to the phenomenon under exploration.

In this study, I recruited African Americans between the ages of 45 to 65 years old, who had one or more siblings, and currently provided or had provided parental caregiving to an elderly parent with AD. Chiriboga, Jang, Molinari, Kim, and Ko (2014) stated that adult offspring not only reported the greatest burden when assuming the caregiver role, but they were also the largest caregiver group to individuals with AD. Paulson and Bassett (2016) further revealed that filial responsibility peaks during the adult offspring's midlife, which is a time denoted by the heightened care needs of an aging parent.

Participants were recruited in one county within in a southeastern U.S. metropolitan area. I provided the director of an adult senior center with an informational letter along with flyers requesting the organization's support. In the information letter, I outlined the selection criteria for participant recruitment and provided information about this study. With permission from the director of the adult senior center, I recruited participants through the dissemination of flyers and by word of mouth. My cell phone number and e-mail address were listed on the flyer as the point of contact. Participants who fit the selection criteria of the study and were available then arranged a time to conduct the semistructured individual interviews. Furthermore, I asked initial interviewees to use their social relationships and connections to recruit others who may fit the criteria for participation.

Inclusion Criteria of Caregiver

The inclusion criteria for selection was that potential participants must be: African American, an adult offspring who currently provided or had provided caregiving supports to an elderly parent with AD, between 45 year to 65 years of age, had assumed the role of a primary caregiver, had one or more siblings, currently provided or had provided supports in a home-based setting, spoke fluent English as a primary language, had provided care for at least 6 months, and had a parent with a formal diagnosis of AD. Potential participants may have performed the following caregiving responsibilities: (a) bathing, (b) walking, (c) feeding, (d) transportation, and (e) maintaining health provider's appointment and other schedules. Additionally, the elderly parent should be between the ages of 70 to 99 years of age (see Halliweel et al., 2017).

Exclusion Criteria of Caregiver

I excluded participants from this study if: the parent resided in an assisted-living facility; participants were unable to speak fluent English; they were an only child; they were under the age of 45 years old; or their elderly parent suffered from another form of dementia, such as dementia with Lewy bodies, Parkinson's disease, mild cognitive impairment, Wernicke-Korsakoff syndrome, normal pressure hydrocephalus, Creutzfeldt-Jacob dementia, frontotemporal dementia, mixed dementia, vascular dementia, or Huntington's disease.

Data Collection

According to Ramadhan (2015), the objective of qualitative research is to offer a description of a person's attitude, sentiment, and personality traits which are something that cannot be obtained through a quantitative study. For this study, I selected an in-depth semistructured interview, so participants could reply to the open-ended questions as they desired (McIntosh & Morse, 2015). Furthermore, I made use of an interview guide and I followed-up with probing questions (Jamshed, 2014). When appropriate, I used prompt questions as a useful technique to maintain the flow of the interview to elicit deeper level responses from interviewees without affecting their answers (Whiting, 2008). Jacob and Furgerson (2012) noted that interviews should be conducted in a quiet semi-private space. Therefore, interviews were conducted in a quiet setting such as a private conference room at the local library. I wanted a location where participants felt comfortable enough to disclose their experiences in an open and honest manner. The interviews took place at a time that was convenient for the participants. Additionally, if an interviewee requested the interview to occur via telephone, I positioned myself in a private location where human traffic was limited.

Invitation letters were distributed to potential participants, and for the interview I discussed the inclusion criteria, the purpose of the study, and I read and discussed Informed Consent. During this time, I encouraged and addressed any questions about the research and the interview process. Subsequently, participants completed the Informed Consent form. I made a copy of the form, kept one for my records and provided the other copy to the participants. An interview may be an emotionally taxing event; therefore, if a participant expressed discomfort, I would have ended the meeting. If it became necessary to stop the interview, I would have offered the participant the choice to reconvene the interview for a later time or stop and withdraw from the research. I made every effort to cultivate a setting in which participants felt safe enough to disclose their experiences and perspectives without feeling judged. Again, I reminded participants that they had the right to withdraw from the process at any time throughout the interview process without repercussions.

The construction of the interview questions was aligned with the exploration into the experiences of the adult filial caregiver. Therefore, the interview questions were designed to collect data relevant to answer the research question. I expected the interviews to take 45 to 60 minutes to complete. Furthermore, I audio recorded and transcribed verbatim the responses of each participant which diminished the possibility for bias or misinterpretation. To protect the privacy and identification of the interviewees, I assigned numerical codes. Namageyo-Funa et al. (2014) recommended that for the protection of participants, numerical codes could be used. Additionally, the transcribed interview data and audio recordings were placed in a locked and secured file cabinet in my home office that can only be accessed by me. For this study, participants received a thank you note along with a $10.00 gift card.

Informed Consent

Before the individual interviews, I gave the informed consent to the 10 participants which informed them of the purpose of the study, interview process, and follow up for further communication. I informed interviewees of their rights and the voluntary nature of the study. Additionally, interviewees were informed of the measures taken that supported confidentiality. Furthermore, I also discussed the benefits and potential harm that may occur when participating in this study. Holt (2010) posited that the level of risk to a participant should be reasonable and safeguards should be taken to mitigate any adverse feelings. Following this presentation of the informed consent forms, I allowed the interviewees time to read and sign forms. Subsequently, I collected the consent forms and stored them in a locked and secured cabinet in my home office.

Debriefing

Debriefing served as a useful method for addressing participants in distress. For instance, a few participants became emotional as they recounted their experiences during the interview while other participants felt talking to someone about their caregiving experience would be helpful. Therefore, I provided a referral list to counseling services or other types of support groups at no cost to the participant and asked if there were any questions. Additionally, I advised each participant that a written transcript of his or her interview was available upon request.

Confidentiality

For this study, I maintained confidentiality by replacing participant's identifying information with a numerical code on materials related to this qualitative study. I advised participants that personal identifiers such as their name and other identifying information would be altered and only the researcher would have access to their responses. Audio recordings, transcripts, consent forms, and my journal were stored in a secured locked file cabinet in my home office. This secured locked file cabinet can only be accessed by me since I have sole possession of a key. Furthermore, the data stored on my desktop computer was password protected. As a back-up, I saved the data on a Universal Serial Bus flash drive and stored in locked file cabinet. After 5 years, the data collected for this study whether electronic or hard copied will be permanently destroyed, shredded, or deleted. The Universal Serial Bus flash drive will be physically destroyed, hard copies will be shredded, and materials stored on my desktop will be permanently deleted. Additionally, I provided a private setting in which participants willingly shared their personal experiences. Therefore, face-to-face individual interviews were held in a closed-door conference room located in the local library. Also, phone interviews were held in the privacy of my home office.

Data Analysis Plan

Braun and Clark (2006) asserted that thematic analysis is frequently utilized in qualitative studies. Therefore, I utilized Braun and Clarke's six stages of thematic analysis after collecting and transcribing the data. The six stages include the following: (a) become familiar with the data, (b) generate initial codes, (c) search for themes; (d) review themes, (e) define and name themes, and (f) write-up. Saldana (2016) contended that a code is a word or short phrase that captures the essence of text or visual data sources and is the initial process in data analysis. I read and reread the written transcripts to obtain codes and themes. Also, given the small sample size for this study, I coded manually. In applying Saldana's suggestion, a technique of highlighting codes and themes was utilized to assess the information. Furthermore, I employed first level coding which was a line-by-line analysis of each transcribed interview (Saldana, 2016). Therefore, the codes drawn from this step revealed concepts and categories within the transcribed data.

Issues of Trustworthiness

Colorafi and Evans (2016) and Morse (2015) not only posited that confirmability and dependability were closely connected, but the authors also outlined the following techniques that supported trustworthiness in a qualitative research study: credibility, transferability, dependability, and confirmability. To maintain rigor and address the issues of trustworthiness of this generic qualitative study, I employed multiple techniques. Since I was the chief instrument throughout the research process (Fusch & Ness, 2015), being transparent was one way to promote trustworthiness (Rubin & Rubin, 2012). Therefore, I maintained a reflexive journal throughout the research process to help evaluate and manage my beliefs, personal experiences, and biases related to AD and caregiving.

I addressed dependability by noting a detailed description of the research design that included data collection, analysis, reflexive journal, and an audit trail. For instance, I included a journal for self-assessment and an audit trail. Cope (2014) noted that an audit trail establishes trustworthiness through a comprehensive recording of the data collection process, the development of codes and themes, transcripts, assumptions, and the decision-making process experienced throughout the study.

Credibility

Credibility includes incorporating a few techniques to enhance the likelihood that credible and accurate findings generate from the data (Houghton, Casey, Shaw, & Murphy, 2013). To address credibility, I included audit trail and member checking (Houghton et al., 2013). I conducted a face-to-face interview with participants to add further insight into experiences related to sibling relationships during their time as the primary caregiver. The allotted timeframe for the interview was approximately 45 to 60 minutes. Audit trail was an approach where I maintained an in-depth record of the study. The record included the interview protocol, notes, and my reflexive journal (Houghton et al., 2013; Nowell, Norris, White, & Moules, 2017). By undertaking this approach, I was able to illustrate that the research results were constructed from the participants' narratives which involved a thorough description of how I collected and analyzed the data. Member checking encompassed participants confirming and validating the accuracy of the transcribed interview. Because of my acquaintance with AD caregiving, I used reflexivity to detect areas of potential bias. Therefore, I maintained a reflexive journal throughout the research process.

Member checking

Member checking (see Appendix B) was critical as I requested the aid of the respondents during the interview process for accurate accounting of their responses. I used member checking to promote trustworthiness since study participants possessed the experience, the reason for the occurrence, and a first-hand rich description of how they responded to the event (Loh, 2013). During member checking, each participant had an opportunity to correct any errors or challenge possible misinterpretations or distortion of their responses (Cope, 2014; Morse, 2015). After participants checked for accuracy, I started analyzing the data.

Transferability

Cope (2014) noted that transferability occurs when the results of the research can have meaning in other circumstances. In other words, the findings can be applied to similar situations because readers were able to make meaningful, informed connections (Anney, 2014; Cope, 2014). Furthermore, I established transferability through a thick, rich description where detailed accounts permitted readers to identify with the phenomenon (Bradshaw et al., 2017). Also, I fostered transferability by providing a detailed description of participant's demographics, data gathering techniques, and data analysis. By providing a descriptive outline of the research process along with participants' narratives, future scholar-practitioners may be able to replicate similar research.

Dependability

Colorafi and Evans (2016) noted that researchers may promote dependability by being consistent throughout the research process. Hence, I promoted dependability by utilizing reflexive journaling, audio recordings to capture the accounts of the participants, a transcription of the interview, and a rich description of the research protocol. The measures taken were necessary so that the study can be replicated by other scholars using similar interviewees and techniques in the same situation (Cope, 2014). To establish dependability and mitigate errors, I assessed and reassessed the written transcripts and repeatedly listened to the digitally recorded statements.

Confirmability

According to Tobin and Begley (2004), establishing confirmability occurs when the results come from the data and not from the investigator. In other words, when researchers accurately transcribe and analyze participant’s responses, they enhance neutrality and objectivity (Tobin &Begley, 2004). For this study, the process of confirmability occurred when I digitally recorded participant’s responses, transcribed their accounts verbatim, and provided participants an opportunity to verify the accuracy of their accounts. Consequently, I was able to capture and analyze the participants experiences in their own words. Furthermore, I utilized an audit trail which included the interview protocol, notes, and my reflexive journal as a method to not only document for replication but to address the rationale behind my analytical decisions (Houghton et al., 2013; Nowell et al., 2017). As the active instrument for this project, I utilized a reflexive journal as a tool to assess and manage biases related to AD caregiving and to be transparent with my decision-making throughout the research process.

Ethical Consideration

Before conducting this study, I submitted required documents to secure approval from Walden’s Institutional Review Board. I established that federal guidelines were adhered to along with the ethical protection of participants. Sanjari, Bahramnezhad, Fomani, Shoghi, and Cheraghi (2014) noted that in establishing trust, deference, and safeguards that protect interviewees from harm, researchers must be committed to avoiding deceptive practices that misrepresent the intention or benefits of the study. One essential element when conducting ethical research is informed consent (Sanjari et al., 2014). It is important in the beginning stages of a research study to offer a thorough description of how data will be collected and utilized (Sanjari et al., 2014). For this study, I informed participants of their rights throughout the process and informed them that participation was completely voluntary. Furthermore, I clarified in comprehensible language, the purpose of the research, the role of the participant, the role and identity of the investigator, and how the findings would be published (Sanjari et al., 2014). Additionally, the consent form included the purpose of the study, benefits of the study, potential harm, the recruitment process, the significance of the study, confidentiality, and disclosure that participants can withdraw at any time.

For this project, I took considerable precaution to adhere to the ethical standards and rigor outlined by Walden University's Institutional Review Board (IRB). Given that the well-being and confidentiality of the participants were vital to the success of this qualitative study, informed consent, permission to audiotape, and confidentiality agreements were incorporated as part of the data collection, process. Following data collection, I preserved the transcribed data on a password-protected desktop computer located in my home office. Additionally, if a participant requested a phone interview, I took the necessary measures to conduct a private interview in a quiet setting. Finally, I will purge, shred, or delete data collected for this study whether electronic or hard copied following a 5 year waiting period per Walden University's guideline.

Summary

For this chapter, the study's site, data collection, the process of analyzing data, trustworthiness, and ethical considerations were discussed at length. In Chapter 3, I offered a comprehensive overview of generic qualitative research design and a rationale for selecting this approach. Additionally, I utilized a semistructured interview guide as an aid in helping to explore participant’s experiences with their siblings as the caregiver for an elderly parent with AD.

Chapter 4: Results

Introduction

The purpose of this generic qualitative study was to explore sibling relationships of African American adult filial caregivers of a parent with AD. As the researcher, my goal was to understand the adult filial caregivers' perspectives of their sibling relationships when providing filial care. In this study, data saturation was reached with 10 participants. The participants' responses to semistructured, open-ended interview questions resulted in emergent themes describing the experiences of their sibling relationships during filial caregiving. When combined with other research, the results of this study may promote the implementation of family-centered interventions and strategies that are specific to the caregiving experiences of African American filial caregivers. This chapter contains: (a) the research study settings, (b) a description of the study participants, which includes demographics and characteristics, (c) the data collection process; (d) data analysis, (e) evidence of trustworthiness, and (f) results and a summary.

Research Setting

Researchers employing a generic qualitative design are seeking to understand people's worldviews or perspectives of a phenomenon (Cooper & Endacott, 2007). To extract information from participants, qualitative researchers cultivate a positive rapport and an environment that is not only private but also comfortable (Rudestam & Newton, 2015). The individual interviews in this study took place in one of the small study rooms at a local county library. However, due to a scheduling conflict and the inability to secure at-home supervision of their parent, 4 of the 10 participants requested being interviewed via telephone.

After I made an initial introduction and discussed informed consent for face-to-face interviews, I obtained signatures from the participants consenting to the study. For participants interviewed via telephone conference, I received a copy of their informed consent by e-mail. In these phone interviews, I discussed the informed consent and requested that participants return the form with their signature if they decided to participate in the study. With participants' permission, the interviews were audio recorded. All of the individual interviews were conducted with no interruptions.

Demographics of the Participants

The participants in this research were African American adults who assumed the primary caregiver role for a biological parent with AD and who had at least one sibling. A purposive sampling method was appropriate for this study because I specifically sought African American adult primary caregivers. The adult offspring of an AD parent serving as an informal caregiver is someone who has not been paid through a healthcare organization or agency. According to Novais, Dauphinot, Krolak-Salmon, and Mouchoux (2017), informal caregivers are typically a spouse or offspring who provides at home supports, supervision, and aid to a loved one with a cognitive impairment.

The caregivers self-identified and met the inclusion criteria of the study. There were eight female and two male respondents. Of the 10 participants, one was a widower, one had never married and was currently single, three were divorced, and the remaining five participants were currently married. Participants ranged in age from 52 to 65 years old; the mean age of the adult child caregiver was 59.8 years. One participant reported having 12 siblings, another participant reported having four siblings, three had three siblings, two had two siblings, and three participants had one sibling. These characteristics were pertinent to this research because the characteristics are congruent with the literature of the typical filial caregivers being daughters; in their 50s; Black; and sandwiched between their responsibilities at home, work, and their role as a caregiver (see Ngangana et al., 2016; Szinovacz & Davey, 2013).

Furthermore, the pinnacle of filial responsibility typically occurs during an adult's midlife, which is a time of increased care needs of an aging parent (Paulson & Bassett, 2016). In Table 1, I provide a demographic breakdown of the 10 study participants. Additionally, the use of a unique identifier allowed me the opportunity to honor the confidentiality of those participants. For the remainder of this study, I will use the assigned unique identifier when referring to the 10 participants.

Demographic Profiles of Participants

In this section, I provide a short biographical and demographic description of each of the 10 participants. The participants provided or continue to provide home-based primary care support to a parent with AD. To honor confidentiality, I removed any personal identifying information.

Participant 1

Participant 1 (P1) was a 62-year old retired educator who cared for her mother. She came from a family of 12 siblings. She was the middle child with nine brothers and two sisters who grew up poor. She lived in a self-described loving home with a strong family bond. All of her siblings resided across the United States. P1 is divorced and had one adult offspring.

Participant 2

Participant 2 (P2) was a 63-year old retired government worker who cared for her mother. She had three sisters with one living in the same southeastern U.S. metropolitan area, and the other two living in different states. P2 grew up in a two-parent, close-knit home. She was married with three sons.

Participant 3

Participant 3 (P3) was a 65-year old widower who worked as an educator at the time of the study. He cared for his father who had AD. He had three brothers and a younger sister. He grew up in a two-parent home where extended family was always present. P3 had one son.

Participant 4

Participant 4 (P4) was a 57-year old woman who worked as a secretary at the time of the study. She never married and had no children. P4 grew up in a two-parent home where her father was a career army officer. She had one sibling and cared for her mother who had AD.

Participant 5

Participant 5 (P5) was a 64-year old woman who worked as a part-time nurse at the time of the study. She had a twin sister who is the oldest and two younger brothers. She was married with two adult offspring. She grew up in a two-parent and was primarily influenced by both her grandfathers who were pastors. She cared for her mother who has AD.

Participant 6

Participant 6 (P6) was a 58-year old married woman with two adult offspring. She was the oldest child with two brothers and one sister. P6 cared for her mother. She was raised in a two-parent home centered around church and the community. All of her siblings lived within the southeastern U.S. metropolitan area where the study took place.

Participant 7

Participant 7(P7) was a 63-year old entrepreneur who was married with adult offspring and cared for her mother at the time of the study. She grew up in a time and place where her community, such as her neighbors and the church, was always present. She had a sister and a brother. Her brother lived in the metropolitan study area, and her sister lived in a different state. She was raised in a two-parent home.

Participant 8

Participant 8 (P8) was a 57-year old married man with two sisters. P8 had twins who are both married and a younger child who was currently attending college. P8 worked at home for a technology company and was hoping for early retirement. He was raised in a close-knit community in a two-parent home. Growing up, the church and community were central to his upbringing. His mother was deceased at the time of the study, and he was currently caring for his father who had AD.

Participant 9

Participant 9 (P9) was a 57-year old divorced woman with two daughters and a son. She had one brother and was currently caring for her mother. Her father passed away over 20 years ago.

Participant 10

Participant 10 (P10) was a 52-year old divorced woman with one son and three daughters. P10 was disabled and did not work a full-time job. She had a brother who was not married and no children. Her brother lived within 25 minutes from her and worked a full-time job. Her father was deceased, and she currently cared for her mother.

Data Collection

The process for collecting data began after I received official approval from the Walden University's IRB (IRB Approval Number 02-13-19-0484175). The approval from Walden's IRB permitted me to recruit and gather information. The data collection period went from February to March 2019. As the sole researcher, I was able to recruit 12 individuals who met the following criteria, they were: (a) African American, (b) an adult who was providing or had provided caregiving support to an elderly parent with AD, (c) between 45 year to 65 years of age, (d) have or had assumed the role of a primary caregiver, (e) had one or more siblings, (f) have provided or were providing support in a home-based setting, (g) spoke fluent English as a primary language, (h) had provided care for at least 6 months, (h) had a parent with a formal diagnosis of AD, and (h) had performed the following caregiving responsibilities: bathing, walking, feeding, transportation, and maintaining health provider's appointment and other schedules.

Although 12 individuals were interested in participating in the study, two withdrew due to personal family reasons. I arranged interviews with the remaining 10 potential participants at a time and date that was convenient for their schedules. Although each participant agreed to a face-to-face interview at the local library, four participants requested a phone interview because they were unable to get a family member to supervise their parent in their absence. Following my initial introduction as the researcher, I discussed the informed consent with each participant, which included the purpose of the study, risks and benefits, the procedure for reporting disclosure or suspicions of elder abuse, and confidentiality. After reviewing this information and allowing for questions to be asked by participants, I obtained their signature at the bottom of the informed consent form.

I conducted individual, semistructured interviews as a means to collect data in this study. Participants were asked the same interview questions. The use of semistructured, open-ended questions promoted data-rich responses with the African American filial caregiver’s experiences related to their sibling relationships when caring for a parent with AD. During the interviews, participants were able to describe their experiences. Some became emotional while answering the questions. For instance, there were two participants whose voices seemed to crack as they were discussing some of the caregiving responsibilities they performed. At that moment, I asked them if they needed to take a break. Both responded with a “no” and wanted to continue with the interview. Therefore, there were no other interruptions or delays during the interviews. Some of the interviews were completed in less than the scheduled timeframe of 45 to 60 minutes as outlined in Chapter 3. For instance, individual interviews lasted between 25 minutes and 48 minutes, with 40 minutes being the average length.

I debriefed participants at the end of their interviews and provided them with a list of caregiver support groups and community-based mental health services. Furthermore, I confirmed the participants' answers from the recorded interviews in order to process their responses for my documentation. Following the debriefing, I thanked each participant for their time and provided them with a $10 gift card.

I then transcribed the audio recordings with identifying information of the participants removed. Each participant received a copy of their transcribed interview, with which they confirmed the accuracy of the presented information. During this time, two participants added additional demographic information. I saved the collected data for this study on a flash drive, which was kept in a secured and locked file cabinet in my home office. I have sole possession of the key to this cabinet.

Data Analysis

The generic qualitative approach was suitable for interpreting the gathered information from the individual interviews because I am seeking to gain an understanding of a person's worldview or perspectives (Cooper & Endacott, 2007). The goal of presenting the interview questions was to elicit responses where I was able to gather in-depth data that informs the research question. I conducted in-depth individual interviews with the shortest interview lasting 25 minutes to the longest interview lasting 48 minutes. Each participant responding to the interview questions provided detailed accounts of their sibling experiences when they functioned in the role of the primary filial caregiver. The data gathered for this study consisted of 10 recorded individual interviews with each response being transcribed. The data yielded approximately 392 minutes and 10 seconds of recorded from participant's responses resulting in 1,306 lines of transcribed information. For organizational purposes, I transcribed participant's recorded responses verbatim into Microsoft Word documents within 24 hours of each interview. Although I hand-coded and highlighted phrases and frequently occurring words in the transcript, I also uploaded the participant's transcript into MAXQDA 18 for further organizational support during data analysis. By utilizing MAXQDA 18 software, I was able to further attain the most frequently occurring words, code, and identify emergent themes which were analyzed alongside the research question. While computer-assisted qualitative software can be useful in the storing and managing recorded information; the researcher is still responsible to analyze and apply meaning to the data (Houghton et al., 2015). I analyzed the data by utilizing the six stages of thematic analysis by Braun and Clake (2006): (a) become familiar with the data, (b) generate initial codes, (c) search for themes, (d) review themes, (e) define and name themes, and (f) write-up. I transcribed the data gathered from the individual interviews and during this activity, initial ideas and thoughts were recorded as it served as an essential phase in the data analysis process.

Not only did I listen to the digital recordings of the interviews several times, but I also read and re-read the transcripts numerous times. This application of repeated reading along with the use of listening to audio recordings of the data gave rise to data immersion (Braun & Clarke, 2006). Furthermore, undivided attention was given to the participants' accounts and expressions connected to their sibling relationships as a primary filial caregiver. In stage 2, I was able to identify frequently occurring words which afforded me the opportunity to begin initial coding. The third stage encompassed probing for themes. In other words, the initial codes relevant to the research question were grouped with similar codes into themes. At this time, any themes that lacked sufficient data to support them were removed. This refinement of the themes came about to foster that the coded data formed a logical pattern and that the pattern formed the themes relative to the entire data set. At the next stage, I reexamined the data to make sure no other emerging themes were overlooked. Once I felt comfortable with how the themes emerged and worked together, I transitioned to stage 5 where themes were named and defined. The last stage involved constructing a report which included choosing examples from the participant's transcript to illustrate elements of the themes. After data analysis, I identified five prominent themes that informed the research question which included: (a) perception of equity, (b) continuing a close sibling relationship, (c) strategies of communication and collaborative decision-making, (d) varying siblings supports, and (e) attitude adjustment towards caregiving and siblings. In Table 1, I provide short phrases and direct quotes from the participants, illustrating the development of themes.

Table 1

Identification of Themes

Themes	Phrases
Perception of equity	We took turns My sibling compensated that way This was an absolute shared caregiving experience I don’t expect this to be a 50-50 even split Siblings are engaged and are willing to help I wouldn’t say shared…. everyone is doing their part
Continuing close sibling relationship	I would describe my relationships with my siblings overall as good, even wonderful I think it was wonderful relationship It’s been helpful We were always a tight knit family I think to have good relationship with my siblings we must respect each other’s opinions
Strategies of communication and collaborative decision-making	We would sit as a group and make decisions about care We discussed and agreed We still disagree but we at least try to communicate and talk it through You have to talk to each other, you have to communicate Communication is key I try to keep everyone informed
Varying sibling supports	What my siblings and I did made it possible for our father to not live in a nursing home It was so important I really appreciate it because by supporting him in this way it is actually supporting me. No one has flat out refused to help care for our parents They are a great help
Attitudes towards caregiving and siblings	It is great to be supported by my siblings We all know our roles even though I am the primary caregiver I never look at what I am doing and compare it to what my siblings are doing My siblings take caregiving seriously

	I know I can depend on them. They are my rock, and I could not have done this without them

Ethical Protection of Participants

I obtained approval from Walden University Institutional Review Board before recruiting and gathering data. Furthermore, I adhered to the ethical standards and practices outlined by the IRB. I gave a detailed overview of the informed consent form to participants who met the selection criteria and who voluntarily elected to participate in the study. The informed consent included the purpose of the study, the risks and benefits, and privacy. Participants were also informed of their right to terminate their involvement at any time during the interview without repercussion. Additionally, I explained to each participant that if there had been disclosure or suspicion of elder abuse, I would be obligated to make a referral to an appropriate law enforcement agency. After this overview, I allowed time for the interviewee to ask questions. Since there were no questions, each participant voluntarily signed the informed consent form. To further establish confidentiality, I removed identifying information from the transcripts. Additionally, I secured the digital recordings, my journal, and transcripts in a locked file cabinet in my home office. I have sole access to this information.

Results

The purpose of this study was to explore sibling relationships of an African American adult who assumed the role of primary caregiver of a parent with AD. The patterns that emerged as themes from the process of moving from the data to codes and categories credibly informs the research question. In this chapter, I address the results relative to the research question. The research question was*:* how does an African

American adult offspring who assumed the primary family caregiving role and responsibilities for their Alzheimer's parent perceive his or her relationship with a sibling? The resulting themes that inform the research question are presented in Figure 1 which includes: (a) perception of equity, (b) continuing a close sibling relationship, (c) strategies of communication collaborative decision-making, (d) varying siblings supports, and (e) attitudes towards caregiving and siblings. Furthermore, I have included passages from the participants' responses, where developed themes support the findings.

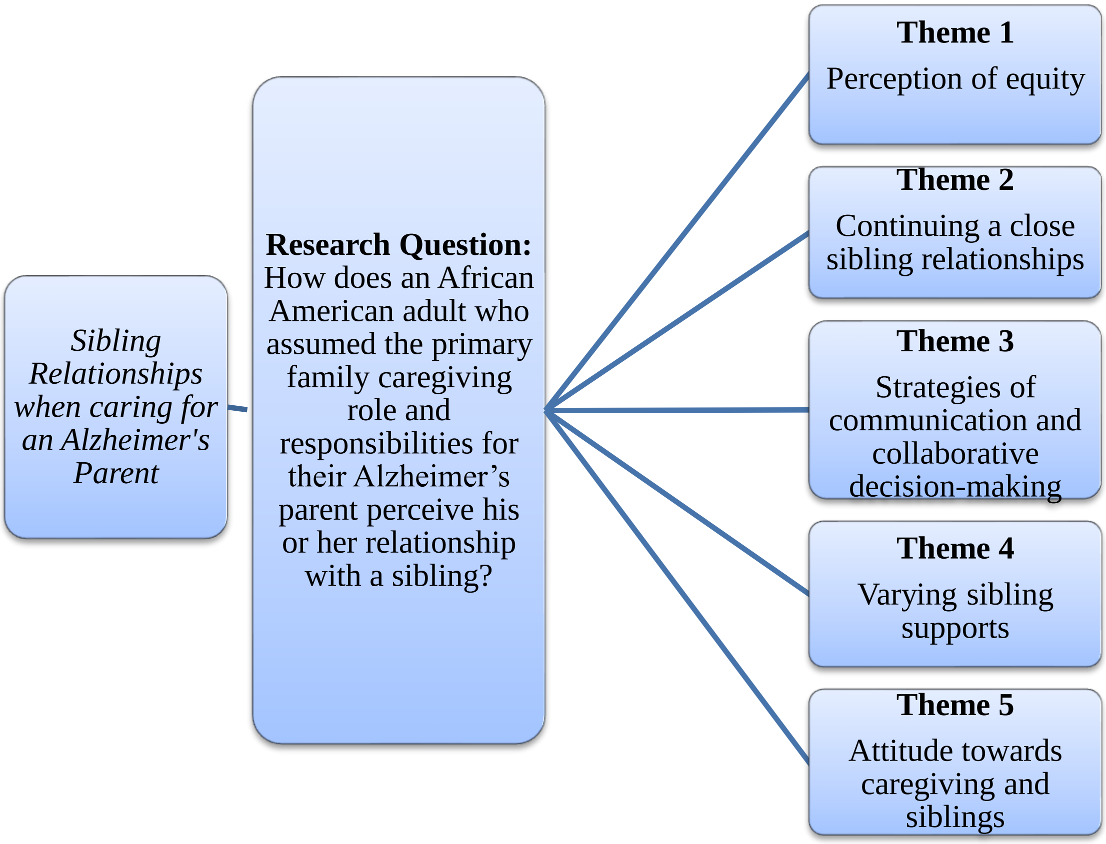

Figure 1. Development of themes.

Theme 1: Perception of Equity

The first theme that informed the research question occurred when I asked participants to respond to Question 6: Please discuss any shared responsibilities of caregiving among your siblings. According to Tolkacheva et al. (2011) siblings can execute their support by offering instrumental and emotional aid to the caregiver which may help alleviate some caregiving hours. The following narratives offer insight into shared filial caregiving:

> P1: They would send money for gas or groceries. So, my sibling compensated that way. But I cannot say caregiving is always a shared responsibility…So, I guess in that respect it was shared; boys had a role, and the girls had a role and together it all worked out.
>
> P2: I don't expect this to be a 50-50 even split. They may not be able to be here in the physical sense all the time, but two of my siblings are always there financially.
>
> P3: They work that out themselves, and they rotate it. Matter of fact, they don't want me to do too much in finances because I am doing all of the other work. But again, they have equally taken on the financial aspect of care which is a big help…It's a trade-off.
>
> P5: Perhaps I could say that we share the responsibilities despite me being the primary caregiver. In all seriousness, it is not like we equally distribute responsibilities. Some contribute more while others contribute what they can. They help according to their ability.

P6: I wouldn't say that we share responsibility. Of course, I do most of the work because she resides with me, but my siblings help financially, and they run errands at times. They also give me a break a couple of times a month. I mean this is something we all agreed on, so everyone is doing their part.

P7: Is there such a thing as shared? I mean it's not a bad thing for me to do a little more work than my brother and sister just if there is this understanding and commitment to helping me. I don't expect her to be here every day, but she is over quite a bit. I appreciate the sacrifice in just driving and getting here. When she is here, she stays over for a few days…My brother gives me money, so it all works out.

P8: It's not really shared; we just agreed on who would do what roles. I take care of dad daily…My first sister may give us a break…It is like some time to ourselves. She brings personal items over as well as some food items, and she contributes financially.

P9: I can't say that this responsibility of caring from mom is a shared role. I mean, I do live with her, so I do most of the work, but we have worked it out that he does what he can. There is no way this could ever be 50-50; I just don't see it that way. He is financially supportive, and he does the hard labor. I attend to my mom's physical needs, safety, medical, and personal needs. This is how we worked our mother's care out, so to us, it is a shared responsibility.

> P10: We share the responsibilities of the finances. My brother is basically in charge of the finances since I am in charge of physical care needs. So, he does that and any medical bills.

Although P4 felt that her brother did not share any caregiving responsibilities, the remaining participants in this study expressed that responsibilities were not equal but were mutually agreed upon tasks that were divided during a family discussion. Next, I asked participants to respond to the following: Tell me about a time where you felt your sibling was not helping you enough as you care for your parent. Several participants spent time expressing how their siblings have been active in helping them care for their parent. For instance, P2, P3, P5, and P9 reported feeling as though there has never been a time in which their siblings were not helping enough.

> P2: I don’t feel like that about two of my siblings. Honestly, I am not really upset with the other one. Again, the two sisters were helpful.
>
> P3: I cannot think of a time that they didn’t come to my aide. We all know our roles, and even though I am the primary caregiver, my siblings have been extremely helpful without being physically present. They have financially helped in so many ways.
>
> P5: I cannot think of a time when my siblings didn’t provide any supports. Some are more active than others, but at the end of the day, they all have helped me in some way.

> P9: He has been very supportive and when he says he is going to do something he sticks to it. We defined our caregiving roles, and so far, it has worked to our advantages. He has a family, and I respect what he can and cannot do.

Additionally, P1 and P8 stated they had to assume primary caregiving responsibilities due to unforeseen health issues of another sibling who initially functioned in that role. According to these participants, they accepted the role as the primary caregiver and embraced the notion that assistance provided by a sibling may not have been shared or proportional but was equal enough.

> P1: I cannot say for myself, but maybe one brother had some resentment in the earlier stages after my mother died. When he started telling us what he was going through, we all jumped in and did more, but he passed, and then I became our dad's primary caregiver with the assistance from my siblings.
>
> P8: There hasn't been a time. My sister could not continue being the caregiver because she couldn't handle dad. She was in a difficult situation with her own family and their schedules. He was doing things that she could not control. So, I took the role over. I understood that and was cool with my new role, and as a family, we divided our responsibilities. It cannot be equal, but it is equal enough.

Although most of the participants expressed favorable caregiving perspectives, three disclosed that there were early challenges related to the division of care with a sibling but indicated no further challenges. For instance, P6 stated, "The only time I feel like they don't help enough is when I have to take her to the doctor, take her out for a ride, to the store, or a restaurant." P7 expressed, "I would say that there was a time, earlier on where my brother was making comments that certain duties were just for women…So, I said to him to get in there and do what needs to be done." P10 stated, "At the very beginning, when this all started, it was very hard for my brother…As time went on, he sees it. It is just better because we are on the same page. We worked through it." However, P4 was the only participant who continue to experience unequal distribution of filial care. P4 expressed, "He wasn't helping at all."

Theme 2: Continuing a Close Sibling Relationship

The second theme that informed the research question occurred when I asked participants to respond to Question 9 of the individual interviews. Tell me how you would describe your relationship with your sibling relationship prior to becoming the primary caregiver? Nine of the 10 participants relayed having a close-knit family.

> P1: I am like most families, I would describe my relationships with my siblings overall as good, even wonderful. Overall with my other siblings, I describe it as a partnership. We were together on everything. I think it was a wonderful relationship.
>
> P2: Well, we were always a tight-knit family. The relationship with my other two siblings has gotten so much closer. I am thankful for them because they put aside their pain to jump in and help me any way they could.
>
> P3: I always had a good relationship with my siblings we might have disagree, but we still come together on who is going to do what, when, and how on a monthly basis, so everyone knows what they are supposed to do. We talk all the time, not always weekly, but we make sure to check in with each other.

> P5: We have always had a wonderful relationship. We respect each other, and we are always supportive of each other. She instilled that family is everything, and so I have always carried it with me even in adulthood.
>
> P6: I think we are a close-knit family. We are not a perfect family, and we have had issues. At the end of the day, it is about taking care of our mother, and doing what is in her best interest.
>
> P7: We had a great relationship, we have always been close, and I think we have gotten closer since we had to take care of our parents.
>
> P8: My sisters and I always had a great relationship; nothing has changed even during this time. We are very protective of each other, and we don't like to see each other in pain. I would say we are very compassionate towards each other.
>
> P9: I would say we have a great relationship. My brother has always been an easy person; we get along. We are very close, and I just love how we support each other.
>
> P10: Now we have bonded over this. If something happens to her, we will still have our relationship.

Although nine participants expressed having a close-knit family, P4 expressed that she did not have a close relationship with her brother prior to assuming the role of primary caregiver. P4 stated, "we really did not get along at all." P4 further stated, "we were not that close growing up, and now we just tolerate each other as we became adult." All participants responded to question 10: How would you describe your relationship with your sibling during the time of providing care to your parent? P4 and P6 further expressed a distant relationship with one or more siblings during caregiving. For instance, at the time of the interview, P4 reported, “although he gives me accolades, there continues to be a distant relationship.” P6 stated despite experiencing some “struggles” between her and her sister; they are still a close-knit family. P6 also noted that she enjoys a closer bond with her brothers. The remaining eight participants noted their relationships with their siblings remained close as they provided care supports to their parent.

> P6: I still believe we are a close-knit family. I may be a little closer to the brother that lives closest to me.
>
> P1: We continue to have a great relationship. I think I said everything about my relationship before and it continued to be true during that time.
>
> P2: I have a beautiful relationship with two of my sisters. The relationship with my other two siblings has gotten so much closer.
>
> P3: It is still a good relationship; I think the key point is talking and getting an understanding. Everyone sees everything eye to eye. If you don’t understand, then what you do is leave and come back to give everyone a chance to calm down. I think we have a good relationship.
>
> P5: Nothing has changed. We are still a close-knit tight family. We continue to talk to each other, and we respect each other. I just value their opinion and enjoy their company. Through this ordeal, we have learned how to express better what we feel.

P7: We continue to have a great relationship. I think to have a good relationship with my siblings; we must respect each other opinions. I mean I don't like what they have to say all the time, but I think that if I show them that I value them, that helps stop any hurt feelings. You respect me, and I respect you and we will be just fine.

P8: I would say that we are still a close family. I try and nurture the relationships with my sisters because we are all we have in this world. I would not change anything about my relationship with my sisters; it's wonderful.

P9: During this time, I think we have a great relationship. He is a supportive brother…We continue to be close and I think with our mom's condition, our sibling bond has gotten much tighter.

P10: Great! He understands fully what is going on with her, there is no magic pill, and we are on the same page. We have a great relationship.

Theme 3: Strategies of Communication and Collaborative Decision-Making

The third theme is strategies of communication and collaborative decision-making. I asked participants to respond to Question 8: How do you handle decision making related to the care of your parent with your siblings? Nine of the 10 participants described how early, open, and ongoing communication helped mitigate any confusion, misunderstandings, or feeling left out of the progress of the parent's treatment plan.

P1: Well, as I said earlier, there were 12 of us and we all respected our older brother and sister. We discussed and agreed! We would sit as a group and make decisions about care.

P2: I try to keep everyone informed of what is going on with mom and sometimes I will wait for a response from my sisters before I decide.

P3: Usually we will do a conference call. We will sit down and talk about it because we are a close family. Anything major or any new information regarding his current physical condition should be discussed among the siblings, but I usually just make the decision on simple issues such as changes to his medication, or changes to his daily routine. I sometimes may try a do a family chat by text and get everyone's opinion.

P5: However brief, I talk to my siblings all the time…I will tell my siblings afterward just, so they know.

P6: So, I discuss major situations first before I act.

P7: Well my siblings and I talked about what care would look like once we started noticing that something wasn't right with momma. When we received the diagnosis that it was AD, we met as a family, and agreed that I was going to be that go to person.

P8: Early discussion is important. The three of us came together and talked about what care was to be for our parents.

P9: My brother and I have always been a team. We consult with each other; we make plans, and we pretty much stick to those plans. He tells me not to wait on his "stamp of approval" when it comes to everyday things like routine paying bills and filling medicines. Now if it something that requires treatment or a decision that requires a big financial commitment, I always call him and get his input.

> P10: It wasn't easy at first because he wasn't around as much. Later, we started going to the doctor together. He had to see and know everything that I knew in order to help me make those decisions. We talk every single day. Sometimes twice a day.

Theme 4: Varying Sibling Supports

The fourth theme related is varying sibling supports. I asked all participants to respond to Question 7: How would you describe assistance you received or are currently receiving from your siblings to help in coping with the responsibilities of caregiving? Nine of the ten participants provided many instances where they believed assistance was helpful.

> P1: I know that I could not have done this alone. The last 5 years was the hardest, and without the support of my siblings, I could not have done it. It is nice coming from a large family because we can lean on each other, and when I needed a break, whoever came by the house always encouraged me to take a break.
>
> P2: It's been helpful. Well, as I said before, the two of them are very helpful. I really expected my siblings to help, and you know it doesn't have to be shared; it just has to be some help. The two sisters are great! I am very pleased with them.
>
> P3: The financial contribution is a big help. I don't have to worry about that. Very helpful! This is a big responsibility that I don't have to worry about…I really appreciate it because by supporting him in this way it is actually supporting me.

> P5: It's been wonderful, great! They are all very helpful. No one has flat out refused to help care for our parents…That is how they help me cope.
>
> P6: Brothers are a great help.
>
> P7: Well, I see it as helpful. It is great to be supported by my siblings. I think I would be mad, disappointed, and even depressed if they weren't emotionally supportive. We are a close family!
>
> P8: My family has been very helpful. If my wife and I are showing signs of stress, they will kick us out of our own house. They will give us a break and watch dad for us. This is a demanding role, you never really get a break and most times you are on edge, so the little things like a break help me to recover and start all over again.
>
> P9: It is irreplaceable! It is important and great! I could not do this task without his help. My brother has his own family that he has to take care of; he still has a teen at home. So, I know that he is making a big sacrifice in coming over and sometimes giving me money.
>
> P10: He does try and give me a break as often as he can. We do try and go to the doctor's appointments together so that there is some understanding and I am not trying to explain to him what the doctors said. He knows just as much about her welfare as I do.

Although nine participants acknowledged receiving helpful assistance, P4 disclosed that assistance from her sibling was "nonexistent." P4 stated the following:

> To me, he just doesn’t really care. In his heart I know he loves our mom; I know he does, but I just feel he is in denial. When you ask him for something, he says let me get back with you, but then he never does…Even though my mom has this disease, she can still sense that something isn’t right, so I just stop dealing with him.

Theme 5: Attitudes Towards Caregiving and Siblings

The fifth theme is attitudes towards the role of caregiving and siblings. In this study, most of the participants shared their perspectives on caregiving and sibling responsibilities. Whether sibling input of caregiving was proportional or not, based on some of the participants responses, mutuality in filial care appeared to be important. For instance, P1 explained, “We all pitched in, and we understood and accepted what people could and could not do.” While P5 expressed, “I never look at what I am doing and compare it to what siblings are doing.” “They help according to their ability.” Also, P6 stated, “I mean this is something we all agreed on, so everyone is doing their part.” P10 disclosed, “he has a family, and I respect what he can and cannot do.” Oher participants provided the following perspectives:

> P2: I know I can depend on them; they are my rock, and I could not have done this without them. When you know it your duty, it really isn’t suffering.
>
> P3: Caring for my dad is a labor of love which has helped me and my siblings to better understand our individual strengths and to be better communicators.

P7: At the end of the day I respect my siblings and I appreciate any help they are willing to give. Taking care of a parent with Alzheimer's is something that no one should do alone.

P9: She was in a difficult situation with her own family and their schedules. He was doing things that she couldn't control, so I took the role over. I understood that and was cool with my new role.

Discrepant Cases

In analyzing the data from the 10 participants, I found one discrepant case. The discrepant case was that of P4 who did not have a close relationship with her brother growing up nor during the time of providing care to her mother. Although P4 shared similar duties with the remaining participants, the narrative she disclosed related to her sibling relationship was unlike the remaining participants. For instance, a few participants disclosed early obstacles with their siblings, but even those acknowledged having a close-knit family. P4 did not have a close relationship with her sibling prior to and during filial caregiving. Furthermore, P4 disclosed unsuccessful efforts in negotiating care with sibling with indications of distress and strain. Typically, the caregiver will attempt employ different types of behavioral approaches as they seek redress (Tolkacheva, van Groenou, & van Tilburg, 2014). However, if efforts are futile, the primary caregiver may experience even more tension and stress (Tolkacheva et., 2014).

Evidence of Trustworthiness

To demonstrate rigor of a qualitative study, researchers may employ certain strategies, techniques, or practices throughout the research process (Colorafi & Evans, 2016; Morse, 2015). Colorafi and Evans (2016) and Morse (2015) noted researchers establish trustworthiness when the following four criteria are met: credibility, transferability, dependability, and confirmability. First, credibility occurred by incorporating techniques to enhance the likelihood that credible findings would be uncovered within the study (Houghton et al., 2013). The approaches included an audit trail and member checking (Houghton et al., 2013). For this study, I conducted one face to face, semistructured interview with 6 of the 10 participants, while the remaining four were interviewed via telephone. The purpose of conducting semistructured interviews was to extend insight into experiences related to sibling relationships during their time as the primary filial caregiver. During the interviews, I remained neutral and avoided providing my personal experiences or opinions.

Because the goal of this research was to explore sibling relationships from the viewpoint of an African American adult filial caregiver, only the participants of this research could validate or confirm the credibility of the results. Therefore, I used member checking (see Appendix B) as a tool in confirming that each participant's responses were a true depiction of their reported experiences. The participants in this current study, evaluated the transcript of their interview and were able to amend any information by striking it out, adding, or changing what was transcribed. Subsequently, all participants approved of the transcripts with two making minor adjustments, additions, or clarifications. For instance, P1 added that she was divorced with one adult offspring, while P10 added her age and her marital status. After making the adjustments to P1 and P10's interviews, all participants indicated they were satisfied with the presented transcription. Additionally, I collected information until saturation was reached, which reinforces the internal validity of a study (Dworkin, 2012). I used a peer reviewer to examine my thought process throughout the data collection, analysis, and findings (Anney, 2014). To maintain and protect confidentiality, participants' names or any identifying information were not shared with the peer reviewer. Additionally, personal identifying information of participants were removed. My peer reviewer was an individual who is currently pursuing a doctorate in Human Services. She is a registered nurse with a 20-year professional background in palliative care and mental health.

Colorafi and Evans (2016) noted that researchers could promote dependability by being consistent throughout the research process. By utilizing an audit trail, audio recordings capturing the accounts of the participants, a transcription of each interview, and a rich description of the research protocol, I established dependability. According to Rudestam and Newton (2015), transferability occurs when researchers provide a comprehensive and detailed report of demographics, data gathering techniques, and data analysis. Therefore, I provided in-depth report related to the method of participant selection and how I adhered to the listed data collection procedures. These dynamics became necessary so that this study can be replicated by other scholars using similar interviewees and techniques in the same situation (Cope, 2014).

Furthermore, I provided a well-documented data analysis plan, and described any warranted changes related to the data gathering process. Also, in Chapter 3, I discussed a detailed account of data analysis by using open coding and thematic analysis methods. The use of an audio recording device, notes, written transcripts, and the documentation of the research process will be kept for 5 years per Walden University. Following the 5 years, the digital records will be purged, and hard copies will be shredded. Third, confirmability was established by managing researcher bias through an audit trail and reflexive journaling. I employed an audit trail and reflexive journal to manage my thoughts, beliefs, and feelings throughout this research process. Furthermore, I conducted member checking with each participant to confirm the gathered information. Also, the audit trail was utilized as a method in documenting the results for replication. To strengthen the confirmability of this study, I also incorporated direct quotes to provide a deep, rich description of the participant's experiences. A peer reviewer served useful in ensuring that the findings emerged from the data and not from any personal predispositions (Anney, 2014). Because these measures were taken, I have determined that any personal experiences did not interfere with the participants' responses, and their narratives are free from influence (Cope, 2014).

Summary

In Chapter 4, I explored and presented the findings of 10 semi-structured interviews focused on sibling relationships among African American adult primary caregivers of an Alzheimer parent through their experience. I created a safe environment that fostered and encouraged participants to express their sibling relationships as the primary filial caregiver. Each participant's interview was transcribed verbatim, and themes were developed by using an initial coding process to answer the research question. Many of the experiences illustrated by each of the participants were similar where communication was a key factor in the way caregiving responsibilities were discussed and disseminated, and where expectations of the parent's medical care were addressed.

Additionally, there were shared experiences in which participants reported feeling that despite some obstacles in filial caregiving; relationships among siblings were close prior and became closer during the caregiving experience. However, there was one exception were a participant acknowledged an ongoing distant and strained relationship with her sibling prior to and throughout the period of caregiving. In Chapter 5, I present the interpretation of the study's findings. Additionally, I then present the implications of this study's findings and describe how gerontologists, mental health practitioners, medical professionals, and other community-based professionals may apply the findings in helping this caregiver group and other types of caregivers with their experiences. At the conclusion of Chapter 5, I describe the limitations of this study as well as recommendations or suggestions for further research on caregiving and sibling relationships.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this generic qualitative study was to explore sibling relationships from the perspective of African American adult filial caregivers of a parent with AD. Although there is prior research on informal or formal African American caregivers, there is a scarcity of studies exploring the effect of parental caregiving on adult sibling relationships (Namkung et al., 2017; Ngangana et al., 2016). I recruited participants by employing a purposive sampling strategy in conjunction with snowballing sampling. In this study, I used a generic qualitative approach incorporating Braun and Clark's (2006) stages of data analysis. This research was exploratory, semistructured interviews were conducted to gain an understanding of this social phenomenon. The interview questions helped me collect participants' perceptions of their sibling relationships during filial caregiving of an AD parent.

My goal with this study was to extend existing knowledge on African American sibling relationships during filial caregiving of a parent with AD. One research question guided this study: How does an African American adult who assumed the primary family caregiving role and responsibilities for their parent with AD perceive his or her relationship with a sibling? Although the division of care may fuel imbalance, conflict, and dissension (da Silva Falcao et al., 2016), 9 of the 10 participants expressed positive aspects regarding caregiving and their sibling relationship(s), which indicated that the African American caregiver tends to experience strong sibling relationships (Spitze & Trent, 2018) and feel emotionally supported by family members (Ngangana et al., 2016).

In Chapter 4, I described the data collection and analysis as well as the research findings. After completing the data analysis, I identified the following five themes: (a) perception of equity, (b) continuing a close sibling relationship, (c) strategies of communication and collaborative decision-making, (d) varying siblings supports, and (e) attitudes towards the role of caregiving and siblings. From the themes, I derived the following key findings: the division of responsibilities did not have to be proportional but needed to be fair; the adult primary filial caregiver continued to experience a close-knit, cohesive sibling relationship; and collaborative decision-making strategies among the primary caregiver and siblings aided in cultivating a harmonious division of care responsibilities, which promoted a positive caregiving experience. Related to equity theory, nine participants did not perceive an imbalance that led to distress or sibling conflict. Considering the results from this study, therapists, geriatricians, and community-based social practitioners may encourage family-centered caregiver support groups among African American filial caregivers as a resource to maintain sibling cohesion and collaborative decision-making in caregiving. Additionally, the findings may be used to inform the development and implementation of culturally responsive awareness and educational programs for African American adult filial caregivers. In this chapter, I offer an interpretation of the findings, a discussion of the limitations of the study and the benefits of participation, my reflections on the study, recommendations for practice in the field of gerontology and further research, implications for positive social change, and the conclusion.

Interpretation of the Findings

In order to address the research question of this study, I employed a generic qualitative approach incorporating semistructured, in-depth interview questions. To interpret the results and understand African American adult filial caregiver's perspective of their sibling relationships, I used equity theory as the conceptual framework for this study. As discussed in Chapter 4, based on the data from the participants' narratives, I identified, coded, and categorized patterns into themes. In this section, my interpretation of the findings and a description of the emergent themes related to the research question and conceptual framework delineated in Chapter 2 are provided.

Themes Related to the Research Question

To address the research question, I developed 12 interview questions to help elicit the experiences and perspectives of the 10 sampled participants. Theme 1 was a description of the adult caregiver's perspective on equity among his or her siblings. Each participant had at least one sibling and caregiving responsibilities were not viewed as proportionate between them. All but one participant expressed similar but varied experiences with shared caregiving responsibilities among their siblings. These participants noted that caring for a parent was not considered to be an equally distributed responsibility. For instance, P7 expressed, "I don't expect this to be a 50-50 even split." P8 stated, "It cannot be equal, but it is equal enough," while P3 noted, "I wouldn't say shared…everyone is doing their part." P1 described the process by saying, "We took turns." For these participants, it was not unusual for siblings to assume financial responsibility, provide respite, or perform some caregiving tasks in the home of primary caregiver.

From the participants' perspective, most siblings ensured that the primary caregiver was not bearing the full burden of caregiving alone. In general, the participants' experiences aligned with the descriptive overview of the five types of sibling caregiving described in Chapter 2, which encompassed the following: (a) routine care, (b) back-up, (c) circumscribed, (d) sporadic, and (e) dissociation care (Tolkacheva et al., 2014). Based on participants' narratives, each interviewee had a sibling who fit one of the types of caregivers described in Tolkacheva et al.'s (2014) work. One participant had a sibling who assumed no responsibilities, which would be classified as dissociation care. In other words, dissociation care occurs when a sibling is no longer involved and cannot be counted on to provide supportive care (Tolkacheva et al., 2014). The remaining participants characterized their sibling responsibilities as either back-up care or circumscribed care (see Tolkacheva et al., 2014). Based on the participants' responses, siblings who functioned in the role of a sporadic caregiver or a circumscribed caregiver did not live geographically close to the primary caregiver and care recipient. In instances where geographic proximity was an issue, the primary filial caregiver and distant caregiver mutually agreed on ways to share caregiving responsibilities. For participants in this study, equitable responsibility in caregiving took the form of financial, instrumental, and emotional support, which was consistent with Tolkacheva et al.'s (2010) findings. Furthermore, the findings in this study supported Kaufman, Kosberg, Leeper, and Tang's (2010) discussion that instrumental supports are provided more often by family members of African American AD caregivers.

Concerning Theme 2, I focused on the participants' views of their continuing close sibling relationships. Nine participants provided feedback expressing that before and during the caregiving experience they enjoyed a close-knit relationship with their siblings. Spitze and Trent (2018) noted that African Americans tend to have strong sibling relationships. From the findings, I also uncovered alignment with Broese van Groenou et al. (2013) and Spigelmyer et al.'s (2018) results, in which they noted African American caregivers reported caregiving as a rewarding experience leading to a closer relationship with family members. Epps (2014) discussed that African Americans tend to possess a stronger belief concerning family obligation, resulting in a more positive caregiving experience than Whites. In Chapter 2, I described familism as a core set of cultural values often embraced by collectivist groups, such as African Americans, where allegiance, duty, obligation, reciprocal support, and collaborative decision-making are what defines commitment to the family network (Fingerman et al., 2011; Potter et al., 2017; Sayegh & Knight, 2011), which is consistent with the overall findings of this study. Furthermore, family cohesion symbolizes positive regard for each other where members feel an emotional bond or connection (da Silva Falcão et al., 2016). Participants such as P6 acknowledged that, "They were not perfect, but we are a close-knit family." Although there were few instances of sibling strain, the overall findings of a close-knit, cohesive sibling relationship from this research were consistent with Suitor et al.'s (2018) scholarship.

Theme 3 was strategies of communication and collaborative decision-making. Communication is a process of moving, cultivating, sharing, or regulating information along with making it known to the family network (Wallace, 2015). McGrew et al. (2018) explained there is an interdependence between the decision-making of care and the family network. In other words, when one member of the family made a decision, it often affected other members (McGrew et al., 2018). When poor communication occurs or when there is a lack of acknowledgment of interdependence in decision-making, the result is inequity in care and support (McGrew et al., 2018).

For participants in this study, communication with their siblings served as a vital dynamic in the filial caregiving process. Without communication, problem-solving and decision-making would make care coordination, emotional or physical support, and monetary support difficult. In the following excerpts, 9 of the 10 participants in this study illuminated various strategies of communication and collaborative decision-making among siblings, which often led to negotiation and distribution of care resulting in the caregiver feeling that filial responsibilities were fair. For instance, P1 expressed, “We would sit as a group and make decisions about care. We never had confusion even with my sister who was a minister…We discussed and agreed.” P2 noted, “I try to keep everyone informed of what is going on with mom, and sometimes I will wait for a response from my sisters before I decide.” P3 stated, “We will do a conference call. We will sit down and talk about it because we are a close family…I sometimes may try a do a family chat by text and get everyone’s opinion.” P5 explained,

> However brief, I talk to my siblings all the time, and of course, my mom is there, so the decision really lies with her. I will tell my siblings afterward just, so they know, but I don't have to seek their approval maybe guidance.

P6 discussed, "So, I discuss major situations first before I act." P7 expressed, "Well my siblings and I talked about what care would look like once we started noticing that something wasn't right with momma." P8 disclosed, "Early discussion is important. The three of us came together and talked about what care was to be for our parents." P9 stated, "My brother and I have always been a team. We consult with each other, we make plans, and we pretty much stick to those plans." P10 explained, "He had to see it and hear it for himself, and know everything that I knew, in order to help me make those decisions."

Theme 4 included a discussion on varying sibling support. Whether the support was provided or not, each participant reflected on this dynamic. Several participants remarked how valuable it was to have supportive siblings who made it possible to keep their parent out of a nursing facility. Furthermore, P1, P2, P3, P5, P6, P7, P8, P9, and P10 described sibling support as extremely helpful. Although P2 had one sibling who was not entirely supportive, she expressed feeling grateful for the support she received from the other siblings. Despite challenging sibling relationships, these bonds may still serve as a protective measure against the burden of caregiving and other caregiving risks (Amaro, 2017). Given the support offered through their extended family, African Americans serving as a primary caregiver tend to express caregiving with positive appraisals (Epps et al., 2019). For instance, three of the participants benefitted emotionally and physically from sibling support, where respite care was offered. Consequently, P5, P7, and P9 characterized the experience of respite care offered by their siblings as a short-term relief of their caregiving duties so they could relax and focus on self.

Theme 5 involved attitudes towards the role of caregiving and siblings. Each participant discussed how they approached and perceived challenging caregiving experiences, such as having a nonparticipating sibling, in order to avoid distress as they dedicated their energy towards the care of an AD parent. As it relates to equity theory, when there is a perception of imbalance, tension and conflict may arise between the primary caregiver and a sibling. During caregiving, a caregiver and their siblings may be brought closer together and work in a cooperative manner to manage parental care or they may be pulled apart due to the stress (Ngangana et al., 2016). Although a few participants disclosed some early caregiving challenges among their siblings, P4 was the only participant who had a strained relationship with her sibling prior to and during caregiving. P4 expressed, "Although I am disappointed with the lack of support from my brother, I cannot allow the strained relationship to interfere with the care provided to our mother." Overall, the participants highlighted positive appraisals of their caregiving role and positive outcomes concerning their sibling relationships. For instance, P2 noted, "I know I can depend on them. They are my rock, and I could not have done this without them." P3 stated, "Caring for my dad is a labor of love," while P7 expressed, "At the end of the day, I respect my siblings."

Although gender was not the focus of this study, 8 of the 10 participants were female. This finding supports da Silva Falco et al. (2016) research where daughters were found to be more consistent with their caregiving, provided more caregiving hours, and delivered a wider range of supportive care which included ADLs and IADLs. However, Willyard et al. (2008) noted that caregiving responsibilities are not equally assumed by all daughters. P1, P2, and P6 disclosed that at least one female sibling did not participate nor collaborate in parental care. For instance, despite having other supportive siblings, P2 remarked, “Sometimes it bothers me that the sister that lives here doesn’t help, but on the other hand if you can’t do it from your heart don’t do it.” Therefore, the perceived evasion of responsibility resulted in a strained relationship between the caregivers and their female sibling. Furthermore, gender roles provide insight into some people’s perception that females are to assume the primary informal caregiver role (del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Martínez-Riera, 2012). For instance, P1 stated, “When it was our turn, the girls helped in doing the cooking, grocery shopping, and the cleaning. Now my brothers, their support was sitting with him and fixing things. My brother would provide financially.” P3, stated, “They don’t offer too much physical supports. On the rare occasions that they come to town they would take our dad out and give me break.” P7 expressed, “Now my brother is less involved in the physical sense.” P5 and P6 participants, noted that the male siblings would typically provide supervision by sitting with a parent watching a television show. The results of this research contradicted Collins’ (2014) findings where sons also provided care supports in the areas of shopping and meal preparation. Although Collins noted that care supports such as meal planning and shopping may signify a growing culturally accepted trend, only one participant had male siblings that would purchase groceries, prepare food, and buy personal products.

In summary, the results complement previous literature highlighting that filial responsibility is often assumed by an adult offspring where care may manifest in emotional support, monetary assistance, and physical aid with ADLs (Chappell & Funk, 2012; Santoro et al., 2016). Further, for this study, participants expressed that caregiving duties provided by siblings did not have to be equal but needed to be equitable. Subsequently, low conflict and strong family cohesion were apparent among the majority of participants when siblings were engaged in caring for the AD parent which complements scholarship by Friedemann and Buckwalter (2014) where African Americans were found to have stronger shared beliefs on caregiving than other racial groups.

Interpretation of the Findings Related to the Conceptual Framework

The research question became significant in extracting information from participants’ responses that informed the conceptual framework in the is study. This research was guided by a social exchange theory known as equity theory. Equity theory was critical in explaining responsibilities in caregiving related sibling relationships. The conceptual framework guiding this study helped in uncovering emerging themes that informed the complex social phenomenon of equity and shared responsibilities in filial caregiving. For primary caregivers and their siblings, equity theorists explained that caregivers may sometimes alter their perception or change comparison of the input or outcome in order to avoid feeling stressed or anxiety (Lashewicz & Keating, 2009).

Further, in situations where there is an imbalance, individuals may experience tension or bitterness towards siblings which may lead to conflict and strain (Lashewicz & Keating, 2009). For this study, participants perceived equity as an act of fairness when providing filial caregiving. Moreover, participants were not concerned with proportional division of care, rather the expression of fairness in caregiving responsibilities. For this study, the findings were congruent with scholarly work conducted by Halliweel et al. (2017) which primary caregivers appreciated siblings being engaged and willing to assume some caregiving responsibilities. According to the authors, their participants recognized that even distribution of responsibilities among siblings was not always realistic or feasible (Halliweel et al., 2017). Therefore, division of care did not have to be equal, just fair (Halliweel et al., 2017) which was consistent with the findings of this study.

Equity theorists propose that in a partnership, benefits are received in proportion to their relative performance (Al-Zawahreh & Al-Madi, 2012; Yum & Canary, 2009). Therefore, perceived imbalance in the distribution of benefits relative to one’s efforts may lead to conflict and other accentuating negative outcomes (Al-Zawahreh & Al-Madi, 2012; Yum & Canary, 2009). Sibling caregivers of an elderly parent often make a comparison of the cost and benefit, and when there is an imbalance the caregiver may become distressed (Lashewicz & Keating, 2009). However, nine participants reported fair division of supports and retention of a close-knit, cohesive sibling relationship.

Therefore, the overall findings from this research were not consistent with the existing scholarship on equity in filial caregiving.

For this present study, overall the nine participants did not perceive an imbalance and believed that caregiving performed by siblings was fair and complementary to their filial responsibilities. Therefore, the African American adult filial caregivers in this study experienced their sibling relationships in a positive manner. In conclusion, I interviewed 10 participants who were primary caregivers of a parent with AD. Nine participants primarily expressed equitable caregiving responsibilities since negotiation and division of assigned parental care were mutually agreed on and were based on ability, capability, or geographical proximity.

Future Recommendations

Given the high prevalence rate of African Americans developing Alzheimer’s, more adult offspring are assuming the role of caregiver (Samson et al., 2016). Fingerman et al. (2011) noted African Americans adults typically assume care of an aging parent. Subsequently, caregivers may seek out family members such as a brother or sister for support in contributing to daily care needs (da Silva Falcao et al., 2016). As noted in Chapter 2, filial caregiving research specific to culture, gender, or ethnicity is scarce in the field of gerontology. The purpose of this current study was to explore sibling relationships of an African American adult who assumed the role of primary caregiver of a parent with AD. Consequently, recommendations for further research stems from the reported results and limitations of this study. Therefore, I recommend continued research that expands on this current study.

The participants were African American adult caregivers between 52 to 65 years of age. For this study, of the 10 adult filial caregivers, two were male. The finding is promising because roughly 30% of caregivers are sons (NAC and AARP, 2015). Considering the increasing presence of male caregivers, I recommend that future researchers conduct a quantitative study investigating gender differences in sibling relationships during AD caregiving. For instance, researchers may consider conducting a comparative study examining variances between male and female filial caregivers concerning the equitable division of AD supports and how levels of supports impact sibling relationships. If researchers discover significant gender differences, they may develop gender-specific caregiver support programs (Sharma et al., 2016). Furthermore, given the male presence in filial caregiving of a home-based elderly parent, medical doctors, nurses, counselors, health administrators, and social workers may utilize the findings as a reference in developing a plan of support for the male adult filial caregivers. Future researchers could also examine the similarities or differences between urban and rural adult filial caregivers and how attitudes towards equitable filial supports might be associated with sibling relationship outcomes.

Given that Asian Americans, African Americans, and Hispanics Americans have a strong sense of duty and family obligation (Pharr et al., 2014), extending this research to investigate these minority groups, may help in gaining further understanding of cultural nuances in AD filial caregiving and the complexities of siblingship. Researchers undertaking a comparative research design where they examine ethnic or racial minority groups seek to identify differences and similarities in attitudes towards siblings and equitable caregiving supports. By limiting the sampling population to just an urban area in the Southeastern region of the United States compromised generalizability. Given this was a small qualitative study, future researchers may consider a larger sample size by broadening the scope of the research to other regions throughout the United States or different types of caregivers. Additionally, I propose future researchers extend this qualitative study where they capture the input of not only filial caregivers but also their siblings. Tolkacheva et al. (2014) asserted that it is common practice for adult siblings to divide AD caregiving of an elderly parent. The method of sharing or participating in caregiving reinforces the notion of examining filial caregiving from the family’s viewpoint (Tolkacheva et al., 2014). By implementing this type of technique, participants may provide further insight into sibling relationships whereby bonds can be preserved and reinforced through family-centered programs.

Furthermore, equity theory may be used as a foundation for scholar-practitioners to understand further sibling relationships related to filial caregiving. For instance, prospective researchers may consider conducting a study examining a link between equity in filial caregiving and sibling bonds. In a family network, many adult offspring share in caregiving duties; however, the variances in their contributions may be considerable (Tolkacheva et al., 2014). According to Tolkacheva et al. (2014), the disparities in care from siblings may become a burden for the primary filial caregiver.

Future studies on sibling relationships and filial caregiving among African Americans may extend results from this research as well as results from existing scholarship. Additionally, results from this current research may promote changes in the way caregiver supports are developed, implemented, and offered to caregivers. I plan presentations at local workshops to increase awareness and understanding on the negative and positive appraisals related to sibling relationships experienced by filial caregivers. In conclusion, it is important for healthcare providers such as counselors, nurses, geriatricians, gerontologists, and other community stakeholders to understand and acknowledge the complexities of AD filial caregiving and division of care with siblings in order to petition for family-centered supports that address this cohort's needs.

Strength and Limitations

The use of a generic qualitative design for this research is a strength since the approach aided in exploring and uncovering a deeper understanding of the experiences and perceptions of an African American adult caregiver. The use of semistructured interviews permitted participants to provide their perspective on this social phenomenon. The participants' narratives were rich, where readers may be able to connect to these personal experiences. Another strength of this study was trustworthiness. Not only were participants asked the same interview questions, I also conducted member checking which aided in correcting any errors and clarifying comments. Furthermore, each participant confirmed the accuracy of the transcribed interview. I sought guidance from my dissertation chairperson and a peer who both provided guidance during the data collection and analysis phases. I also maintained my reflexive journal to monitor thoughts, reactions, and any biases.

Furthermore, I often referred to the literature to explore any parallels and variances between this current research results with that of extant findings. Although there were some strengths where the findings illuminated valuable information related to sibling relationships and filial caregiving, the study also contained some limitations. The sample size for this research (*N* =10) may restrict representation of the findings to larger population of filial caregivers. Also, the inclusion criteria may be a limitation of this study. For instance, this research was only open to African American filial caregivers who had a least one sibling, lived in Southeastern United States, spoke English, and provided home-based caregiving to a parent with AD. Although this research offered some insight into sibling relationships among African American adult caregivers, conclusions may not be transferred to other types of African American caregivers or the greater population. Due to the limited scope of this research, I propose that future researchers focused on filial caregiving and sibling relationships consider broadening sampling characteristics that include a diverse cultural background, broader age range, or a different geographical region to promote transferability and generalizability. I further recommend for future research, that scholars consider also obtaining the viewpoint of siblings to gain further insight into the positive and negative appraisals of filial caregiving as a family unit. Despite these limitations, the results from this research may serve as a catalyst for future researchers to explore this social phenomenon of filial caregiving and sibling relationships.

Implications for Positive Social Change

The prevalence of AD is high among African Americans, which may indicate a high need for AD informal caregivers (Wilkes et al., 2018). African Americans hold a strong sense of familism, which is often rooted in upbringing and cultural belief (Epps, 2014). The strong sense of familism expressed by participants helped portray caregiving responsibilities as a welcomed role which is a dynamic often embraced in the African American community (Epps, 2014). Furthermore, African Americans possess strong attitudes toward family obligation resulting in more positive appraisal of the caregiving experience than Whites (Epps, 2014). Therefore, the implication for positive social change may evolve into gerontologists, medical doctors, nurses, mental health therapists, and community-based social service organizers being encouraged to develop and implement culturally responsive strategies and supports for filial caregivers to address the unique issues related to siblingships and filial caregiving among African American caregivers. According to Wilkes et al. (2018), nurses and other health professionals are skilled in evaluating the needs of caregivers during the course of their AD caregiving journey.

The results of this research may also contribute to retooling and improving existing intervention programs designed to address the unique caregiving experiences of African American caregivers (Wilkes et al., 2018). Consequently, individuals may benefit from intervention programs pinpointing the presenting issue such as needs, strengths, caregiver resources, the quality of care provided by the caregiver, skills needed to manage challenging behaviors of their loved one, and learning skills needed to successfully communicate with family (Wilkes et al., 2018). Further, it is critical that these strategies also focus on the condition of the family relationships in order to reestablish, maintain, and preserve resiliency and cultural fortitude that are essential for the caregivers' survival (Rozario & Simpson, 2018).

Additionally, the results from this research may affect positive social change by contributing to the field of gerontology by helping to fill the gap in knowledge related sibling relationships and filial caregiving. Ultimately, it is hoped that developing culturally responsive and family-centered programs will encourage minority caregivers to actively seek and access supportive services for the betterment of the family network.

Implications for Gerontology

Alzheimer's is a pervasive disease where African Americans more vulnerable in developing dementia than other races (Mayeda et al., 2016). In the state of Georgia, currently, 140,000 have a diagnosis of AD, which is expected to increase to over 190,000 individuals (Alzheimer's Association, 2018). Informal caregivers are finding themselves in a caregiving situation that may affect family relationships in a positive or negative manner. Based on the research findings, African American adult filial caregivers commonly expressed having a positive caregiving experience with a cohesive sibling bond, which was consistent with work conducted by (Namkung et al., 2017). African American adult filial caregivers may benefit from culturally responsive support systems such as a behavioral health advocate or mental health specialist to help them better understand and navigate through their caregiving experiences.

During the individual interviews, some participants expressed how helpful it was to have participated in this research. P1 and P2 stated, "Thank you for listening because this has been very helpful." Although P4 expressed some painful memories related to the current condition of her mother, she wanted to continue with the interview. Sharing their caregiving experiences, both positive and negative, seemed to be helpful for many of the participants in this research. Furthermore, these findings may support gerontologists in recognizing sibling strain during filial caregiving. P1, P2, and P4 noted that although the discussion of their experiences was in an interview setting, being able to speak openly and freely helped release some of what they had been feeling related to their siblings. The caregivers expressed faith, prayer, reliance on some family members and close friends, and journaling as mechanisms used to help them cope with the demands of caregiving and the complexities of their sibling relationships instead of accessing formal supports. At the end of each interview, participants received a referral list to community-based caregiver-support groups and counseling services. Furthermore, several participants expressed relief in speaking about their experiences with someone other than a family member or friend.

Scholarly literature coupled with the results from this research support the need for counseling services or psychoeducational awareness programs (Llanque et al., 2015). It is therefore recommended that support services can be group sessions for the family members to talk about challenges in caregiving and how to allocate responsibilities (Desin, Caban-Holt, Abner, Van Eldik, & Schmitt, 2016). Since many African Americans are likely to use spiritual coping as a protective tool to mitigate caregiver stress (Wilks, Spurlock, Brown, Teegen, & Geiger, 2018), health practitioners may also consider this dynamic when developing a support plan. For caregivers who are able to leave their home, health advocates may want to consider helping them access supports through community-based organizations. Thus, affiliating with an Alzheimer’s social service agency to access psychoeducational intervention supports may be beneficial

(Llanque et al., 2015). For caregivers who are unable to leave their home because of their caregiving responsibilities, transportation issues, distance, or lack of a replacement caregiver, counselors and gerontologists may consider online support programs such as distance counseling (Kovaleva, Blevins, Griffiths, & Hepburn, 2019). Ultimately, linking the caregiver with a provider who can offer culturally considerate therapy, especially if the caregiver experienced insensitivity and racial bias in earlier health interventions may be significant (Samson et al., 2016).

Summary and Conclusion

AD is a medical condition that significantly affects the aging population. Informal caregivers, such as a spouse or an adult offspring typically provide home care supports focused on ADLs and IADLs (Grant & Ferrell, 2012; Spigelmyer et al., 2018). The purpose of this generic qualitative research was to explore sibling relationships from the perspective of an African American adult filial caregiver of a parent with AD. For this research, participants willingly communicated their sibling relationships as the self-described primary filial caregiver. When there are many siblings the primary caregiver can benefit from dividing caregiving duties; however, when some of their brothers or sisters do not share in filial care, there is a possibility for greater family strife and strain (Kwak et al., 2012). Despite conflict, Fingerman et al. (2011) noted that African Americans subscribe to a positive viewpoint of care supports to elderly parents. Further, filial caregiving may bring other sibling groups closer together (Ngangana et al., 2016). Since this study occurred in Georgia, a Southern state in the United States, the findings resonated with Lincoln et al. (2012) assertion that Southern African Americans experience few unfavorable exchanges with family members.

Echoing Amaro and Miller’s (2016) account that siblingship is a multi layered relationship, I also found different layers of siblingship when there is negotiation or division of filial care. Although there were some obstacles, 9 of 10 participants reported their siblings often assisted with the care supports of their elderly parent. Ultimately, when caregiving responsibilities were divided across the network without conflicts or dissent, the primary caregiver felt lower burden (Tolkacheva et al., 2011). Moreover, results from this study illuminated positive and negative consequences in caregiving which mirrored research conducted by Ngangana et al., 2016 and Samson et al., 2016). Ngangana (2016) further noted caregiving not only generates family strife and tension, but it can also elicit positive appraisals that may bolster family relationships. Five themes emerged based on the participants’ narratives: (a) perception of equity, (b) continuing a close sibling relationship, (c) strategies of communication and collaborative decision-making, (d) varying siblings’ supports, and (e) attitudes towards caregiving and sibling relationships.

Findings from this study may advance knowledge related to changes in sibling relationships that African American adult caregivers face during filial caregiving of an AD parent. Since ethnicity and culture may shape the family caregiving experiences, it is vital that professionals in the health field be cognizant of these distinctions (Wilkes et al., 2018) when providing supports. Human service providers working in the field of gerontology may find that the results from this research informs the way they develop comprehensive, family-centered support programs and culturally responsive strategies. Although there is a scarcity of scholarship on sibling relationships and filial caregiving (Namkung et al., 2017; Ngangana et al., 2016) among African American primary caregivers, the results of this research aligned with existing literature (Lashewicz & Keating, 2009; Sechrist et al., 2017; Yum & Canary, 2009). Therefore, this research was valuable because it may have filled a gap in the literature and added to the existing body of knowledge on this social phenomenon of filial caregiving and sibling relationships.

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Appendix A: Participant Interview Questions

1. Tell me about your family.
2. Please explain what influenced your decision in assuming the role of primary caregiver
3. Let’s begin with your role as a primary caregiver. Can you provide some examples as to the types of duties you perform on daily basis?
4. What are some strategies you use to help cope with being a caregiver?
5. Please discuss the role, if any, your siblings play in providing supports to you as the primary caregiver.
6. Please discuss any shared responsibilities of caregiving among your siblings.
7. How would you describe assistance you received or are currently receiving from your siblings to help in coping with the responsibilities of caregiving?
8. How do you handle decision-making related to the care of your parent with your sibling?
9. Tell me how you would describe your relationship with your sibling prior to becoming the primary caregiver.
10. How would you describe your relationship with your sibling during the time of providing care to your parent?
11. Tell me about a time where you felt your sibling was not helping you enough as you cared for your parent.
12. Please feel free to share anything else about your relationship with your sibling during your time as a caregiver.

Appendix B: Member Checking for Participants

Dear Participant,

I appreciate and value your participation in my current study. At this time, I am presenting you with a transcript of the individual interview that was held on _____________ (date) at __________ (time and location). To ensure the account of your experiences was transcribed accurately, please take some time to confirm your responses. If it is necessary to make edits, please do so on the subsequent lines.

Thank you again for your time.

Cynthia Smith
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