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African American Family Structure of Caring for a Member with Alzheimer's Disease and Dementia

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Abstract

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MA, Walden University, 2021

Dissertation Submitted in Partial
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Abstract

Alzheimer’s disease and related dementia (ADRD) affect African Americans (AA) more than other ethnic or racial groups. It is common for AA diagnosed with ADRD to be cared for in the home. Historically, family members that provide care consist of significant others, relatives, and extended family. The United States Census Bureau showed an increase in Americans aged sixty and older from 55.7 million to 74.6 million. Due to the increase in the AA elderly population, the need for family caregivers will increase for this minority group. This study explored how AA family caregivers described their experiences and unique family structure when caring for a member diagnosed with ADRD. Bowen’s family system theory (BFST) was the conceptual framework used to explore family relationships and the well-being of AA caregivers caring for family members with ADRD. For this qualitative study, six AA participants from four families responded to 10 open-ended interview questions related to the care of members diagnosed with ADRD and their unique family structure. The results of the thematic analyses of the collected data showed six main themes: honoring a legacy of family caring, family unity, and relationship dynamics, motivation and personal sacrifice, responsibility, and roles in communication and discussion, relationship dynamics and insight, and stress and coping. The knowledge gained from the research study may be helpful for healthcare professionals, caregivers, and families. The study's findings will initiate positive social change through much-needed insights into the lived experiences of significant others, relatives, and extended family who care for AA families diagnosed with ADRD.

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Chapter 1: Introduction to the Study

Introduction

Due to the aging population in the United States, there exists a need for care for individuals diagnosed with Alzheimer's disease and related dementia (Alzheimer's Association, 2019). Alzheimer's disease and related dementia (ADRD) is a devastating chronic disease affecting millions of elderly individuals and families, not just in the United States but worldwide (Alzheimer's Association, 2018). ADRD is one of the top 10 causes of death in the United States. In 2019, more than 5.6 million people were diagnosed with ADRD (Alzheimer's Association,2019). Although Alzheimer’s disease is the most common type of dementia for people over 60, other forms of dementia, such as Lewy bodies, vascular dementia, mixed dementia, and frontotemporal dementia, are prevalent among this population (Centers for Disease Control and Prevention [CDC], 2016). African Americans (AAs) are more prone to ADRD than other nationalities (Moss et al., 2018b). AAs are at more significant risk of developing ADRD because of late diagnosis and risk of hypertension, diabetes, heart disease, and strokes (Hughes et al.,2009; Leung et al., 2011). It is believed that 6.9 million AAs will be over 65 and older by 2030. Therefore, the need for informal caregivers will increase for this minority group (Alzheimer's Association, 2018). Most AAs with ADRD receive informal care from relatives, extended family members, and significant others (Alzheimer's Association, 2019).

As the disease severity progresses, the person living with ADRD will become more dependent on family (Montgomery, 2018). Therefore, it is essential to understand the psychological and behavioral patterns of AA’s unique family system of care (Montgomery, 2018). Scott (2013) asserted that family caregivers have an essential role in providing care for family members diagnosed with ADRD; the care provided allows patients diagnosed with ADRD to sustain the comfort and familiar environment of being cared for in the home (Alzheimer's Association, 2018). Among the 5.5 million people living with ADRD in the United States, AAs comprise 33% of those affected (Mars, 2016). Minimal research addresses the AA family caregivers' family structure in caring for families diagnosed with ADRD (Mars, 2016). The psychological and behavioral patterns of the AA family system of care for loved ones with ADRD are important because AAs are more likely to suffer from this disease (Mars, 2016). Understanding the family dynamics may result in positive social change by establishing support systems for the family caring for loved ones with ADRD. In this chapter, I will briefly discuss the background and purpose of the study, introduce the research question, the nature of the study, assumptions, limitations, and the significance of this study.

Background of Problem

Research shows that by 2060, the ethnic minority population in the United States could reach 57% (241.3 million, US Census Bureau, 2014). The rapidly increasing geriatric population is at risk of developing ADRD (Pierre, 2021). Pierre (2021) explains that the prevalence of being diagnosed with ADRD is greater among AAs. Among the 5.5 million people living with ADRD in the United States, AAs comprise 33% of those affected (Mars., 2016).

Dilworth-Anderson et al. (2004) stated the importance of culture when researching AA caregivers. Although much research on caregiving exists among various ethnic or racial groups, my research on ADRD caregivers' family relationships from the perspective of significant others, extended family, and relatives produced limited results. Forbes (2018) explained the importance of addressing ethnic groups and minority caregivers to bring awareness of ADRD. Walker (2018) noted the importance of understating the diverse culture of minority family caregivers and their experiences. The increase in the minority geriatric population warrants changes to meet the needs for ethnic and cultural diversity (Walker, 2018). Therefore, research such as this can help create culturally sensitive literature to support programs and inform the healthcare community.

Informal family caregivers provide an estimated 17.4 billion hours of unpaid care for families with ADRD (Mars, 2016). Researchers postulate that paying families for caring for family members would cost $43.6 billion yearly (Mars, 2016). However, AAs are underrepresented in ADRD research. I reviewed pertinent literature on AA adult caregivers, family relationships, sibling relationships, female caregivers, and male caregivers to look at the family caregiving relationships for this study. My goal for this study is to add to existing literature and to gain an understanding of caregiving by adult family AA caregivers that may include significant others, relatives, and extended family.

Statement of Problem

The United States Census Bureau showed an increase in Americans aged 60 and older from 55.7 million to 83 million by 2050 (US Census Bureau,2023). Additionally, research shows that the racial minority population is expected to grow by 115% compared to European American (non-Hispanic) nationality (Alzheimer's Association, 2018). AAs are one of the largest minority groups in the United States; it is believed that 6.9 million AAs will live to be over 65 years old and older by 2030 (Alzheimer's Association, 2018). Therefore, the need for family caregivers will increase for this minority group.

Historically, minimal research addresses the AA family caregivers' family structure in caring for families diagnosed with ADRD (Mars, 2016). Family members that provide care consist of significant others, relatives, and extended family (Alzheimer's Association, 2019). The psychological and behavioral patterns of the AA family system of care for loved ones with ADRD are important because AAs are more likely to suffer from this disease (Mars, 2016). Cothran et al. (2020) explained that caregivers are affected by the experiences of those they care for who have ADRD. Consequently, AA contextual family experiences are not explored due to insufficient participation in research studies (Potter et al., 2017). Because racial minority participation is limited, research findings are on the caregiving experiences of European American, nonminority persons. Therefore, exploring the experiences and family structure of AA families caring for members diagnosed with ADRD is essential to the literature on this disease.

The family system of caregiving consists of significant others, extended family, and relatives who care for members diagnosed with ADRD. Colapinto (2019) explained that there needs to be more research on the effects of the caring experience, including the unique family structure of AA family caregivers. They were considering the gap in existing scholarship on the AA unique family structure and their interaction in the family relationship while caring for members diagnosed with. ADRD, further research is warranted.

Badana et al. (2019) emphasized that AAs spend more hours caring for members with ADRD; therefore, they are at a greater risk of heart disease and increased mortality. Caregivers score lower on stress scales than caregivers of other nationalities; recent studies show that AA caregivers experience stress and the burden of care as different nationalities (Badana et al., 2019). This study includes needed information to produce culturally appropriate services for this minority group

Purpose of Study

In this qualitative study, I explored how AA family caregivers describe their experiences and unique relationships within the family structure while caring for a family member diagnosed with ADRD. Due to AAs with ADRD living longer with the disease, family members who care for them will experience psychological and physical health problems that affect the caregiver's well-being (Colapinto, 2019; Mars, 2016). Therefore, there is a need for interventions and policies that support AA caregivers. I used a phenomenological qualitative approach to gain narratives from AA family caregivers regarding their experiences and attitudes toward family relationships between care recipients and their methods of informal caregiving. Through in-depth interviews with significant others, relatives, or extended family members, I addressed the gap in the literature on the experiences of AA caregivers and their unique family structure while caregiving for families diagnosed with ADRD.

Research Question

I used the following research question to guide this study: How do AA family caregivers describe their experiences and unique family structure when caring for a member with ADRD?

Conceptual Framework

For this research study, I used Bowen's family system theory (BFST) as a conceptual framework for exploring the dynamics of AA families in caring for a loved one with ADRD (Bowen,1978). Murrey BFST is considered the starting point of any study of family therapy (Papero, 1990). Bowen posits that individuals and families can use his family system theory to understand and accept individual contributions to the emotional functioning of the family (Bowen,1978). Bowen concluded that how the person thinks creates the reality for the person and family structure (Bowen, 1978). BSFT was developed to examine the family as a functioning interrelated network to form a unique family structure. A family is defined as a system composed of individual members and how they are interrelated to create the dynamics of the family structure (Colapinto, 2019; Harris, 2010). BFST focuses on the behavioral aspects of the family structure and how family members interrelate. In this study, I answered the research question about how AA family caregivers describe their experiences and unique family structure in the context of caring for a member with ADRD.

Colapinto (2019) explained that the family system theory developed from the influences of general system theory (GST), psychoanalysis, developmental psychology, and disassociated family structures in the forties. Helm (2021) argued that the family systems theory is a method of understanding and treating problems within the family structure. Colapinto (2019) argued that the family system is formed by interrelationships within the family structure (Colapinto, 2019). Minuchin explained that the family structure's well-being of individual family members translates into the well-being of family relationships (Helm, 2021). Additionally, the family system theory shifts the focus from the caregiver's unique experiences to the exchange and behavior of the network of all family members. I used the family system theory to understand the lived experiences of the AA caregiver's family structure and their unique family structure while caring for a member with ADRD.

Nature of the Study

I used a qualitative phenomenological approach to study the phenomenon of AA families who care for loved ones with ADRD and how the family described their experiences and family structure in caring for a member diagnosed with ADRD. Creswell (2017) and Merriam and Tisdell (2015) asserted that a phenomenological study involves comparing the accounts of family and extended family accounts that meet the characteristics or fall into a specific category. Guillen (2019) suggested that the phenomenological approach seeks to understand the complexity of lived experiences and the structure that defines human science and then apply social science. Van Manen (2014) explained phenomenological research as intermingled with practice. For instance, the subject's experiences and the structural framework of the subject's life experiences about specific issues allow the study to describe the phenomenon.

The data in this study came from volunteer families and extended families who meet the criteria of being AA caregivers who are caring for their loved ones with ADRD more than 3 days per week. I conducted this study in the Southeastern United States. Smith (2016) emphasized that there is no universal consensus about an appropriate sampling size for saturation. Researchers suggest six to 10 interviews for a smaller study, two to four interviews for a focus group, and 10 to 100 for secondary sources (Body, 2016; Fugard & Potts, 2015; Hageman & Wutich, 2017). I chose to seek rich, quality information to saturate; I interviewed six participants, as suggested by Hennink and Kaiser (2017).

I used the phenomenological method to explore the lived experiences of AA family caregivers and describe their experiences and family structure. Aker and Edwards (2012) concluded that qualitative research encompasses using subjective data that deepens the emotions, attitudes, and mental state of the participant's experiences of a phenomenon.

Definition of Key Terms

Alzheimer's Disease: A is a slowly progressive neurodegenerative disorder that impairs memory, speech, and the ability to function. Progression of the condition affects the person's mental and cognitive functioning (Adler et al., 2018).

Caregiver: I defined a caregiver as an AA adult. Between the ages of 20 and 65 years of age, male or female, currently function in an unpaid capacity, either part-time or full-time, as a caregiver for a family member diagnosed with Alzheimer's Disease or related dementias (Haley, 2019).

Dementia: The clinical symptom describes a decline in cognitive ability, behavior, spoken language, and thinking (Robinson et al., 2018).

Extended Family: Extended family is a relational network that includes grandparents, cousins, aunts, and uncles. And others. Relational networks extend beyond that family structure. Extended family members are outside the nuclear family (Ruvo,2020).

Family Caregiver: A family caregiver is a relative, significant other, or neighbor who provides care (Schulz, 2016).

Family Dynamics: Family dynamics is the unique family structure of the family (Ruvo,2020).

Family System Theory: Family System Theory focuses on the family structure's behavioral aspects and how family members interrelate (Colapinto, 2019).

Well-being: Well-being is considered the state of the life balance affected by events and challenges the family caregiver faces in caring for a family with ADRD **(**Dodge et al., year 2013).

Assumptions

In this study, I assumed the sampling population would be willing to discuss their experiences caring for someone diagnosed with ADRD. The sampling population included significant others, relatives, and extended family members. I further assumed that participants would provide candid accounts of their family dynamics and relationships as they have experienced as caregivers to older adults with ADRD.

Scope and Delimitations

I focused on AA adult caregivers, including significant others, relatives, and extended family. I defined a caregiver as an AA adult between the ages of 20 and 65, male or female, who currently functions in an unpaid capacity, either part-time or full-time, as a caregiver for a family member diagnosed with ADRD. Additionally, the caregiver provided home-based support to a relative with Alzheimer's. Given these participant parameters, the findings of this study may not be transferred to all AA adult caregivers.

Limitations

This research is limited to AA adult family caregivers who provided home-based support to patients or family members with ADRD. Participants were residents who lived in the Southeast United States. Furthermore, caregivers of other racial or ethnic groups were not considered in this study; therefore, the results of this qualitative study may not be transferred or generalized to different nationalities. Another limitation of this study was the small sample size.

The minimum sample size was open to six participants, which may include significant others, relatives, or extended family. Burmeister and Aitken (2012) posited that the sample size should be "large enough to address a research question and small enough to reach saturation" (p. 29). Hayter and Horsfall (2014) noted that researchers could use a limited number of participants with expert knowledge about a specific subject matter.

Significance of Study

Using elements of BFST and allowing for new theoretical themes to unfold, my goal was to understand AA family caregivers in the context of caring for members diagnosed with ADRD. I explored the experiences and unique family structure of AA families caring for members diagnosed with ADRD. I described the family care system's family interaction and family structure through phenomenological research.

Because AAs are more likely to be diagnosed with ADRD, the need for informal family care is expected to increase (Alzheimer's Association, 2019). The results of this study may be used to inform new efforts in education about AA family caregivers and the dynamics of their family network when caring for family members with ADRD.

Social Change

ADRD has become prevalent in the United States. Lloyd et al. (2019) concluded caregivers al. (2019) concluded caregivers experience significant stress and health impact while caring for a family member with ADRD. The caregiver's psychological well-being is also affected when long-term care is needed (Bradshaw et al., 2017). Most studies on ADRD are primarily based on non-Hispanic European Americans. The knowledge gained from this study on AA family caregivers caring for a member with ADRD may be helpful to healthcare professionals by providing programs and public policy that help guide better health initiatives that are culturally sensitive to this minority group.

Policy administrators' lack of research-based outcomes on this demographic has created a void in health care delivery and a public policy that is significant to this minority group. Data from this research shows a need for culturally relevant interventions and culturally important programs for AA family caregivers that could provide social change for this community. Additionally, the study's findings will provide much-needed insights into the lived experiences of significant others, relatives, and extended family who care for AAs with ADRD (Colapinto,2019; Mars, 2016).

Summary

In Chapter 1, I introduced the primary direction and purpose of the research. Additionally, I provided a brief overview justifying the need to focus on the AA family caregiver network relationship in caring for a member with ADRD. I concluded Chapter 1 with a description of the significance and the implications for positive social change. In Chapter 2, I will discuss the literature that will help establish the relevance of the phenomenon and a detailed review of the literature exploring ADRD, AA family the caregiver, the aging population, the prevalence of Alzheimer’s disease, the effect of Alzheimer’s disease has on the family, the prevalence of ADRD on AA community, and AA caregivers.

Chapter 2: Literature Review

Introduction

The purpose of this phenomenological research study was to explore how AA family caregivers describe their experiences and unique relationships within the family structure while caring for a family member diagnosed with ADRD. Researchers have studied caregiver burden and caregiver stress and how it affects the caregiver's well-being, focusing on non-ethnic nationalities (Forbes,2018). The availability of research on specific ethnicities and cultural areas, such as the AA family structure, is limited (Bekhat,2015). My literature review found limited information from a qualitative research perspective focusing on AAs' unique family structure and experiences. I found a gap in the literature from a qualitative research perspective focusing on the AA family dynamic or unique structure.

I will begin the literature review section with an overview of the literature search strategy and conceptual framework of the family system theory and how it relates to the caregiving of the AA family. I reviewed the aging population and the prevalence of Alzheimer's disease in the age population and Alzheimer's disease and family. Additionally, I examined the prevalence of Alzheimer's disease in the AA community. Lastly, I present studies that assist in obtaining the main aim of the family structure when caring for a person diagnosed with ADRD.

In this qualitative study, I explored how AA family caregivers describe their family dynamics or unique family structure when caring for a member with ADRD. Understanding the AA family's unique family structure phenomenon, which includes significant others, relatives, and extended family, is necessary to gain insight into caring for loved ones diagnosed with ADRD.

Literature Search Strategy

I conducted a review of the extracting literature using several different resource sites. The resource sites used included psychology, social psychology, social work, nursing, and mental health. In my search for peer-reviewed journal articles, doctoral research, and books, I accessed the following databases, websites, and search engines: My literature search involved using Walden University. Library. MEDLINE, PsycARTICLES, Ebsco Host, ERIC, Google Scholar, SAGE Journal, Research Gate, PubMed. ProQuest Central, Thoreau, National Institute on Aging, Centers for Disease Control and Prevention, Alzheimer's Association, Scholar. Computerized databases include Thoreau, Sage Journal, ProQuest Central, PsycARTICLES, and PsycINFO. The terms I used to search titles and abstracts include *caregiving, caregivers,* AA *caregivers,* AA*s, Family caregivers,* AA *family caregivers, family care system, Alzheimer's Disease*, *familism, dementia caregivers, family theory, and family system, informal caregiver*, *formal caregivers, sibling relationships and caregiving, family structure and caregiving, Dementia, dementia caregiver, caregivers' well-being*, and *well-being*. I reviewed studies and articles on dementia, AA caregivers, Alzheimer's disease, and caregiving for relevance to my research concerning method and content. Apart from seminal scholarship dating back to 1970, I focused on peer-reviewed journal articles published from 2016 to 2022. The literature review includes current information and studies about AA family caregivers who care for loved ones with ADRD. Additionally, I reviewed journals on family dynamics, caregiver well-being, and structure. Understanding family dynamics is essential in exploring AA caregivers’ actions within the family structure to guide the optimal functioning of the system and the member with ADRD.

Conceptual Framework

BFST is the conceptual framework for understanding the family caregiver structure related to caring for loved ones diagnosed with ADRD (Bowen, 1978; Erdem & Safi, 2018; Colapinto, 2019; Helm, 2021). Murrey’s BFST is considered the starting point of any study of family therapy (Papero, 1990). Bowen posits that his family system theory helps individuals and families understand and accept individual contributions to emotional functioning individually and with the family (Bowen,1978). Bowen concluded that how the person thinks creates the reality for the person and family structure (Bowen, 1978). BFST was used to explore the family as an active network that interrelates to form a unique family structure. Bowen posited that the purpose of his family system theory is for individuals and families to understand and accept individual contributions to emotional functioning individually and with the family (Bowen, 1978). Bowen concluded that how the person thinks creates the reality for the person and family structure (Bowen, 1978). BFST viewed the family as a functioning, interrelated network to form a unique family structure (Bowen,1978). BFST was developed from psychoanalysis and developmental psychology. BFST evolved into other types of family therapy that helped explain family relationships, the behavioral pattern of extended family, and how the family unit works together.

Colapinto (2019) emphasized that the family's cohesiveness is characterized by their ability to relate. Analyzing the family structure became famous in 1950 during World War II (Colapinto, 2019). Anderson (2011) proposed that Bowen's theory is relevant and more relevant for understanding family dynamics from a unique perspective than Freudian thinking. Anderson concluded that Bowen's approach focuses on making sense of human functioning rather than the autonomy of the individual caregiver (Anderson, 2011). According to Jokogbola et al. (2018), family caregivers caring for members diagnosed with ADRD have a lack of training and understanding of caring for a dementia patient; because of the complexity of the role, family caregivers suffer from depression, caregiver stress, and abuse. Researchers posit that BFST can improve family communication and bring awareness of family roles and responsibilities (Jokogbola et al., 2018). Jokogbola et al. (2018) emphasized the importance of developing training for family caregivers. Researchers posit that BFST can improve family communication and bring awareness of family roles and responsibilities (Jokogbola et al.,2018). Jokogbola et al. (2018) emphasized the importance of paying attention to family caregivers and their interaction with the family dynamics.

Erdem and Safi (2018) proposed that the BFST of family structure influenced the interaction and family dynamics of families extending care to patients with Alzheimer's and related dementia. Colapinto (2019) concluded that the foundation of the Family Structural theory is the family dynamic and interaction of significant others, relatives, and extended family. Eddy et al. (2021) explained that family dynamics and exchange have a considerable bearing on how the family functions in stressful situations. Eddy et al.

(2021) also noted that the family structure was like a sports team; researchers use this theory to study the relationships between significant others, extended family, and relatives to examine caregiving and care recipients.

The BFST has been at the forefront of guiding family therapy (Erdem & Safi, 2018). This treatment system has evolved to include culture, ethnicity, race, social class, sexual orientation, family history, and values (Erdem & Safi, 2018). Erdem and Safi (2018) concluded that when using BFST as a research tool and looking through a cultural lens, a change in basic assumptions in studies of human development and family relationships is evident. The Bowen system defines the family as a two-system construct; the family system is a relationship and emotional approach that allows family members to influence and be influenced by one another (Erdem & Safi, 2018).

The BFST system proposes that the family is governed by “similar rules as other natural systems” (Erdem & Safi, 2018, p. 470). Bowen argued that chronic anxiety and differentiation of self are the primary factors of family functioning. These two-family-to-family two-family attributes set the structural tone within the family structure (Erdem & Safi, 2018). Erdem and Safi (2018) stated that chronic anxiety is formed when family members maintain themselves while having meaningful connections within the family system. The second factor, differentiation of self, occurs when family members learn strategies to regulate anxiety (Erdem & Safi, 2018). Researchers concluded that members practice “management tools and learn to tolerate the dilemma of conflicting and recurring forces to favor togetherness and separateness” in the family system. They have a healthy level of differentiation of self (Erdem & Safi, 2018).

Differentiation of self is the nucleus of the BFST theory of family functioning (Erdem & Safi, 2018). This process shows how family alliances are made; it includes roles, rules, boundaries, and functional and dysfunctional values set within the family (Erdem & Safi, 2018). Researchers provide empirical evidence to validate the constructs of BEST theory (Erdem &Safi, 2018).

Colapinto (2019) explained that the family system theory developed from the influences of GST, psychoanalysis, developmental psychology, and disassociated family structures in the forties. Helm (2021) argued that the family systems theory is a method of understanding and treating problems within the family structure. Colapinto (2019) asserted that interrelated relationships within the family structure form the family system. Helm (2021) indicated that Minuchin's theory of the family structure's well-being of individual family members translates into the well-being of family relationships. Additionally, the family system theory shifts the focus from the caregiver's firsthand experiences to the family members' exchange and behavior (Colapinto, 2019). The family systems theory was developed from psychoanalysis and developmental psychology. The family systems theory evolved into other types of family therapy that helped explain family relationships, the behavioral pattern of extended family, and how the family unit works together. Colapinto (2019) emphasized that the family's cohesiveness is characterized by their ability to relate. Analyzing the family structure became famous in 1950 during World War II (Colapinto, 2019), as well as the influence of GST, psychoanalysis, development psychology, and the dysfunction of the family structure. Anderson (2011) proposed that Bowen's theory is relevant for understanding family dynamics from a perspective different from Freudian thinking. Anderson (2011) concluded that Bowen's approach focuses on making sense of human functioning rather than the autonomy of the individual caregiver. According to Jokogbola et al. (2018), family caregivers caring for members diagnosed with dementia have a lack of training and understanding of caring for a dementia patient; because of the complexity of the role, family caregivers suffer from depression, caregiver stress, and abuse. Researchers posit that BFST can improve family communication and bring awareness of family roles and responsibilities (Jokogbola et al., 2018). Jokogbola et al. (2018) emphasized the importance of developing training for family caregivers.

Von Bertalanffy

Von Bertalanffy examined the family as a phenomenon and holistic unit instead of reviewing each person’s behavioral aspect (Colapinto, 2019). I did not focus on the dysfunction of the family network but on the team and individuals and how the parts work together in caring for someone diagnosed with ADRD. Understanding the family structure and how the family interacts may result in improved levels of caregiver stress. Bowen believed that the family system and the emotional development of family unity "was the primary source of human emotion" (Colapinto, 2019, p. 113). The theory explains dynamic interdependence and how the family functions in reciprocal relationships (Colapinto, 2019). Bronner et al. (2019) described the BFST as a framework for family members to stay emotionally connected and interconnected to their family structure while defining the self. BFST is made up of systems and subsystems within the dynamic of the family (Bronner et al., 2019). It supports the impact on caregivers caring for members diagnosed with ADRD because ADRD is considered a family disease (Bronner et al., 2019).

Salvador Minuchin

Salvador Minuchin examined the family and focused his studies on how the family system interrelates (Helm, 2021). He discussed how the family interacted with a stressor and determined the level of functions or dysfunction based on these principles (Helm, 2021). He explained how families set social boundaries within the family system (Helm, 2021). Minuchin focused on families' psychological, financial, and emotional problems when providing informal care to members with cognitive impairment (Helm, 2021). Garcia (2021) stated that when family caregivers share responsibilities, the well-being of the person or person providing care increases. This results in better health outcomes for the patient and the caregiver. This theory illustrates how emotionally connected family members are when caring for family members (Garcia, 2021). For instance, if a family member alters their behavior toward caregiving, it may influence other family caregivers, creating a realignment of goals and behaviors (Garcia, 2021).

I used the BFST of care to explore the experiences of AA families as a significant network and how they interact within the family dynamics. Often, families face psychological, financial, and emotional problems when caring for a member diagnosed with ADRD (Garcia,2021). The structural family methodology was developed within the treatment setting; this research study will emphasize the lived experiences and dynamics of the family structure in caring for a person diagnosed with ADRD.

BFST describes the family and the family members' ability to change depending upon the circumstances and situations the members face (Bowen,1978). The process emphasizes the family and the family's ability to establish and reestablish boundaries for members. This process is focused on the relationship between family members. Thus, the goal of the structural family network is to preserve the structure of the family network (Colapinto, 2019).

The Aging Population

According to the World Health Organization, the elderly 60 and over are the fastest-growing group in the world (Pritchard, 2020). Pritchard (2020) stated that the increase in longevity is due to better overall healthcare, disease treatment, and preventive measures. Research shows that 40% of the population is comprised of seniors; the increase in the aging process will result in new challenges in health-related issues for older Americans (Pritchard,2020). Corrada et al. (2017) explained that the aging population will be the oldest. Baby boomers are considered the largest and most aged population. Baby Boomers are those born between 1946 and 1964 (Wilson, 2002). Researchers concluded that seventy-six million people are the baby boomer generation (Wilson,2002). Pritchard concluded that the aging population and cognitive decline that results in dementia and Alzheimer's disease are expected to increase (Pritchard,2020).

Prevalence of Alzheimer's Disease

Consequently, most patients diagnosed with ADRD are over sixty-five. An early sign of Alzheimer's Disease includes short-term memory loss, wandering, inability to cook, clean, bathe, read, diminished appetite, and speech impairment (Alzheimer's

Association, 2018). Disconnection with life occurrences is also one of the significant symptoms of this destabilizing disease (Alzheimer’s Association,2019). Alzheimer's disease is one of the most common dementia-related illnesses for individuals over sixty-five. All forms of dementia will result in memory loss, subsequent behavioral and personality changes, and impaired judgment and functioning. (Alzheimer's Association,2019). Approximately 15.7 million individuals are affected by ADRD (National Institutes of Health. (2015).

According to research, Alzheimer's disease is the sixth leading cause of death in the United States (Alzheimer's Association,2019). Often, family members who care for the person diagnosed with ADRD are informal, unpaid caregivers who receive little to no outside assistance. Among demographic groups, 21% of the caregivers are AA, 19.8 are Hispanic, and 16% are. 9% are European Americans (National Institutes of Health. (2015).

Coping Strategies

Kosberg et al. (2007) explored AA caregivers and European American family caregivers in rural Alabama and their coping experiences. The research focused on similarities and differences in caregiver interaction and the burden associated with caregiving duties (Kosberg et al., 2007). Interviews were random telephone interviews used in a probability sample of 67 AA caregivers, seventy-four non-Hispanic caregivers, and 67 European American caregivers. Kosberg et al. (2007) found that AA caregivers were more likely to have different coping strategies than European American caregivers. Research showed that AA caregivers served more hours or gave more hours of care and used religion in denial to help manage. Researchers concluded that additional research is needed for urban and rural areas to explore caregivers' experiences and ethnic backgrounds of diverse cultures and nationalities (Kosberg et al.,2007).

Cost of Caring for ADRD Patients

ADRD affects those diagnosed and the families that care for them. Families often experience financial hardship, emotional confusion, and challenges managing their loved ones (Alzheimer's Association,2019). Because ADRD-related illness patients are cared for by family, the whole family structure is impacted by the disease. (Alzheimer's Association,2018) Alzheimer's disease is the leading cause of dementia. Alzheimer's disease affects more than five million adults over sixty-five; it is the third costliest disease and the fourth leading cause of death for this age demographic (Alzheimer's Association, according to Alzheimer's Facts & Figures,2018), the cost of care for a person diagnosed with ADRD will exceed $234 billion in informal care. 'ADRD affects people of all nationalities and races (Alzheimer's Association, 2019).

In another study, Dilworth-Anderson et al. (2004) emphasized the importance of culture as an essential factor in the outcome of AA caregivers who provide care for family members diagnosed with ADRD. Researchers asserted that AAs caring for older adults with Dementia underutilize legal support services (Dilworth-Anderson et al., 2004). Although the research of Dilworth-Anderson et al. (2004) focused on the stress model, the researchers looked at the cultural values and beliefs of the AA caregiver and their effect on the caregiver.

Subsequently, Han and Radel (2015) used a qualitative study to explore spousal family caregiver perceptions about caring for a spouse with ADRD. Five caregivers participated in the study. Researchers noted that family members are often the primary caregivers who support daily functioning and emotional support for those diagnosed with ADRD. The research study lasted for eight months and focused on the lived experiences of the individual and family members in the context of their experiences. The methodology research used recommends a minimal sample size for the case comparison. Han and Radel (2015) searched for patterns across cases and shared themes of participation.

A qualitative study by Forbes (2018) explored the lived experiences of AA women who cared for loved ones with ADRD. A conceptual framework of attachment theory guided this qualitative study. Researchers sought to learn from women's experiences caring for loved ones with ADRD. The study included ten participants. One participant was a spouse caring for her wife; another a great-niece caring for their great aunt; a daughter-in-law caring for her mother-in-law; two nieces caring for their aunts; all women were AA.

The question that guided the study is, how do AA women cope with caring for a loved one with ADRD? Forbes's research concluded that the women felt a sense of obligation to the family member, several mad promises to care for the member as filial promises; all women agreed that caring and giving were challenging and that their spirituality was how they coped with challenges and difficult times. Forbes (2018) adds to the limited body of knowledge on research on ethnic groups. Additionally, further analysis can address ethnic groups and other minority caregivers. Although the availability of research has increased, researchers agree that research involving cultural diversity is limited (Forbes,2018). Forbes emphasizes the lack of studies on AA women who care for family members with ADRD

Prevalence of ADRD in the AA Community

ADRD affects more than five million adults over sixty-five; it is the third costliest disease and the fourth leading cause of death for this age demographic (Alzheimer’s Association,2019). ADRD affects people of all nationalities and races. However, AAs have a greater risk than other racial and ethnic groups (Alzheimer's Association, 2019). Stepler et al. (2020) noted that AAs are more prone to ADRD than different nationalities. AAs are the largest minority group in the United States; it is believed that 6.9 million AAs will live to be over 65 years old and older by 2030. Trovinia et al. (2019) explained a higher prevalence of ADRD among AAs due to hypertension and diabetes than in other nationalities. Matthews et al. (2018) research agreed with Trovinia et al. (2019) that AAs and Hispanics are at greater risk of having ADRD. Perdomo-Romero et al., (2017) concluded. However, AAs are at a greater risk of ADRD because they are diagnosed with the disease later than other nationalities. Research shows that AAs are more likely than European Americans to have cognitive impairment related to ADRD (Alzheimer’s Association, 2019). Trovinia et al. (2019) stated that families normalize cognitive impairment and memory loss as personality problems due to late diagnosis.

Understanding AA caregivers' psychological and behavioral patterns is essential because AAs are more likely to suffer from this Disease (Stepler et al., 2020). Therefore, the need for informal care for this population has increased. Those caring for patients diagnosed with ADRD are family members or relatives (Association, A. S, 2018). Mars (2016) concluded that minimal research addresses the well-being of AA caregivers. Thus, it leads to a need for more literature studying culturally diverse caregivers (Perdomo-Romero, 2017).

Mars (2016) used a qualitative research methodology to explain the lived experience of 16 AA informal family caregivers. Research showed that caregivers utilized the family network rather than seeking outside help to care for ADRD patients. The primary purpose of this qualitative study was to explore the lived experience of an informal AA family caregiver who cares for a member with ADRD. Consequently, AA caregivers report more positive appraisals and less stress than caregivers of other nationalities (Epps et al., 2019). In contrast to Epps, Rose, and Lopez’s suggestion that AA caregiver is believed to be more resourceful and suffer from less stress and anxiety than other nationalities, Hunter and Watson (2016) explained that AAs may experience tension in diverse ways and react to stressors differently. For example, research has shown that AA women redirect life’s pressure into "resilience and power” (p.47). Waites (2009) suggests that AA caregivers depend on cultural values and beliefs masked in compassion.

Ramírez-Perdomo (2017) argued that caregivers are affected by the experiences of those they care for who have ADRD. AA contextual experiences are often not explored due to insufficient participation in research studies (Ramírez Perdomo,2017). Thus, it leads to a lack of literature on studying culturally diverse caregivers (Mars, 2016). The psychological and behavioral patterns of the AA family system of care for loved ones with ADRD are essential because AAs are more likely to suffer from this disease (Mars, 2016).

AA Caregivers

Smith (2019) explained that family members care for aging parents in the United States. Dilworth-Anderson et al. (2005) asserted that AA families provide more support in caregiving than European Americans. Additionally, AA has stronger beliefs about caring for older adults than other racial groups (Smith, 2019). Dilworth-Anderson et al. (2004) proposed that due to AA's cultural beliefs, shared care assistance from family and extended family assistance in care for elderly members.

Roth et al. (2015) concluded that AA family caregivers report different experiences, emotional comments, and attitudes toward caring for an ADRD patient in the home. Roth et al. (2015) suggest that racial and ethnic group was a determinant in the care of diagnosed patients. Epps et al. (2019) posit that a better understanding of the functioning of the family network could explain psychological and physical outcomes for a family caring for a person diagnosed with ADRD.

Epps et al. (2019) assessment of racial and ethnic caregivers agreed with Roth et al. (2015) that cultural differences are prevalent in caregiving. Epps et al. (2019) characterized the outcome of caring for someone with ADRD by the racial or ethnic background of the family caregiver. Epps et al. (2019) posit that familism is another reason AA caregivers display strong family ties. Familism is the devotion to one's family network and the AA community (Epps et al., 2019).

Researchers used qualitative methods to identify and group AA family caregivers who cared for loved ones diagnosed with Dementia (Epps et al., 2019). The thematic analysis characterized three themes that emerged: (a) Religiosity, (b) Familism, and (c) Complexity (Epps et al., 2019). Epps et al. (2019) suggested that the family network has specific functionality. Understanding this paradigm could explain AA's physical and psychological well-being in caring for a family diagnosed with Alzheimer's and related Dementia.

Epps et al. (2019) explained that family expectations play a significant role in caring for family members. Additionally, the AA culture practices familism, which builds resilience and redirects stressors associated with caregiving (Epps et al.,2019). Epps et al.'s (2019) research included twenty-six family caregivers from eighteen families' networks. Familism is the family's culture or the sense of belonging to the family network. The network in this research study comprised non-kin relatives, cousins, grandchildren, church members, neighbors, children, and spousal relations. The third theme examined in this study was Religiosity (Epps et al., 2019). AA families exhibit strong beliefs in God and church. Epps et al. (2019) used a social gram to help characterize the AA family network.

Additionally, AA caregivers report more positive appraisal and less stress than caregivers of other nationalities (Epps et al., 2019). In contrast to Epps et al. (2019), the findings of Watson and Hunter (2016) suggested that AA caregivers are believed to be more resourceful and suffer from less stress and anxiety than other nationalities. However, Epps et al. (2019) explained that AA family caregivers have stronger beliefs regarding family obligations and more help from extended members, providing a more robust care network and less stress when caring for members with ADRD.

In another descriptive study, Hunter and Watson (2016) concluded that AAs might experience and react to stressors differently. For example, research has shown that AA women redirect pressure into "resilience and power" (p.47). Waites (2009) suggests that AA caregivers depend on cultural values and beliefs masked in compassion. Research indicates that AA's family network and obligation help build resilience that may buffer the negative aspects of caring for someone with ADRD (Epps et al., 2019). Researchers hoped to bring awareness to AA families by suggesting that the

AA family is accurately explained and viewed as a network rather than dead dyads. Researchers believe looking at the AA family as a network will help “expand the definition of family for both research and practice” (Epps et al., 2019, p. 24). Epps et al. (2019) concluded that additional research on the family structure and familism related to caregiving is needed to understand the influence of the caregiving experience. Although there is research on ADRD and caregiving, there is limited information on AA family caregivers caring for members with ADRD. Therefore, this study may fill a gap in the existing literature by offering insight into the lives of the family structure of an AA family that includes significant others, relatives, and extended family members. Mars (2016) concluded that the lack of AA participation in research causes a need to understand cultural diversity in caregiving.

Summary

Chapter 2 reviewed existing literature on AA caregivers, relationships, and the reality of caring for someone diagnosed with ADRD. In this chapter, I discussed relevant and existing scholarships and listed supporting studies and the significance of the studies. I began by outlining the literature search strategy and conceptual framework. I examined the prevalence of ADRD and the prevalence of ADRD on AA families and how the disease impacts the AA community and AA caregivers. In Chapter 3, I described the research methodology and discussed data collection, analysis, issues of trustworthiness, and ethical considerations.

Chapter 3: Research Method

Introduction

I explored how AA family caregivers describe their well-being and family dynamics in caring for ADRD members. This chapter discusses the qualitative research method, specifically the phenomenology methodology I used in this study. Chapter 3 provides for the study, research design, rationale, the research question, my role as the researcher, methodology, procedures used to collect and analyze data, ethical considerations, and informed consent. The chapter will conclude with a summary of the research method.

Research Design and Rationale

Both quantitative and qualitative data are necessary to understand human behavior. Researchers use the quantitative research paradigm to evaluate hypotheses and make assumptions about human behavior (Wienclaw, 2021). The qualitative research paradigm is used when the scholarship is limited. Antwi and Hamza (2015) asserted that quantitative and qualitative methodologies examine phenomena through different worldviews. A quantitative study, or generalized measure, measures the sample size and quantify or generalized measures the sample size and quantifies or generalizes to a large population (Malagon-Maldonado, 2014). Qualitative researchers gather data from the real-world experiences of others and then use inductive reasoning to develop theories (Wienclaw, 2021). Smith (2019) explained that a qualitative research approach may be a valuable method to explore the outcome of individuals who deliver care and advance knowledge of research-based interventions.

The qualitative method was appropriate for this inquiry on family caregiving and dynamics because of its person-centered approach. Qualitative researchers are active instruments that observe, interact, and attempt to make sense of the participant's lived experiences with a phenomenon (Merriam & Tisdell, 2015; Malterud et al.,2016). My role as a researcher was to observe and attempt to make sense of the participants' lived experiences in the structure of their family dynamics.

I used a qualitative, phenomenological study to explore the human experiences of AA family caregivers and their well-being, family interaction, and reaction to care for a member with ADRD. I used a descriptive, retrospective, in-depth analysis of an AA caregiver's family dynamics (see Patton, 2015).

Research Question

I used the following research question for this study: How do AA family caregivers describe their experiences and unique family structure when caring for a member diagnosed with ADRD?

Role of the Researcher

Researchers who employ qualitative design seek to understand the participant's experiences, worldviews, and perspectives about the studied events or issues (Smith, 2019). Burns and Grove (2007) posited that a researcher must take a naïve approach to research and collecting data. Smith (2019) explained that researchers must be cautious against bias and preconceived ideas about the phenomenon under investigation. I collected data through face-to-face Zoom meetings and over the telephone due to COVID-19 restrictions.

I am an AA woman who has worked in management and community service for over 25 years. I have had the opportunity to work with unserved and underserved populations in my career. I understand the need for AA to participate in research studies and the value it can bring to the scholarship of research studies. In addition to my work experience. I have been a family caregiver and witnessed other AA family caregivers who cared for family members with ADRD. As the researcher, I served as the primary observer and collector of information for those participating in the study. I methodically collected and structured data based on the approach selected for this study. I maintained a neutral position throughout the research process.

Methodology

In this study, I used a qualitative, phenomenological approach to explore the experiences and unique family relationships of AA families that care for a member with ADRD. I used open-ended questions during the interviews with AA caregivers. They reflected on their experiences and family structure when caring for their member with ADRD.

I examined the AA caregivers' thoughts about the experience of being a caregiver and the family network. Percy et al. (2013) explained that a qualitative study is used so that participants can account for their worldviews, perspectives, and beliefs and reflect on their thoughts and feelings.

Instrumentation

Qualitative research is unique because the researcher is considered the instrument used to gather data for the research project (Rossman & Rallis, 2003). The researcher is the primary instructor in qualitative research (Merriam & Tisdell, 2015). Merriam and Tisdell (2015) concluded that researchers seek to understand the individual's perspectives on the phenomenon using qualitative design mythology. As the researcher, I collected data from face-to-face interviews via the Internet (Zoom or Facetime) and over the phone. Due to public contact mandates, social media tools were the most effective. I methodically collected and structured information based on the approach selected for this research study. I maintained a record of the data and upheld a neutral position throughout this process.

Instrumentation for this study included an audio recorder for each interview, observation notes taken during the interview, and prepared interview questions (See Appendix A) to elicit the perspectives of AA adult family caregivers of members diagnosed with ADRD. During the interview, I allowed the family caregivers to express their opinions and experiences concerning the dynamic and interrelationship of the family dynamics.

I collected all data using three instruments: the demographic data form (See Appendix D), verbatim transcripts from in-depth interviews, and file notes or personal diaries (Polit & Beck, 2010). As the AA family caregiver's family structure network experiences in caring for members are a phenomenon, the researcher takes on specific responsibilities to transform the information (Speziale & Carpenter, 2007).

Sampling Size

I recruited AA adult family caregivers in this study. Cleary et al. (2014) stated that if the sample size is too small, it could compromise the depth and breadth, and if the sample size is too extensive, the results could be a superficial volume of data. I accepted six participants from different family networks. Collecting and analyzing data concludes when no current information, new themes, or codes become evident, or data becomes redundant (Bowen, 2008; Guest et al., 2020). Research has become saturated when there is no current information. Guest et al. (2020) defined the saturation process as the point where the researcher identified no further communication from qualitative interviews. Empirical research has been used to address how and when data are measured to saturation. The study found that the first five to six interviews contributed the newest information (Guest et al.,2020). Consequently, further information was not discovered when the data set approached 20 consultations. (Guest, et al., 2020).

Selection of Participants

I used purposive sampling to select AA family caregivers, significant others, relatives, and extended family. Etikan et al. (2016) stated that purposeful sampling provides rich content from specific populations. Researchers deliberately select individuals or groups that can help answer the research questions or questions (Bradshaw et al., 2017). I recruited family participants from the Southeastern United States. Inclusion criteria were (a) being an adult family caregiver, (b) caring for a noninstitutionalized adult 60 or older living with Alzheimer's or related dementia, and (d) self-identifying as AA.

Inclusion Criteria

The inclusion criteria for the selection process were that participants must be AA family members who provided care for a member with ADRD. The Participant had to have provided care for over 6 months as part of the family care network. Additionally, the family caregiver must be over 21 and speak English.

Exclusion Criteria

Establishing a rapport with participants is essential in qualitative research. Only participants who spoke English were included in this study. Additionally, if the person diagnosed with ADRD resided in an assisted living facility and was not cared for by family members, the participants were not selected.

Data Collection

According to Smith (2019), qualitative research offers a person's description of the family caregiver's attitude, expression, and family dynamics. The interview questions consisted of 10 open-ended questions (See Appendix A). Smith (2019) noted that interviews with participants should be done in a quiet, semi-private place. The discussion with participants consisted of online interviews via Zoom in a home office. Four interviews with participants were conducted via Zoom. The meeting time was convenient for participants. Additionally, if an interviewee requested that the discussion occur via telephone, I positioned myself in a location where human traffic was limited. Two interviews with participants were conducted via telephone.

The construction of the interview question aligned with the exploration of the family caregivers' experiences. I designed the research interview questions to collect relevant data to answer the research question. The expected duration of the interview was 40 to 60 minutes to complete. I used an audio recorder to transcribe each participant's responses verbatim, diminishing the possibility of bias or misinterpretation. According to

Namageyo-Funa et al. (2014), using a numerical coding system protects participants' identities. Therefore, each participant was assigned a numerical code by family number and letter. The interview data and audio recordings will remain password-protected in my home office's locked and secured file cabinet.

Informed Consent

Before the individual interview, participants were informed of the measures that support confidentiality in a pre-interview phone call. Furthermore, I discussed the benefits and potential harm of participating in this study (Holt, 2010). Holt (2010) posited that participants' risk levels should be reasonable, and safeguards should be taken to mitigate any feelings related to issues.

Debriefing

Researchers use debriefing to address participants under duress (Smith, 2019). Often, participants become emotional when recounting experiences during the interview. However, in this research study, participants were only asked about care and their family structure; no risk was involved. The participants received a written transcript of their interviews for accuracy once the transcription was complete. Participants were notified by phone once the study was completed, and I had the opportunity to discuss the interview questions and the participant's answers for accuracy. Only one participant wanted a written transcript.

Confidentiality

I maintained confidentiality by replacing participants' identifying information with a numerical code on material related to this qualitative study (Ravitch &

Mittenfelner, 2016). I advised participants that their names and other personal data should be altered to maintain their identities. Audio recordings, transcripts, consent forms, and my journal will be stored under lock and key, password-protected in my office. All data stored on my personal computer is backed up and password protected. After 5 years, the data collected for this study will be destroyed, shredded, or deleted.

Data analysis requires researchers to familiarize themselves with the data and become immersed in the phenomenon under investigation (Smith, 2019). My goal in this study was to convey the experience of the AA family caregiver by exploring their well-being and family dynamics in caring for a member with ADRD.

Braun and Clarke (2006) explained that qualitative studies often use thematic analysis. Ravitch and Carl (2016) stated that using analyzing strategies allows the researchers to develop codes and how they will be combined, clustered, and analyzed. I used Ravitch and Carl's (2016) theme development stages. After collecting and transcribing the data, I used a six-step process to determine themes. The steps included the following.

1. Read all coded data.
2. Group and combine codes
3. Document themes and what they mean
4. Recode data
5. Tell the story of the theme in writing
6. I wrote memos to make sense of data and develop patterns

Furthermore, I used line-by-line first-level coding of transcribed interviews (see Saldana, 2016)

Data Analysis Plan

Data analysis requires researchers to familiarize themselves with the data and become immersed in the phenomenon under investigation (Smith, 2019). The purpose of this research study was to convey the experience of the AA family caregiver by exploring their experiences and family structure when caring for a member with ADRD. Braun and Clarke (2006) explained that qualitative studies often use thematic analysis. Ravitch and Carl (2016) stated that using analyzing strategies allows the researchers to develop codes and how they will be combined, clustered, and analyzed. I used Ravitch and Carl's (2016) theme development stages.

After each interview, the process of data analysis began. After data collection, I organized and reviewed the data. I analyzed the data to formulate an understanding of the information. Ravitch and Carl (2016) explained that having a plan to organize data is essential to the research process. I managed and collected data after each interview with participants. I used Ravitch and Carl’s three-pronged data analysis process. Ravitch and Carl’s (2016) three-pronged data analysis process includes the following: (a) data organization and management, (b)writing and representation, and (c) immersive engagement. Saldana (2016) explained that a code is a word or short phrase that captures the essence of the text or data source and is the initial process in data analysis. Therefore, read transcripts to obtain codes and themes. Also, due to this study's small sample size, I manually coded. I utilized Saldana’s suggestion of highlighting principles and themes to assess the information during the immersive engagement process. Additionally, I employed first-level coding, which is a line-by-line analysis of each transcribed interview (Saldana, 2016). The codes from this step revealed concepts and categories within the transcribed data.

Issues of Trustworthiness

For a researcher to establish trustworthiness, a qualitative research study must be credible, transferable, dependable, and confirmable. Colorado and Evans (2016) agreed that these techniques help develop trustworthiness in a study. Rubin and Rubin (2012) emphasized the importance of transparency in research to help establish reliability.

The instrument is used in qualitative research to develop and collect data (Smith, 2019). Since the researcher is the chief instrument in the research process, transparency is essential to help establish trustworthiness in the study (Fusch & Ness, 2015). Therefore, I maintained a reflexive journal throughout the research process (Fusch & Ness, 2015). Also, the journal described the dissertation's research design, data collection, and analysis. My goal as a researcher was to achieve high accuracy by revisiting facts, experiences, and interpretations collected from the research.

Credibility

As the researcher, I maintained an audit trail and member checking to address credibility. The allotted time for the interview was 45 to 60 minutes. I also used the audit trail to maintain an in-depth record of the study. The document includes the interview protocol, notes, and my reflexive journal. This approach was constructed from the participants' narrative, which thoroughly describes how data was collected and analyzed

(Ravitch & Mittenfelner, 2016). Member checking encompassed participants confirming and validating the accuracy of the transcribed interview.

Member Checking

Smith (2019) argued that member checking promotes trustworthiness in research because study participants relay reasons for the phenomenon, how they felt during the event, and their responses. Cope (2014) stated that member checking allows participants to correct any errors or misinterpretations of their responses. Participants know their experiences and how they respond to the events and challenges in their worlds. Therefore, after the interview, I requested the participants' aid for the accuracy of their responses. After participating family caregivers checked for accuracy, I analyzed the data. Participants received phone notification of the project's completion and discussed the results with the researcher. Only one participant chose an email copy.

Transferability

Transferability occurs when data can be applied or transferred to another context (Cope, 2014). The process of transferability allows readers to use results from research to compare. I established transferability through detailed data descriptions and results extracted from such data (Bradshaw et al., 2017). I described the participants' demographics, data-gathering techniques, and data analysis (Bradshaw et al., 2017). Using techniques to assure transferability allows other researchers to transfer aspects of the study design (Cope, 2014)

Dependability

The dependability of the data refers to the data's stability and ability to answer the research question. Miles et al. (2014) ascertain that dependability is consistent and stable research over time. In this study, the researcher will promote dependability by using instruments such as reflexive journaling, audio recordings of participants' responses, written transcription of interviews, and detailed descriptions of extracted data. The above processes will allow other practitioners to apply data in a different context. As the researcher, I established dependability by double-checking data and written transcripts. Additionally, I compared written transcripts with audio recordings for accuracy.

Confirmability

Tobin and Begley (2004) explained that confirmability is established when researchers extract data from the research and do not interject subjective opinions into the results. To confirmability, the researcher presented and analyzed the Participant's experiences in their own words. An audit trail includes the interview protocol notes and a personal reflective journal to document information. Since the researcher is an active instrument for this project, she utilized an automatic journal to assess and manage ADRD caregivers' family dynamics and network biases. This method will allow for transparency in decision-making throughout the research process.

Ethical Consideration

Before conducting this study, I submitted the required documents to secure Walden's International Review Board approval. I established that federal guidelines are adhered to, including the ethical protection of participants. Another essential element of moral consideration is informed consent. The consent form will establish: (1) participation is voluntary and that participants can withdraw at any time, (2) state the risk and potential gains, and (3) establish that all information is confidential. Furthermore, I Stated in incomprehensible language the purpose of the research, my role as the researcher, and how the research findings will be utilized (Ravitch. & Mittenfelner, 2016).

Summary

This chapter discusses data collection, analysis, trustworthiness, and ethical considerations. In Chapter 3, I offered a comprehensive overview of the qualitative research design and rationale for selecting qualitative methodologies and rationale for choosing this approach. I additionally utilized a semi-structured interview guide to explore participants' experiences with family caregivers caring for an ADRD member.

Chapter 4: Results

Introduction

In this qualitative phenomenological study, I explored the experiences and unique family relationships of AA families that care for a member with ADRD. The goal was to use the experiences of the AA family caregiver to give voice to a culturally nuanced aspect of the AA family structure and relationships of a network of relatives, significant others, and extended family caregivers while providing care for a member with ADRD. Ten open-ended interview questions were used to elicit rich data from participants. I used the interview questions in this study to explore the family dynamics of individuals caring for a loved one with ADRD.

I reached data saturation with three families, including six total participants. I label the families in the study as Family 101, Family 102, and Family 201. Family 101 had two participants (A and B). Family 102 had three participants (A, B, C). Family 201 had the participation of two family members, and one backed out. The participants' responses to semi-structured, open-ended interview questions resulted in emergent themes describing the experiences of family, extended family, and relatives. When combined with other research, the results of this study may promote the implementation of family-centered learning, information about minorities and healthcare disparities, and different strategies specific to the caregiving experiences of AA families, extended families, and relatives of AA families. This chapter contains (a) the research study setting; (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 the summary.

Research Setting

I used a phenomenological qualitative approach to gain narratives from family caregivers regarding their experiences and attitudes towards their unique family relationships before and after caring for a member with ADRD. Through in-depth interviews with significant others, relatives, or extended family, participants retrospectively reflected on their experiences and family structure. My goal was to cultivate a positive environment that was private and comfortable for the participants (Rudestam & Newton, 2015). Therefore, due to COVID-19 restrictions and concerns, most of my interviews were scheduled via Zoom, and two interviews were conducted by telephone because some participants were not computer savvy. The individual interviews took place in a quiet area with limited public contact and surrounding noise.

After I made an initial introduction of informed consent for the phone interviews, I obtained verbal confirmation from the participants consenting to the study. The Zoom meeting and phone interviews were audio recorded with the participants' permission. All the individual interviews were conducted with minimum interruptions.

Demographics of the Participants

The participants in this research were AA adults in a family where family members participated in the care of a member who had been diagnosed with ADRD. I used a purposive sampling method because I specifically sought AA families that cared for family members in the home. According to Smith (2015), informal caregivers are family or extended family members who provide care to the family with a cognitive impairment (See Table 1). I give each participant a short biographical and demographic description in this section. The participants provided or continue to provide home-based support to a family member with ADRD. For confidentiality, I removed any personal identifying information.

Participant 1

Participant 1(101A) was a 65-year-old disabled veteran who cared for his mother diagnosed with Alzheimer's and crippling arthritis. He was the oldest brother in the family and decided to care for his mother in the family home rather than let her go to a nursing home. Participant 1(101A) is divorced and has a daughter living outside his state.

Participant 2

Participant 2(101B) was a 66-year-old woman who helped care for her mother. She worked for a long-term care organization in her city. She was married and cared for her sick, retired veteran husband. Additionally, three times per week, she was treated for dialysis herself.

Participant 3

Participant 3(102B) was a 32-year-old woman who was part of a family network of caregivers. She was a lawyer, wife, and mother of a small child who cared for her father, who was diagnosed in the preliminary stages of dementia.

Participant 4

Participant 4 (102A) was a 39-year-old married woman who cared for her father, who had been diagnosed with the preliminary stages of dementia. She worked as a full-time public relations person. She was married with no children, and her husband was also a part of the family network, caring for her father. Her husband was a potential participant but later stated he did not have time.

Participant 5

Participant 5(102C) was a 32-year-old man who helped care for his father-in-law, who was diagnosed with the preliminary stages of dementia. He worked full-time as a computer technician.

Participant 6

Participant 6(201A) was a 66-year-old woman who cared for her mother, who had been diagnosed with Alzheimer's disease and related dementia; she also cared for her father, who was diagnosed with Parkinson's disease. She worked at the county sheriff's office part-time. Her two sons were a part of the family network but canceled their interviews.

Table 1

Demographic Information

Participant	Age	Gender	Marital Status	Occupation	Education
Family201A	66	Female	S	911Clerk	BS
Family101B	67	Female	M	Caretaker	None
Family102A	39	Female	M	PR Rep	Masters
Family102B	31	Female	M	Lawyer	PHD
Family102C	31	Male	M	Computer Tech	College
Family101A	65	Male	S	Veteran	

Data Collection

The process for collecting data began after I received official approval from the Walden University Internal Review Board (04-10-23-0305638). Walden University's IRB approval permitted me to recruit and gather information. The data collection went from February to August 2023. As the sole researcher, I was able to recruit 10 individuals who met the following criteria they were (a) AA, (b) an adult family caregiver who was providing care to a family member with ADRD, (c) provided care or support in a home-based setting for over 6 months (d), over the age of 21 years old, and was a relative, extended family member, or sibling, that performed caregiving duties.

Although nine individuals were interested in participating in the study, two participants withdrew for personal reasons, and one decided not to participate. I arranged

Zoom meetings and phone interviews with the remaining potential participants at a time and date that was convenient for their schedules. Following my initial introduction as the researcher, I discussed the informed consent with each participant, including the study's purpose, the risks and benefits, the procedure for reporting disclosure, and the benefit of social change. After reviewing this information and allowing for questions to be asked by the potential participants, I obtained their verbal consent to participate in the study.

Location

I conducted individual, semi-structured interviews over Zoom and the phone to collect data for this study. Instrumentation for this study included an audio recorder for each participant. Participants were asked the same interview questions. I used semi-structured, open-ended questions to prompt data-rich responses from the AA family caregiver’s experiences, thoughts, beliefs, and family relationships while caring for a family member with ADRD. There were no interruptions or delays during the interview process. Four interviews were completed in less than the scheduled time of 45 to 60 minutes, as outlined in Chapter 3. Two interviews lasted between 35 to 45 minutes.

Data Analysis

The qualitative approach was suitable for interpreting the gathered information from AA family caregiver interviews because my goal was to convey the experiences of the AA family caregiver by exploring their experiences and family structure when caring for a member with ADRD (Braun & Clarke, 2006). I used thematic analysis to develop codes and how they would be combined, clustered, and analyzed. I used Ravitch and Carl’s (2016) stages of developing themes.

I conducted in-depth individual interviews, with the shortest interview lasting 35 minutes and the most extended interview lasting 60 minutes. Each family participant responded to the interview questions and provided detailed accounts of their experiences as a family caregiver; the data gathered for this study consists of six individual interviews, with each response being transcribed. For organizational purposes, I transcribed participants' recorded responses verbatim into Microsoft Word documents within 24 hours of each discussion. Although I hand-coded and highlighted phrases and frequently occurring words in the transcription, I also uploaded the participants' transcriptions into MAXQDS 2022 for the organizational process. I used MAXQDA to organize the obtained data, simplifying the process of identifying emergent themes. I analyzed the data by using 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 family participants' interviews. Initial ideas and the researcher’s thoughts were recorded as essential in the data analysis during this activity.

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frequently occurring words in the transcription, I also uploaded the participants' transcriptions into MAXQDS 2022 for the organizational process. I used MAXQDA to organize the obtained data, simplifying the process of identifying emergent themes. I recorded my initial ideas and thoughts as essential in the data analysis.

The excerpts include ideas of the participants’ thoughts about their experience as a family caregiver and insight into the dynamics of the AA family structure when caring for a member with ADRD. A review of the categories and codes is listed in Table 2. This includes a complete list of themes, the number of sources for each theme, and the number of times each participant referred to each theme, which appears in Table 3.

Table 2

Categories and Codes

Family Dynamic	Caregiver Roles	Personal Sacrifice and Cost
Relation Dynamic	Responsibilities	Motivation
Family Unity and Support	Quality care	Stress and Coping
Family values	Communication	Role Shift
Communication and decisions	Discussions	Caregiver role description

Table 3

Themes

Themes	Source	Number of references from sources
Honoring a legacy of family caregiving	6	9
Family dynamics and unity	6	17
Communication and discussion	6	13
Motivation and personal sacrifice	6	13
Roles and relationships	6	20
Stress and coping	6	8
Dedication to family unit	6	6
Relationship dynamics and insight	6	12

Results

Theme 1: Honoring a Legacy of Family Caring

All the participants discussed their caregiving relationship with the person diagnosed with ADRD and their specific family role in the family dynamics. The first emergent theme was a sense of responsibility and comment towards their parents. Their families were interviewed, and each family shared their need to honor and respect their mother or father by caring for them in their home. Several participants reported seeing their parents care for grandparents, children, and other relatives. Respondents discussed their views about family dynamics, dedication to the family, and the relationship within their family structure. Participants acknowledged the differences that each family member played when caring for the member diagnosed with ADRD. For example, Participants discussed the sadness that they experienced because of the parental role shift involved when a parent has ADRD. Respondents expressed that they were not prepared for the mental or physical decline associated with the disease.

Family 101A stated: “I looked back over the times when my mother took care of her family and her mother, and she took care of my father, and now it was her turn. I was not going to throw my mother away.” Family 201A stated, “I promised my parents I would care for them.” Family 102B said:

> Although he was not my caregiver growing up, he was a different part of my life. Um, so what I try to do is try to mitigate any risk of harm to himself, whether physical, financial, or blowback on my family, because I know that we must support him if he messes something up in his decision-making.
>
> Family 102B: we have a shared understanding that while both of our parents, specifically him, since he is the one who has been sick, are still here with us, we must do our best to be there for them. The second thing would be how we were raised regarding what care means: giving a hand. We may have yet to be told this is how you do it or how you become a caregiver. However, my older sister was our caregiver while my mom was away at work; she was a caregiver for myself

and my brother. So that was instilled in her. She understood how to give care. Moreover, the same goes for me and my little brother. My sister was away at college, and he and I were away while my mom was away at work. So, that was also instilled in us as a part of our upbringing.

Family 102B: He had no one besides his kids, my sister and me, and our husbands. His insurance does not cover him for having someone come in, so we love and care. My sister and I are in different seasons. Whether we are going through our own thing, our level of involvement may change based upon what we are going through personally, but we are there for him.

Family 102B: We have a unified front and understanding that we love him and want him to be okay. So, he has a good quality of life because we love him. Two things: number one, we are unified, for we both want the same thing related to his care. We both want him to be okay, how that had affected us, and how it affected him.

Family 102C: But, you know, when it deals with an illness like this, especially being unfamiliar with it, it does pose challenges because you have to take a step back and not look at it through your lens. We try to understand it through others' viewpoints, which helps with growth. It works patience and makes you more selfless.

Family 102B: My sister mirrors the care I give, and I reflect on the care she provides. She was in the same state as my father until I finished law school, and then I moved to help with his care.

Theme 2: Family Unity and Relationship Dynamics

All participants stated that their relationship with family was okay before taking on the responsibility as a caregiver. However, insight was different and often more complex after being in the role. One participant believed that since the illness, their sibling relationship was closer. One participant expressed that when family members did not participate, other extended family and relatives took on the role of family caregivers. Another participant discussed how often the person diagnosed with ADRD will feel comfortable with one family member who may call them first. Below is a review of their responses.

Family 102A:" As the eldest child, I feel obligated to care for my father. My responsibility is to honor my parents and be there for them in their time of need".

> Family 102B: We have a unified front and understanding that we love him and want him to be okay. So, he has a good quality of life because we love him. I would say two things: number one, we are unified, for we both want the same thing related to his care. We both want him to be okay, how that has affected us, and how it affected him.
>
> Family 102A: My sister and I have gotten closer during these times. She has more of an understanding of what I have been going through.
>
> Family 101B: My mother told us always to stick together; you can have friends but stay with your family
>
> Family 201A: "My parents told us to stay close, always."

Theme 3: Responsibilities and Roles in Communication and Discussion

The participants discussed the sadness they experienced because of the parental role shift involved when a family member suffers from ADRD. Respondents expressed that they were not prepared for the mental or physical decline associated with the disease. The family caregiver says the role shift is related to being a caregiver. Most families agreed that roles and responsibilities were shared in diverse ways.

Family 201A: "One brother started to help and stopped, and the others did not help."

Family201A:" Some family members felt I was trying to take over."

Family102A: "No responsibilities are shared equally because sometimes people get caught up in their own lives and worlds, and their availability is based upon that."

Family 102B: "Even if I weigh in on a situation, certain decisions would be in my sisters' hands."

Theme 4: Relationship Dynamics and Insight

Another theme that emerged from this interview was unity in decision-making. Although participants did not always agree on every aspect of decision-making, they were able to put differences aside to move forward for their loved ones. Participants talked about working toward a common goal for their mother or father to provide care to give them the best outcome possible. One participant felt left out of the decision-making process, while others believed their opinion was vital. One common goal all participants shared was that they are willing to do whatever it takes for the patient to be okay.

> Family 101B: When caring about her, we usually discuss it and determine what best works for that person. Everybody loves her, so everybody is going to do something.
>
> Family 101B: “And when it came to the time that we thought maybe she would need, um, to go into a facility, we talked and decided, hey, we need help. I did my part, and everybody had specific things to do. One person combed her hair, some gave baths, and others stayed with her over the weekend.
>
> Family 101A: My sisters wanted to put my mother in a nursing home, but my brother and I did not, so I decided to move back home to care for her. I quickly decided to take care of my mother, and maybe God put it on my heart, and everybody agreed.

Theme 5: Motivation and Personal Sacrifice

This theme provided rich dialogue from participants because they wanted to share what influenced their decision to care for members and the personal sacrifices made to provide care.

> Family 102A**:** After I got married, his health declined more, and my husband assisted me; it did strain our relationship because instead of investing time in developing as a newlywed couple and taking time to get to know one another more as a married couple; we invest all our energies and emotions into making sure that my father sustained life.
>
> Family 102C: There have been bad days or moments where he has issues, whether getting somewhere or getting something from the store, and he may need help to

work through a situation where he cannot remember how to get home; he calls me.

Family 102B: I saw him as a strong figure and protector. Even though he was not my caregiver coming up, he was a part of my life differently. I was the child, and he was the parent. He is still my parent, but the roles have switched in that I now care for him, and he relies on me like a child will depend on a parent.

Family101B: I understood what was happening to her. I knew what was happening, and she would take her clothes off and get rid of them, accusing you of stealing things she put up. I knew it was the disease because I work with it daily, but we love her.

Family 101A: My mother could not bathe herself, and I had to bathe her, although she did not want me to. I had to change her diaper and put lotion on her. I gave her a bell, and if she wanted something, she could ring the bell.

Family 201A:" You must love and respect the person you care for."

Theme 6: Stress and Coping

The following participants describe their stressors while providing care and how they cope or ignore stress. One family caregiver stated they lacked self-care but did not want to complain. A family caregiver from another family said she would occasionally sip wine and take long baths. Another family caregiver admitted to being stressed.

Family 201A: “Take long baths, sip wine, and be alone.”

Family 101A:” I do not deal with stress but internalize it.”

> Family 102A: I do much praying, and I internalize it and keep moving forward because of his need because life does not stop, so I just internalized this because I do not want to be a burden on the other or seem as if I am complaining because everyone feels as if they are doing something to contribute and the weight of the responsibilities are not acknowledged.
>
> Family 102B: This is so emotionally depressing, it saddens me, and it is scary because I have to develop this new relationship with my parent, as his mental capacity has declined over the years.

Discrepant Cases

In analyzing the data from the six participants, I found no discrepant data. Although there were situations where sibling relationships were stained, and they often disagreed, they maintained loyalty to the family network. Although 201A acknowledged the breakdown in the family communication, her brothers started to help and stopped; two grandsons then began to help with bathing and cleaning. Additionally, she maintained that if she had to work two jobs to help pay her family's bills, she would do so. All participants argued that the family network was significant, strong, robust, and solid, even if they disagreed on the behavior of the individual family members and the responsibility level.

Evidence of Trustworthiness

Qualitative researchers adhere to strategies, techniques, or practices to assess the validity or trustworthiness of research (Smith,2015). Ravitch and Mittenfelner-Carl (2016) and Smith (2015) noted that researchers establish credibility, transferability, dependability, and confirmability standards. First, credibility occurs when the research can implement validity strategies. I use reliability and validated methods to preserve credibility and trustworthiness in this study. I use triangulation and data analysis stages to further strengthen the credibility and validity of the data collected. Triangulation refers to several data sources in qualitative research to develop a comprehensive understanding of the phenomena (Ravitch & Mittenfelner-Carl, 2016). This technique involves reviewing the data collected through interviews and questionnaires in my personal observation period. I gathered data from participants' interviews and transcribed the data several times.

Member Checking and Dependability

I confirmed the data analysis using the member-checking process to verify and ensure the accuracy of the discussions. Because the goal of this research was to explore the family relationships of an AA family while providing care for members diagnosed with ADRD, only the research participants could validate or confirm the credibility of the result. Therefore, I used member checking, verifying, and ensuring participants' responses were true and accurate depictions of their reported experiences. The participants in this current study evaluated interviews and the transcripts of their discussions. Cope (2014) ascertained that member checking allows participants to correct any errors or misinterpretations of their responses. They had the opportunity to amend any information that she then deemed necessary. Subsequently, all participants approved of the transcripts. Ravitch and Mittenfelner-Carl (2016) stated that the dependability of data is established if the research data is consistent and stable over time. I used participants in a family network and allowed them to describe their lived experiences to show dependability. Researchers can obtain reliability by using triangulation methods as a data collection plan.

Transferability

Transferability aims to provide research to compare contextually (Cope,2014). Transferability occurs when data can be applied or transferred through detailed data descriptions (Bradshaw et al., 2017). I described the participant's demographics, data-gathering techniques, and data analysis. I extracted rich data descriptions of participants' experiences, thought processes, and beliefs about being an AA caregiver who was part of a family network that cared for a person diagnosed with ADRD.

Summary

This qualitative, phenomenological research aimed to understand the AA family structure's experiences and dynamics while caring for a member with ADRD. I collected data from six participants. I conducted phone interviews, transcribed, analyzing with transcribed the data, and analyzed the data to develop a theme. The data analyzing process emerged eight themes. The experiences of AA family caregivers help broaden the knowledge of the lived experiences of AAs caring for a member with ADRD.

Additionally, there were shared experiences in which participants reported feeling overwhelmed and stressed about the role shift when caring for a family member diagnosed with ADRD. Participants also expressed overlooking the everyday stress associated with taking responsibility for caring for the member and not wanting to complain. In Chapter 5, I present the interpretation of the study's findings. I describe this study's limitations and recommendations or suggestions for further research on the AA family care network when caring for a member diagnosed with ADRD.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

I explored how AA family caregivers describe their experiences and unique family relationships when caring for members diagnosed with ADRD. Due to AAs living longer, the need for family caregivers will increase (Colapinto, 2019; Mars, 2016). My goal was to use the experiences of the AA family caregiver to give voice to a culturally nuanced aspect of the AA family network while performing caregiver duties. Although there is prior research on informal African American caregivers, there is a need for more studies in which researchers explore the AA family dynamics and their unique family structure. Chapter 5 discusses the results and their meaning correlating to social change. I will also discuss the strengths and limitations that arose in the study, offer recommendations for future research to increase the scope of this study, and provide a conclusion that shows the impact of the study.

Conceptual Framework

I recruited participants by employing a purposive sampling strategy. In this study, I used a qualitative phenomenological approach to study the AA family structure while incorporating BFST as a conceptual framework for exploring the dynamics of AA families in caring for a loved one with ADRD (Bowen, 1997). According to Papero (1990), Murrey’s BFST is considered the starting point of any study of family therapy. As the researcher, I believed that a conceptual framework using the Bowen concept was appropriate because this system is built upon the foundation that the family system theory is to help individuals and families understand and accept individual contributions to emotional functioning (Bowen, 1978).

This theory helped explain various aspects of family relationship dynamics when caring for a member with ADRD. BFST theory posits that the purpose of the family system theory is to help individuals and families understand and accept the individual contributions to the emotional functioning of the family (Bowen, 1978). In this study, I gathered information from interviewing six participants; each person assessed their family's contributions and well-being while caring for a member with ADRD. Of the six participants, four were daughters caring for a mother or father, one was a son caring for his mother, and one was a son-in-law caring for his wife's father. A family is defined as a system composed of individual members and how they interrelate to form the dynamics of the family structure (Colapinto,2019). This qualitative phenomenological research study directly responded to the questions. It gave insight into the research question about how AA family caregivers describe their experiences of a unique family structure in the context of caring for a member with ADRD.

Interpretation of the Findings

To address the research question in this study, I employed a generic qualitative approach incorporating semi-structured, in-depth interview questions. I interpreted the results using this method to understand AA family caregivers and their unique family structure. Additionally, the family system theory shifts the focus from the caregiver's individual experiences to the exchange and behavior of the network of all family members. For example, one participant explained that differences in opinion were put aside to ensure their parents were cared for. Participant 102B stated that she and her sister mirror the care they provide for their father. However, the participant shared that she did not trust everything her sister said. An additional example is Participant 102A expressing how she may have been depressed but did not want to complain because everybody in the family had problems. These are a few examples of how the family members think and create the reality for the family structure (Bowen, 1997). I identified, coded, and categorized patterns into themes related to the research question.

Research Question

The research question that I addressed in this study was: How do AA family caregivers describe their experiences and unique family structure when caring for a member diagnosed with ADRD? Although much research existed on caregiving among various ethnic or racial groups, this study on ADRD caregivers' family relationships from the perspective of significant others, extended family, and relatives produced limited results (Forbes, 2018).

In this study, I had a unique context of the lived experience of a network of family caregivers. Walker (2018) noted the importance of understanding the diverse culture of minority family caregivers and their experiences. I used the rich data I extracted from this research to produce six themes about the unique family structure of four individual families. Most family structures had many similarities in experiences and attitudes towards the family.

The first four themes: Honor a legacy of family caregiving, family unity, and relationship dynamics, relationship dynamics and insight, and motivational and personal sacrifice; These themes describes the structural family dynamics of the AA caregiver's family network. The other theme, responsibility, and roles in communication and discussion, describes how family or AA family caregivers in a family network communicate and their duties and functions as they relate to caring for the person diagnosed with ADRD. Stress and coping describe stressors while providing care and how they cope or ignore stress while providing caregiver duties.

Theme 1 included a discussion on honoring the legacy of family caregiving. My findings extend what has been previously highlighted in caregiving literature referencing AA caregivers. Prior researchers explained how AA's reasons for caregiver duties include familism, honor and duty, obligation, reciprocity or giving back, and religious or spiritual beliefs (Dilworth-Anderson et al.,2004;2005) common cultural reasons for caregiving. Moreover, for this study, the findings were congruent with scholarly work conducted by Halliwell et al. (2017), in which proportional division of care was not a priority but appreciated family engagement and willingness to assume caregiving duties, which was consistent with the findings of this study.

All six participants discussed their relationship in the family network and their sense of responsibility and commitment to their parents. Additionally, participants discussed the tradition of caring for their mother towards her parents and other relatives. Participants showed an emotional connection to the legacy of family caregiving. Four participants discuss the challenging role shift as they watch their strong parent's mental and physical health decline due to ADRD. One participant stated that he was not aware of anyone with Alzheimer’s disease and was not prepared for the toll it would take on his mother’s body. Each family’s unique family dynamics determined how the family functioned. However, the common thread was that all participants wanted to provide care and support to the member diagnosed with ADRD.

Theme 2, family unity and relationship dynamics, gave the participants insight into family roles and dynamics experienced when caring for their member with an ADRD. Concerning Theme 2, I focused on participants' sense of obligation and the impact of family togetherness. Epps (2014) concluded that AAs possess a stronger sense of family obligation and togetherness than other nationalities. McGrew et al. (2018) explained that decision-making was influenced by togetherness within the family network. All the participants I interviewed showed some obligation to others within the family network concerning care for the member with ADRD.

Participants stated that they felt a strong sense of responsibility and obligation to honor their parents in their time of need and that it was their duty to provide care. One participant also emphasized the importance of family unity and love to ensure that the quality of life for the person is diagnosed. One participant shared how their relationships with family members evolved during caregiving. This theme shows the significance of family support, unity, and the impact of togetherness on family units.

Theme 3, relationship dynamics and insight: The impact of caregiving on their relationships with other family members. Relationship dynamics and insight give insight into family unity's context in caregiving. This theme concerns the interplay of structural family relationships and the understanding gained from the experience.

All participants expressed that their relationship with family was positive before taking on the caregiving role. Moreover, this theme highlighted the significant part of family dynamics understanding unity in the context of caregiving for individuals with ADRD. These findings aligned with those of Eddy et al. (2021). Eddy et al. (2021) concluded that the family structure could be compared to the dynamics of a sports team; the family dynamics and how they interact have a bearing on the overall care of the person with ADRD (Eddy et al.,2021). In a prior study, Eddy et al. (2021) used the Bowen family system to examine the relationship between significant others, extended family, and relatives to explore the caregiving process and care recipients. Additionally, Erdem and Safi (2018) defined the family as a two-system construct in which family members influence and are influenced by one another. Relationship dynamics and insight are a by-product of family dynamics and unity.

Theme 4: motivation and personal sacrifice: Motivation and personal sacrifice show why AA family caregivers care for their family members with ADRD. Participants described the emotional, financial, and physical gifts they and their families make to care for their loved ones. Some participants described their unique relation to the person diagnosed and their family dynamics. Other participants expressed their promises to their parents not to throw them away. The participants' motivation and personal sacrifice show their love, respect, and commitment to their families. Other participants admitted to being depressed over the role shift. These findings were related to the research of Smith (2018), Pascual (2021), and Forbes (2018). The results highlighted that family sacrifice can be emotional, financial, and physical support (Amaro, 2017; McGrew et al., 2018).

Although some participants did not feel that duties were divided equally, they all agreed that the member diagnosed with ADRD was better off being in the home.

Theme 5, responsibility and roles in communication and discussion: The theme of responsibility and roles affected all participants except one. Participant 101B was not affected by her mother's mental and physical decline because she worked in a long-term care setting where her job duties included caring for patients with ADRD. Therefore, she was better prepared than other participants. The research findings showed the need for families to communicate and openly share. Family communication and discussion highlight the vital role of open, collaborative decision-making when providing care within a family network.

Participants openly acknowledged that often, family members did not agree on issues that were presented when caring for members with ADRD. However, participants also agreed that communication was vital for family network cohesiveness. Participant 102B stated there was distrust because her sibling did not do what she said regarding care for the member with ADRD. These finds were consistent with McGrew et al. (2018), who explained that decision-making within the group is interdependent. Participant 101B explained that the family would get together and decide what was best for their mother. From these findings, I also uncovered alignment with Smith’s (2019) results; families use a collaborative approach to work together for the best possible outcome for the family member. They overcame differences and prioritized the best-case situation for the patient. All participants admitted to differences but highlighted the importance of communication in family teamwork when defining roles and the responsibility of caregiving.

Theme 6, stress and coping: Family caregivers admitted that they did not have a self-care plan because they often ignored being stressed. Participants agreed that they did not have a coping plan or outlet when they felt depressed. Stress and coping were topics that participants were open to whether they practiced coping mechanisms or not. Some participants managed stress, and others ignored it, although they responded emotionally and physically. Recent research shows that AA may experience stressors due to caregiving more than previously reported (Dilworth-Anderson et al., 2004).

Some participants ignored being stressed. One participant mentioned taking long baths and sipping wine alone, while others chose to internalize their feelings. Both male participants had similar responses; for example, 101A expressed that he did not deal with stress and just internalized it, and male participant 102C said that he does not think about it, he will do what is asked of him, so his wife does not have to stress about it. My findings aligned with Amaro (2017) that the supportive bonds of the family dynamics served as a buffer for stress. Although participants recognized they were emotionally burdened, they refused to complain; for their family, they were more than willing to make sacrifices. These results align with other research studies that offer insight into AA caregivers' challenges and stress when surrounded by environmental and social-cultural factors (Mars,2016).

Strengths and Limitations of the Study

This study included several limitations. This study focused on AA families with relatives and extended family members who cared for members diagnosed with Alzheimer’s disease and related dementia. The participants were individual family members who were AAs over 18 years old. As stated in Chapter 2, I only gathered information from AA family caregivers in the Southeastern United States in Alabama. The study results were not generalized to all AA caregivers or other races, as I only collected data for this demographic. I only managed the data format of the specific participants who volunteered. I recruited a sample of six participants from three different families. Another limitation of this study was that four participants were college graduates, one was a 20-year retired military person, and one was skilled in caring for dementia patients. The lived experiences, perceptions, and insight might yield different data with a different demographic. Due to the small sample size, the results are not generalized to all AAs diagnosed with ADRD. A discussion of recommendations for future studies is listed in the following section. Although the survey included limitations, many strengths were highlighted in the study. For example, rapport was built between the researcher and the participants. As the researcher, I aimed to go beyond rapport to authentically engage participants to develop an equitable research relationship (Ravitch &Mittenfelner-Carl,2016). Participants opened up about their fears and emotional well-being because I identified with the participants' cultural identity. Therefore, they provided rich data that gave insight into their experiences, perspectives, and worlds.

Recommendations

Given the high prevalence rate of AA developing ADRD, more relatives, extended family, children, and spouses will assume the role of family caregivers. Researchers noted that AA extended family and relatives typically take caregiver roles for aging family members. As pointed out in the chapter, research specific to AA family caregivers is scarce; therefore, I recommend continued research that expands on the current study of exploring and describing the AA family relationship when caring for members. A mixed-method design study assessing AA families' caregivers' experiences would add to the literature to fill this gap. Looking at the family AA relationship and the family network structure may identify culture-specific concerns and help healthcare professionals establish effective programs and support materials for individuals and families.

As noted in Chapter 2, research on specific cultural areas, such as AA families, is lacking. Therefore, further research may widen the scope of this research by increasing the number of participants and using a different research theory to extract rich data. Additionally, research that targets AA caregivers and how the role of being a caregiver affects their health and well-being would benefit the literature. Research studies often do not focus on how caregivers and stress affect their health. Eddy et al. (2021) explained that family dynamics and exchange have a considerable bearing on how the family functions in stressful situations. Although AA scores lower on the stress scales than caregivers of other nationalities, recent studies on AA caregivers show that they experience stress and the burden of care as different nationalities (Badana et al.,2019). The participants that I interviewed acknowledged that stress exists in their unique situations, but they did not have the tools necessary to deal with caregiver stress

Implications for Positive Social Change

The results of this study add to the knowledge base of ADRD caregivers, family caregivers, AA family caregivers, and cultural caregivers. The knowledge gained from this study on AA family caregivers caring for members with ADRD may be helpful to healthcare professionals and how they might provide support services to help AA family caregivers because AAs are diagnosed later in the progression of the disease (Alzheimer's Association, 2019). Due to the diverse needs of the AA aging population, the need for human services, research, and assistance will also increase (Forbes, 2018). Thus, professional community organizations can form partnerships with local area churches to heighten awareness of ADRD for early detection (Forbes, 2018).

Studies on ADRD can give insight into culturally diverse groups' lived experiences, perspectives, and cultural similarities and differences. Additionally, the study findings will provide much-needed insight into the lived experiences of significant others, relatives, and extended family and how stress is associated with being e for AA with ADRD (Colapinto,2019; Mars, 2016). Research shows that studies that address culturally diverse groups, their similarities and differences, and lived experiences can help produce needs and differences, and lived experiences can help create need differences, and lived experiences can help make needed programs and public policies that help guide better health initiatives that are culturally sensitive to this minority. For example, when researchers can produce culturally sensitive data, effective programs, approaches, and interventions can provide needed support to caregivers and the communities in which they live.

Conclusion

Much research has concluded that ADRD is not an inevitable outcome of aging and AAs or more substantial to this disease than other nationalities (Smith,2019).

However, my primary goal of this qualitative phenomenological study was to explore the lived experiences and personal perceptions and understand how AA family caregivers make sense of the constructed reality of the family structure when caring for a member with ADRD. Six participants voluntarily shared their caregiving experiences for this study. Six common themes emerged for the interviews: honoring a legacy of family caring, family unity, and relationship dynamics, relationship dynamics and insights, responsibility and roles in communication and discussion, motivation and personal sacrifices, and stress and coping. Evident from both the study findings and the literature was that the family network is essential when caring for a member diagnosed with ADRD. Family members may have differing views on every aspect of health management or day-to-day care, but the AA family network's cultural legacy remains a foundational structure.

The findings from this study add to the body of knowledge and the available information about AA caregivers when caring for family members diagnosed with ADRD. While racial and ethnic differences have been noted in the literature, research has not always referenced racial differences in family relationships (Gilmore-Bukowski et al., 2018). Therefore, there is a gap in cultural awareness of differences or suggestions for the next steps in care for this minority (Gilmore Bukowski et al.,2018). The results also highlight the cultural dynamics of the AA family care network and how and why this family structure exists. Because there are limited studies on the AA family caregiving network, this study's findings were significant because they filled the gap in the literature and the body of knowledge. This knowledge can inform practitioners about the importance of the family system in caregiving for members diagnosed with ADRD and develop support systems to leverage and guide these family systems.

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Appendix A: Participants' Interview Questions

1. Tell me about your family.
2. What is your relationship to the person diagnosed with ADRD?
3. Can you describe the roles of the other family members in caring for this individual?
4. Please explain what influenced your decision to assume the role of a caregiver
5. As a caregiver, can you provide examples of daily duties?
6. What are strategies you use to help cope with the stress of being a caregiver?
7. How do you manage decision-making about caring for your family member ADRD?
8. Tell me how you describe your relationship with your family before becoming the caregiver.
9. How would you describe your relationship with family while providing care to members with ADRD?
10. Please feel free to share anything else about your family relationship 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 confirm your responses.

Please do so on the subsequent lines if necessary to make edits.
Thank you again for your time.

Sherry L Perry
Walden University
Doctoral Student

Appendix C: Demographic Information

The following questions concern you, the caregiver, and the family circumstances. Please select the appropriate response or fill in the blanks. As a volunteer participating in this research study, you do not have to answer any questions or questions due to personal reasons. Please note that any unanswered questions will void your participation in this study.

1. Name: _________________________
2. Gender: a. Male b. Female
3. Marital Status: a. Single b. Married c. Divorced d. Widowed
4. Educational Level: a. Less than High School b. High school diploma or equivalent. Some college, no degree, d. associate degree, e., bachelor's degree, f. master's degree, g. Doctorate
5. Employment Status: a. Employed b. Self-Employed c. Unemployed d. Retired
6. Overall Physical Health Status: a. Excellent b. good c. Fair d. Poor
7. Length of time since diagnosis: ________
8. What is the current stage of Alzheimer's for patients? ________
9. Relationship to care recipient: ______________________________
10. Race/Ethnicity: __________________________
11. Length of time as a caregiver: _______________________________
12. Do you receive any assistance from family members? a. Yes, b. No
13. Are you a caregiver to anyone else? a. Yes, b. No; If yes, is the individual a family member or friend? _____________________