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African American Women Caring for Loved Ones With Alzheimer's Disease and Dementia

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Walden University
2018

Abstract

African American Women Caring for Loved Ones With

Alzheimer's Disease and Dementia

by

Lisa M. Forbes

MS, Central Michigan University, 2005

BA, University of Michigan, 1993

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human Services

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Abstract

In 2016, a dramatic shift occurred in demographics in the United States because the oldest people in the baby boomer generation, which consists of people born between 1946 and 1964, reached age 65. The larger aging population and longer lifespans have produced an increased need for care and services. There are an estimated 5.4 million Americans of varying ages living with a diagnosis of dementia or Alzheimer's disease. Diagnoses of Alzheimer's disease are more prevalent among African Americans than other ethnicities. With little research found on culturally appropriate interventions for specific ethnic groups, a more detailed review of the experiences of African American women was necessary to explore the relationship between caring for loved ones with dementia and managing lifestyles. The purpose of this study was to explore the lived experiences of African American women who care for their loved ones with dementia and Alzheimer's disease. Guided by the conceptual framework of attachment theory, a phenomenological study design was used with semistructured interviews of 10 caregivers to examine their experiences and how they cope with caring for loved ones with dementia and Alzheimer's disease. The results of the thematic analyses of the collected data uncovered 6 main themes: sense of responsibility, grounded in faith, guidance for future caregivers, difficult journey, caregiver challenges, and coping strategies. The study may positively impact social change by informing health care professionals who may use the findings to help African American families caing for loved ones to apply interventions, use services, and manage resources more efficiently.

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Dedication

I want to give honor and glory to God for his unwavering love and grace. Many years ago, he planted a seed in my heart to begin this doctoral journey. Over the years, through many trials and triumphs, I have watered and nurtured this desire and now it is ready to bloom. This has been one of the hardest tasks in my life to complete. I could not have done it without the love and support of my circle. To God be the Glory!

This dissertation is dedicated to my beloved grandmother, Rose M. Bryant, and my best friend, Charnette M. Raheem. I started this journey with both of you here on earth, and now you are the wind beneath my wings, watching me from heaven. I love and miss you so!

To my grandparents, Fredrick Buckner, Rose M. Bryant, Cleotha Forbes, Sr., and Effie Lois Forbes; my beloved father, Cleotha Forbes, Jr.; and all of my loved ones who passed before me—I love and miss each of you dearly. I am the first doctoral graduate in the family and may this legacy continue.

I want to thank my mother, Martha J. Jackson, for her unconditional love and support. You always told me to be greater and pushed me to go further. I dedicate this work with love to you.

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Finally, I would like to thank all my friends, family, and fellow classmates. I truly appreciate each of you, who have supported me with kind words, encouragement, and support. You are my circle of life, and for that I am grateful.

Table of Contents

List of Tables

Chapter 1: Introduction to the Study

Introduction

Family caregiving is likely to become a part of over 50 million American lives over the next 40 years because of expanded longevity, growth in population, and significant medical advances with treatment and research (National Alliance for Caregiving & American Association of Retired Persons, 2015). As the baby boomer generation grows older, the risk for age-related problems and chronic disease, such as cancer, diabetes, cardiovascular disease, and dementia or other forms of cognitive impairment that include Alzheimer's disease, becomes greater (Alzheimer's Association, 2016). An increase has occurred in individuals who need health care services, which has caused an economic crisis in the health care system (World Health Organization, 2015). Census data from 2015 listed the following top 10 causes of death: heart disease, cancer, chronic lower respiratory diseases, stroke, unintentional accidents, Alzheimer's disease (dementia), diabetes, nephritis, influenza/pneumonia, and suicide (National Center for Health Statistics, 2015).

These diseases accounted for more than 2.5 million deaths in 2015, with Alzheimer's disease responsible for more than 93,000 deaths (World Health Organization. (2015)). The number of people with Alzheimer's disease in the United States is likely to grow to nearly 13.8 million by midcentury (Alzheimer's Association, 2016). In 2015, an estimated 5.4 million Americans of varying ages were living with a diagnosis of dementia or Alzheimer's disease (Alzheimer's Association, 2016). The expected increase of people with dementia and Alzheimer's disease and the increased

assistance needed to provide care make this issue an important public health issue (World Health Organization [WHO], 2015).

Background of the Problem

The United States is facing a major public health crisis because of its aging population, with people living longer and an increased need for care and services for people diagnosed with Alzheimer's disease and dementia. In 2015, physicians diagnosed more than 5.4 million people with Alzheimer's disease (Alzheimer's Association, 2016). The number of people over the age of 65 with Alzheimer's disease is likely to triple by 2050 (Alzheimer's Association, 2016). In 2015, more than 15 million caregivers were helping to provide care for someone with Alzheimer's disease or related dementia (Alzheimer's Association, 2016). Because of the expected increase in the need for services and care to help people with dementia and Alzheimer's disease, a need exists for more assistance with caregiving.

Researchers at the WHO (2015) defined dementia as a syndrome or group of syndromes in which there is deterioration in cognitive function. Dementia has an association with progressive memory loss and other intellectual functions that are serious enough to interfere with activities of daily living (WHO, 2015). Alzheimer's disease is the most common form of dementia and accounts for 60%–70% of cases (Alzheimer's Association, 2015). Other types of dementia include vascular dementia, Lewy body dementia, and front temporal lobe dementia (WHO, 2015). A concern exists because Alzheimer's disease is a silent epidemic among African Americans (Alzheimer's Association, 2015). A silent epidemic is projected since research findings have indicated

that Alzheimer's disease is more prevalent and that a higher familial risk exists among African Americans because of genetic and environmental factors than among other cultures (Alzheimer's Association, 2015). Because of these findings, more care and assistance are necessary for families and caregivers.

In 2015, more than 15 million family members and other people provided more than 18.1 billion hours of unpaid care to people diagnosed with Alzheimer's disease or dementia (Alzheimer's Association, 2016). Women comprise more than half of the caregivers who assist people with dementia and Alzheimer's disease in the African American community (NAC, 2009). Female caregivers account for two thirds of all unpaid caregivers and often report difficulty with health-related problems (Alzheimer's Association, 2016; Pinquart & Sorenson, 2005). African American women often provide a large majority of informal caregiving to older African American adults (NAC & AARP, 2015). These women demonstrate strong coping skills and have reported caregiving as rewarding (Sheridan, Burley, Hendricks, & Rose, 2014). African American women who reported positive outcomes with caregiving also had increased emotional, physical, and financial strains because of their role as a caregiver (Sheridan et al., 2014).

Research about the lived experiences of dementia caregivers has grown as the awareness of how dementia and Alzheimer's disease has begun to noticeably affect family caregivers has increased (Garand et al., 2012; Sheridan et al., 2014). Previous research studies have been mostly comparative and often reported that African American caregivers are less likely to experience caregiver burden than are European American caregivers (Schulz & Sherwood, 2008; Skarupski, McCann, Bienias, & Evans, 2009) and

reported high levels of caregiving reward (Sheridan et al., 2014). The reason for the variance in feelings remains unknown. Because of such concerns, a need existed for more information related to African American caregiving experiences to assist in the care and assistance of people with dementia in the African American community.

Statement of the Problem

Alzheimer's disease and dementia are silent epidemics in the African American community because of the higher prevalence of these diseases in this population (Alzheimer's Association, 2015). African Americans are two times more likely than European Americans to develop Alzheimer's disease (Alzheimer's Association, 2016). Because of the increasing numbers of African Americans diagnosed with Alzheimer's disease and other dementia-related illnesses, the need for assistance and care is likely to increase as well. In the African American community, females are usually the primary caregiver for family members needing assistance (NAC & AARP, 2015). All these factors led to a need to explore the lived experiences of African American female caregivers who care for their loved ones with Alzheimer's disease and dementia.

In reviewing the literature, I found many studies on European American family caregiving (e.g., Harmell, Chattillion, Roepke, & Mausbach, 2011; Herbert & Schulz, 2006; Wuest, Ericson, Stern, & Irwin, 2001), while a deficiency of studies on multicultural and ethnic caregiving emerged. Psychologists at the American Psychological Association have called for more research studies on caregiving topics, such as the special needs of caregivers from diverse cultural backgrounds (American Psychological Association, 2017). The U.S. Census Bureau (2015) projected that, by

2050, 42% of older adults in the United States will be members of ethnic minority groups. A review of the literature showed a need for more knowledge and understanding of cross-cultural differences in caregiving experiences. In this study, I examined the phenomenon of the lived experiences of African American female caregivers caring for their loved ones with Alzheimer's disease and dementia.

Research showed that caring for someone with dementia or Alzheimer's disease has many adverse outcomes related to physical and mental health (Joling et al., 2015; Sorenson & Conwell, 2011). A few researchers found that African American caregivers reported experiencing less stress, high self-efficacy in managing problems, and less depression when compared with a European American comparison group (Knight, Silverstein, McCallum, & Fox, 2000; Skarupski et al., 2009). Researchers have indicated that African American caregivers possess unique emotional strength that buffers the experience of providing care to older family members (Dilworth-Anderson, Williams, & Cooper, 1999; Pinquart & Sorenson, 2005). A gap existed in the research regarding an understanding of the phenomenon of dementia caregiving by African American females, so I designed this study to address this problem. My review of the literature revealed a significant gap regarding the experiences of female caregivers of loved ones with dementia. The importance of cultural beliefs and the effects on caregiving duties need further exploration (Rozario & DeRienzis, 2008).

The focus of this study was the lived experiences of African American women who care for their loved ones with Alzheimer's disease and dementia. According to the Alzheimer's Association (2016), African Americans are two times more likely to have

Alzheimer's and dementia than are their European American counterparts. The care for a loved one with Alzheimer's disease and dementia is challenging and stressful (Harmell et al., 2011). Caregivers for loved ones with Alzheimer's disease and dementia experience increased demands, lack of social interactions, financial difficulties, frustration, reduced leisure activities, anxiety, and worry about the future (Alzheimer's Association, 2016; Bekhet, 2013; Etters, Goodall, & Harrison, 2008). However, African American caregivers often report less stress and caregiver burden than do caregivers of other ethnicities (Picot, Debanne, Namazi, & Wykie, 1997; Sheridan et al., 2014). In this study, I explored this phenomenon.

Purpose of the Study

Researchers have studied ethnic-specific attitudes, beliefs, and values about caregiving for people with Alzheimer's disease and dementia, usually as a comparison with other ethnicities (Gonyea, Paris, & de Saxe Zerden, 2008; McCallum, Longmire, & Knight, 2007; Wermuth, 2011). The role of ethnicity and race has received increased attention in family caregiving because of the projected increases in these populations (Napoles, Chadiha, Eversley, & Moreno-John, 2010; Pinquart & Sorenson, 2005). The racial and ethnic background of caregivers might affect their role in caregiving because ethnicity and race may influence a caregiver's appraisal of stressful caregiving events and coping measures (Napoles et al., 2010; Pinquart & Sorenson, 2005). Research has shown burden, familism, and coping strategies have a correlation with ethnicity and the mental health of caregivers (Kim, Knight, & Longmire, 2007; Napoles et al., 2010). African American female family members who were primary caregivers reported greater

satisfaction and less burden in caring for loved ones than other female family members from other races and ethnicities who were also primary caregivers (Hargrave, 2006).

Although there is a considerable amount of evidence of cultural, racial, and ethnic variations in caregiving, there is a scarcity of research regarding culturally appropriate interventions for specific ethnic groups. A more detailed review of the experiences of African American women was necessary to explore the relationship between caring for loved ones with dementia and management of lifestyles. The purpose of this qualitative study was to explore the phenomena of the lived experiences of African American women caregivers of loved ones with Alzheimer's disease and dementia.

African American women are at higher risk of diabetes, heart diseases, obesity, hypertension, and clinical depression than any other racial or ethnic group in the United States (Kim, Knight, & Longmire, 2007). African Americans also have higher incidences of mortality and morbidity related to these diseases (Kim, Knight, & Longmire, 2007). African American female caregivers generally take on the responsibility of informal caregivers for their loved ones, and because of this, face higher risks of illnesses and diseases (Rozario & DeRienzis, 2008). Caregivers of family members with dementia-related illnesses may experience psychiatric and physical illnesses (Samson, Parker, Dye, & Hepburn, 2016), although some studies have shown psychological resilience in coping with caregiving (Haley et al., 2004; Hargrave, 2006). Due to these factors, continued research involving African American female caregivers was necessary. Data collected in this study contribute to research on problem-solving interventions, which may help not

only African American female caregivers but also female caregivers of all races and ethnicities.

The findings from the data gathered from African American female caregivers addressed a gap in the current knowledge base. A thorough detailed review of the African American caregiving perspective was overdue and needed, especially with regard to providing care for the estimated increase of people who will need services due to the diagnosis of dementia and Alzheimer's disease. A review and exploration of African American caregiving experiences led to increased knowledge about this experience. Researchers have often compared African American caregivers to caregivers in other cultures without providing much detail on the reasons for variation and differences of outcomes (Bertrand, Fredman, & Saczynski, 2006; Dilworth-Anderson, Knight, & Gibson, 2002; Shurgot & Knight, 2005). The results of this study showed ethnicity-specific ways that caregivers provide care to loved ones. In this study, I explored the phenomenon of the lived experiences of African American females who care for a loved one with dementia in a home environment.

Research Questions

This qualitative phenomenological research study involved exploring ways that African American females manage and cope with caring for loved ones with dementia. I developed the following research questions to guide this study:

RQ1: What are the lived experiences of African American women caregiving for loved ones with dementia?

RQ2: How do African American women manage and cope with caring for loved ones with dementia?

Theoretical Framework

In this study, attachment theory served as the theoretical framework for understanding caregiver behavior and relational experiences of caring for people with dementia (see Kokkonen, Cheston, Dallos, & Smart, 2012; Nelis, Clare, & Whitaker, 2014). Bowlby's (1979) attachment theory proposed that attachment styles formed earlier in life influence people's proficiency in interacting with and caring for other people. Caregivers' attachment styles also affect their ability to cope with the caregiver role. The foundation for the contemporary attachment theory is attachment behaviors with bonds that are developed by people early in life and then present and active through the life cycle (Bowlby, 1982). The correlation of attachment and caregiving appeared early in the formulation of the attachment theory, which researchers used to study the dyadic relationships between a caregiver and a care recipient, such as mother and child (Carpenter, 2001).

Bowlby (1982) proposed that attachment and caregiving are two distinct but closely related behavioral systems that operate in a reciprocal manner. Research that includes attachment theory concepts applied to caregiving among older adults falls into two general areas: the influence of attachment models on the caregiver and the influence of attachment models on the elderly care recipient (Browne & Shlosberg, 2006; Nelis et al., 2014). Attachment theory and caregiving have a relationship because of the close relationship family members may have with loved ones needing care. Researchers have

used attachment theory to identify individual differences regarding how prior experiences and close relationships with loved ones form the basis of an individual's view of self and others (Browne & Shlosberg, 2006; Nelis et al., 2014). People develop different attachment styles because attachment figures may fulfill roles in equally reliable ways (Kokkonen et al.,2012). The focus of attachment theory is others' responses to a person's own needs, and it is useful for explaining an individual's reactions to others' needs (Bowlby, 1982; Kokkonen et al., 2012).

According to Bowlby (1979), people have a caregiving system designed to protect and support others who are dependent or temporarily in need. However, challenges to a person's own subjective security inhibit the caregiving system, and people egotistically focus on their own attachment needs and distress (Bowlby, 1979). Attachment theory lays a foundation for bonds and feelings that may explain why a person is a caregiver; however, it does not explain a cultural or ethnic basis of caregiving. I used attachment theory as a framework to explore the lived experiences of African American women who care for loved ones with Alzheimer's disease and dementia.

Nature of the Study

I used a qualitative phenomenological approach to study the phenomenon of African American women who care for loved ones with Alzheimer's disease and dementia and the ways they cope with and manage the stress and burden of this task. A phenomenological study involves comparing the accounts of those who meet a characteristic or fall into a specific category (Creswell, 2017; Merriam & Tisdell, 2015). The data in this study came from volunteer participants who met the criteria of being

African American women who were caring for their loved ones with Alzheimer's disease and dementia.

I conducted semistructured interviews with women who had experienced the phenomenon of caring for their loved ones with dementia until saturation of data occurred. These semistructured interviews enabled the collection of information on caregivers' experiences of caring for loved ones with dementia and Alzheimer's disease. A more detailed accounting of the research methodology, procedure, design, data collection, analysis, and interview protocol will appear in Chapter 3.

Definition of Key Terms

Alzheimer's disease: The most common form of dementia. It is a progressive degenerative disease caused by amyloid and tau proteins, senile plagues, neurotic tangles, and progressive neuron loss in the brain (Alzheimer's Association, 2014; Scheltens et al., 2016).

Caregiver: An individual who cares for others with mental and physical disabilities and does not receive monetary compensation (NAC & AARP, 2015).

Caregiver burden: The negative reaction or multidimensional response to psychological, physical, emotional, social, and financial stressors associated with caregiving (Kasuya, Polgar-Bailey, & Takeuchi, 2000).

Dementia: A term that describes the loss of a group of symptoms, such as cognitive motor skills, judgment, memory, language, and other intellectual functioning, caused by the permanent damage of nerve cells in the brain (Alzheimer's Association, 2014).

Familism: The strong normative feelings of dedication, loyalty, reciprocity, and attachment to family and familial relationships (Lim, Ahn, & Ahn, 2016; Sayegh & Knight, 2010).

Assumptions

In this study, I assumed that all the adult participants would respond truthfully to the information presented in the survey for accurate data collection. I also assumed the qualitative phenomenological design would support the use of attachment theory as a lens to review and study African American caregiving. The need for capable and competent caregivers to provide care has increased, so my last assumption was that a person needing care would receive assistance from someone who has some form of attachment bond with that person.

Limitations

One limitation of this study was the small sample size chosen for the study. The sample does not represent the general population. Another limitation was the participation criteria for volunteers. Participants were volunteers who were African American women, 18 years old or older, and caring for loved ones diagnosed with Alzheimer's disease or dementia and living in a metropolitan area in the state of Michigan.

My role as a researcher and data collector was another limitation due to possible researcher bias. I am a licensed social worker with 20 years of experience working in long-term care and with families caring for loved ones with Alzheimer's disease and dementia. To mitigate this possible bias, after collecting data in participant interviews and

transcribing and analyzing it, I used member checks to confirm the accuracy of the data and informed all participants of the measures taken to ensure their confidentiality and privacy.

Scope and Delimitations

The delimitation of the study involved the geographic area of the participants. I recruited the volunteer research participants from a metropolitan area in the state of Michigan. Because the study took place in a metropolitan area, the sample was only a small representation of the African American population.

Significance of Study

The focus of this study was on African American women and their lived experiences as caregivers for loved ones with Alzheimer's disease and dementia. Through a phenomenological investigation, I explored the challenges and struggles African American female caregivers face in caring for loved ones with dementia. An exploration of this culturally specific population is significant given the higher prevalence of dementia and Alzheimer's disease in the African American population. Research shows that African Americans are two times more likely than are European Americans to develop Alzheimer's disease (Alzheimer's Association, 2016). Because of the increasing number of older African Americans receiving a diagnosis of Alzheimer's disease and other dementia-related illnesses, the need for assistance and care for the person with the disease is likely to increase as well.

The knowledge gained from this reseach study may be helpful to health care professionals, caregivers, and families, who might learn about the resilience and coping

techniques of African American women who care for their loved ones with Alzheimer's disease and dementia. Caregivers who read this research study might gain knowledge and information to assist in understanding and providing a better quality of care to their loved ones. The results will also help broaden research on dementia caregiving by demonstrating how African American females manage their lives while being the primary caregivers for their loved ones with dementia. Health care professionals will be able to use this information to assist African American families in more efficiently using interventions and services as well as managing resources. Health care professionals may also be able to have a better understanding of the challenges and needs African American caregivers face and assist them with recommendations for services. The findings from this research study might also be useful in the development of future educational programs for culturally specific care to assist people with similar caregiving experiences.

The need for social work and human services support will increase significantly because of the growing needs of the aging population. The caregiving role affects both families and individuals, and social workers and health professionals need to understand the caregiving role and the ways it relates to different cultures and ethnicities. The results from this study might also be helpful for social workers and other professionals in the human services field to provide culturally appropriate and effective interventions for family caregivers in the African American community.

In summary, Chapter 2 will include a literature review and an evaluation of the literature related to the focus of the study. Chapter 3 will follow and contains a description of the methodology, data collection, and data analysis plan used to conduct

the study. In Chapter 4, I will provide a detailed analysis of the data, and in Chapter 5, I

will discuss the results of the study.

Chapter 2: Literature Review

Introduction

The purpose of this phenomenological research study was to explore the lived experiences of African American women caring for their loved ones with Alzheimer's disease and dementia. Research about caregiving for a loved one with dementia has increased since the mid-1990s because of the rapid increase in the aging population in the United States (Wermuth, 2011). Studies about the lived experiences of caregivers for family members with dementia increased as the awareness of how dementia and Alzheimer's disease began to noticeably affect family caregivers also increased (Garand et al., 2012; Haley & Bailey, 2004). The availability of research on specific cultural areas, ethnicities, or gender-specific subjects, such as African American women, is limited. However, there is a projected increase in diagnoses of Alzheimer's disease and dementia among older African Americans over the next 20 years, and the need for care is also likely to increase (Alzheimer's Association, 2016). Researchers have explored the relationship of caregiving to caregiver burden and stress (McCallum et al., 2007; Pinquart & Sorenson, 2005) in Caucasian and Hispanic races, but in my review of the literature, I found a limited amount of information from a qualitative research perspective with a focus on African American female caregivers.

In this literature review, I will identify and support the significance of the current study. I will also provide information on the prevalence of and on social and cultural issues related to caregiving and African Americans. The first section will start with a review of the literature search strategy. The ensuing sections will include a review of the

factors that supported the characteristics of this study. I will begin the literature review section with an overview of the theoretical base of attachment theory and the ways it relates to caregiving. A review of the evolution of dementia and Alzheimer's disease follows. In the literature review section, I will review studies about caregiving, caregiver burden, female caregivers, cultural caregiving, and African Americans. I will also present studies that assisted in obtaining the main objective of this study, which was learning how African American female caregivers manage care for their loved ones with dementia and Alzheimer's disease.

My goal with this qualitative study was to explore the phenomenon of the lived experiences of African American women who care for their loved ones with dementia and describe the quintessence of those experiences to assist others. An understanding of the phenomenon was necessary to gain insight into caring for loved ones with dementia and Alzheimer's disease. The results of this study add to the knowledge base on creating detailed programs to assist caregivers and health care professionals and families might be able to use the findings to provide care in the future.

Literature Search Strategy

My search for literature involved using the Walden University Library and Google Scholar. Computerized databases used included PsycARTICLES, PsycINFO, Academic Search Complete, Medline, and ProQuest Central. The terms I used to search titles and abstracts included *caregiving, caregivers, African American, female caregivers, attachment theory, phenomenology, dementia, African American female caregivers, dementia caregivers, Alzheimer's disease, caregiver burden, familism, cultural*

caregiving studies, cultural studies in dementia, and *caregiver stress*. I reviewed studies

and articles representing the research on dementia, Alzheimer's disease, and caregiving

for relevance to my study with regard to method and content. The purpose of the

literature review was to summarize current information and studies available about

African American women who care for their loved ones with Alzheimer's disease and

dementia.

Theoretical Foundation

The theoretical orientation for this study was attachment theory. John Bowlby

conceptualized the theory after studying the effects of infants and children hospitalized

after World War II (Bowlby, 1979). Bowlby (1979, 1988) described how children looked

to their mother or primary caregiver for their needs, which created a bond and formed a

basis for attachment. Attachment is a meaningful caring bond with a significant other

(Bowlby, 1979; Nelis et al., 2014). Bowlby (1979) introduced the description of

attachment behavior, which described any form of behavior that results in a person

retaining or attaining proximity to a preferred individual (Browne & Shlosberg, 2006).

Once the attachment bond forms, a child feels confident and will try to explore the

surroundings; however, at times of stress or unfamiliarity, the child will act out

behaviors, such as crying, clinging, or calling out, to seek out care and comfort from the

primary caregiver (Bowlby, 1979; Nelis et al., 2014). This attachment base has become

the framework for many developmental relationships (Bowlby, 1979; Nelis et al., 2014).

Mary Ainsworth worked collaboratively with Bowlby and contributed to the

theory of attachment (Ainsworth, Blehar, Waters, & Wall, 1978). Ainsworth conducted a

study to examine how children reacted to the threat of separation and established the vital role of a secure base (Ainsworth et al., 1978; Browne & Shlosberg, 2006). The results of Ainsworth et al.'s (1978) study showed that a parent's responsiveness and sensitivity is an important part of secure attachment relationships. Ainsworth et al. also found that young children used the interactions developed with their mother as a basis for determining how they will interact with others.

Attachment theory is a useful framework for understanding how caregiving dyads regulate emotions and maintain feelings of security in reaction to a loved one's chronic illness (Monin, Schulz, & Kershaw, 2013). The depth of responsibility of the primary caregiver affects all relationships and social interactions (Ainsworth, et al., 1978). Attachment relationships often become a basis for comfort and assistance as well as providing psychological security when needed (Bowlby, 1988; Nelis et al., 2014). Attachment theory also provides an understanding of how people work with others who may be chronically ill. Attachment theory works well when applied to caregivers who care for loved ones with dementia. As dependency grows with the decline of cognition, the person receiving care may have increased attachment feelings such as security and safety.

Researchers have used attachment theory to review and explain different areas in development, interactions, and human development. Researchers have added to the theory as they identified relationships between the attachment style of a person and behaviors, characteristics, and future relationships (Browne & Shlosberg, 2006; Nelis et al., 2014). The main use of attachment theory in research has been to understand

caregiving is lacking. According to Browne and Shlosberg (2006), attachment theory is a useful framework for understanding the experiences of both caregivers and individuals with dementia because it serves as a basis for understanding the relationship between the tendency to seek help from others and the tendency to care for others. Monin et al. (2013) explored the attachment orientation between people with dementia and their caregivers as well as how they associated the psychological and physical well-being of persons with dementia. Attachment theory is a way of thinking about people with dementia and how their attachments with others developed throughout the life cycle and then reemerged during the dementia cycle (Browne & Shlosberg, 2006; Nelis et al., 2014).

Carpenter (2001) examined associations between attachment bonds and the care that daughters provided to their mothers at home. In the study, Carpenter looked at adult daughters, 40 African Americans, and 40 European Americans, and examined the relationships between attachment dimensions and completed assessments. The study involved using the life span developmental framework of attachment theory to examine associations between caregiving and the socioemotional bonds of daughters who cared for their mothers. The findings showed a direct correlation with attachment patterns and the nature of care provided to parents and that the security of the attachment bond affected the stress of caregiving (Carpenter, 2001).

A few studies showed a correlation between attachment relationships and caregiving styles. Magai and Cohen (1998) found care recipients' future behavioral disturbances became predicable when caregivers recognized the type of attachment personality style of the person with Alzheimer's disease. Steele, Phibbs, and Woods

(2004) observed the daughter caregivers of their mothers with Alzheimer's disease during a separation and reunion experiment. Steele et al. posited that the same caregiver characteristics associated with attachment security in children, namely the ability to provide a clear and coherent account of a person's attachment history, would have a connection to evidence of secure attachment relationships between the daughters who provided care to their mothers with Alzheimer's disease.

Miesen (1992) found the experience of dementia broke down feelings of safety and security, which activated attachment behaviors. Individuals with dementia used those feelings of attachment behaviors and the closeness of the caregiver, such as crying or calling out, to seek reassurance from familiar others (Miesen, 1992). Dementia is progressive, and as care recipients worsen, their memory and the knowledge of familiar things decreases, and as things become less familiar, attachment behavior may become less useful (Miesen, 1992). A strong attachment bond to the mother or primary caregiver during childhood leads to stronger protective behavior exhibited by the adult caregiver to the parent (Miesen, 1992). In the study, Miesen used the theory to provide an overview of how dementia and attachment correlate. Many people express the process of dementia through feelings of loss, insecurity, and separation (Miesen, 1992). The attachment bond was helpful for caregivers who provided care; however, as dementia progressed, the strength of the bond varied (Miesen, 1992). Researchers can use attachment theory to provide an overview of why a person with dementia may exhibit certain behaviors, which can lead to formulating better interventions to cope with the behaviors. Attachment

theory assists with formulating an overall framework for future dementia care programs and services.

Bowlby (1979) proposed the attachment system might evolve to meet the changes and challenges of aging. Researchers have recognized the importance of attachment in older people. Attachment is relevant for people with dementia because as independence decreases due to a decline in functional and cognitive skills, a person may feel the need to seek security and safety from others, especially from caregivers (Nelis et al., 2014). Insecure attachment may cause a person with dementia to look for security in other places or not trust the caregiver, which can lead to negative behaviors or distress (Nelis et al., 2014). People with dementia with secure attachment bonds usually seek assistance from others whom they trust and are comfortable with receiving help and support (Nelis et al., 2014).

Researchers may use attachment styles to provide guidance on how caregivers respond and coordinate care with people with dementia and Alzheimer's disease. In this study, I explored how African American female caregivers cared for their loved ones with dementia and how the lens of attachment theory served to fulfill those bonds. Further research in this area of theory was necessary to explore how to meet the attachment bonds of loved ones with dementia and to develop more knowledgeable interventions with caregiving.

Alzheimer's Disease and Dementia

Dementia-related illnesses and Alzheimer's disease are debilitating diseases that not only affect the person afflicted but also their whole family financially and

emotionally. In 2015, approximately 15.7 million individuals provided care for someone diagnosed with dementia or Alzheimer's disease, and most often those caregivers were women (Alzheimer's Association, 2015). Family or informal caregiving refers to unpaid assistance provided by family or friends for another individual needing care (NAC & AARP, 2015). Women who have full-time employment provide the majority of all kinds of in-home care, which creates increased pressures and distress in their lives (NAC & AARP, 2015; Wermuth, 2011). Caregivers of people with dementia are more likely than noncaregivers to experience signs and symptoms of anxiety and depression (Joling et al., 2015). More than one third of households in the United States have active caregivers, comprised of 66% women and 34% men (NAC & AARP, 2015). Among demographic groups, 20.3% of the caregivers are African American, 19.7% are Asian American, 21% are Hispanics, and 16.9% are European Americans (NAC & AARP, 2015).

The number of people with dementia continues to grow as baby boomers (people born between 1946 and 1964) age, and more people will develop dementia and other cognitive impairments (Wermurth, 2011). Dementia is an umbrella term used to describe a variety of diseases and conditions that develop when nerve cells in the brain die or no longer function normally (Alzheimer's Association, 2014). Dementia is a major neurocognitive disorder because it interferes with both cognitive function and performing everyday activities (American Psychiatric Association, 2013). Cognitive function refers to memory, speech, language, judgment, reasoning, planning, and other thinking abilities (Alzheimer's Association, 2016). Dementia is a degenerative condition that causes loss of memory, functional abilities, and communication (Alzheimer's Association, 2016).

Several conditions and symptoms describe dementia, with the most common being Alzheimer's disease. Some types of dementia, such as vascular dementia, which is dementia caused by mini-strokes; Parkinson's disease, a movement disorder; and Lewy body dementia, lead to significant cognitive and functional decline (Alzheimer's Association, 2015). Alzheimer's disease causes brain changes that eventually impair a person's ability to perform basic bodily functions such as swallowing, walking, and breathing (Alzheimer's Association, 2016). Alzheimer's disease is an irreversible type of dementia that leads to memory loss, behavioral problems, and ultimately death (Alzheimer's Association, 2016). Alzheimer's type of dementia is the most common and affects every aspect of the afflicted person's life (Alzheimer's Association, 2015).

Alzheimer's disease is the most common form of dementia and is the sixth leading cause of death in the United States (Alzheimer's Association, 2016). Dr. Alois Alzheimer, a psychiatrist, discovered the disease in 1906 after conducting a study on a patient and finding significant deterioration of brain tissue (Alzheimer's Association, 2015). Alzheimer's disease is a chronic, neurodegenerative, progressive disease that gradually affects total memory recall and cognitive ability (Alzheimer's Association, 2016; Fortune, Lang, Cook, & Byrd, 2013). No prescribed medications currently available slow or stop the destruction or damage caused by neurons that cause Alzheimer's symptoms and make the disease terminal (Alzheimer's Association, 2016). This disease renders the person afflicted helpless and needing assistance and care from others.

Researchers at the Administration on Aging estimated that, by 2050, more than10 million African Americans aged 65 and older would be at risk for Alzheimer's disease (Alzheimer's Association, 2016). Older African American have a greater risk of dying from Alzheimer's disease than from any other type of dementia (Alzheimer's Association, 2016; Fortune et al., 2013; Freels, Nyehuis, & Gorelick, 2002). Because there is no cure for Alzheimer's disease, physicians try to manage symptoms with different medications and other interventions. African Americans are twice as likely as non-Hispanic Whites to have Alzheimer's disease and have higher prevalence, incidence, and cumulative risk (Alzheimer's Association, 2015). Several risk factors affect a person's chance of developing dementia or Alzheimer's disease. African Americans are at greater risk for developing the disease because of sociocultural, biological, and lifestyle aspects.

African Americans may be more at risk for Alzheimer's disease because of genetics, family history, and relationship to certain diseases (Barnes & Bennett, 2014; Fortune et al., 2013). Age and genetics have strong links to risk of the disease, as evidenced by people 65 and older, who are at a 10% higher risk, and by those ages 85 and older, who are at a 50% increased risk. Another risk factor is vascular conditions, such as diabetes and risk of stroke. Body mass index, chronic kidney disease, and low or high hemoglobin are also risk factors. Many psychosocial risks influence the risk of disease among African Americans, such as living in rural conditions in childhood, low levels of education, or poor quality education (Hall, Gao, Unverzagt, & Hendrie, 2000; Pharr, Francis, Terry, & Clark, 2014). Social and economic factors increase the risk factors of

developing Alzheimer's disease. African Americans are a disadvantaged group having low income and low levels of education. African Americans also do not seek treatment or the assistance of community resources when available.

Alzheimer's disease has identifiable stages of early, middle, and late stages of the disease. Symptoms of early to middle stages are memory lapses and forgetfulness of familiar names, words, or locations (Alzheimer's Association, 2015). The middles stage has decreased knowledge of recent events or dates, increased memory lapses, and decreased ability to manage finances, pay bills, or make appropriate decisions (Alzheimer's Association, 2015). The third stage is the late or end stage of the disease, when the person is unable to walk or follow simple commands, unable to eat, and is easily susceptible to secondary health concerns that lead to death. The duration of each stage varies for each individual and may include dealing with unpredictable behaviors and personality changes. Caregivers are necessary for providing care for their loved ones in a consistent and comfortable environment.

Alzheimer's disease and dementia care affect families in a variety of ways. Many families experience economic hardship and difficulties because of the challenges of providing care to their loved ones. The longevity of a person diagnosed with dementia or Alzheimer's disease can average at least 6 years (Alzheimer's Association, 2015; Herrmann, Gauthier, & Lysy, 2007). More than 80% of people with dementia receive care at home by spouses or other family members. Dementia caregivers may feel more stress and burden than those who care for others with different illnesses because of the increased cognitive and behavioral problems associated with persons afflicted with

dementia. The Alzheimer's Association referred to Alzheimer's disease as a silent epidemic in the African American community because of its increased scope, prevalence, and nature (see Alzheimer's Association, 2009).

Dementia and Alzheimer's caregivers experience a heavy burden of care compared to other caregivers because of permanent and progressive care needed for the disease. Alzheimer's disease and dementia affect the individuals diagnosed, their family, and their caregivers. A person diagnosed with dementia or Alzheimer's will eventually need assistance in all areas of activities of daily living, such as bathing, dressing, fixing meals, and eating.

<div align="center">

Caregiving

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The expected increase of the aging population of the United States is causing a caregiver crisis, and the pressures for providing care are overwhelming. A caregiver is someone who cares for others with mental and physical disabilities (NAC & AARP, 2015). The two types of caregivers are formal and informal. Formal caregivers are paid care providers or volunteers who conduct caregiving duties with a service system, such as an agency or hospital. Informal caregivers are family members, neighbors, or friends who provide care and do not receive monetary compensation. Formal caregivers are an added cost for families because they are expensive and not covered by most insurance (Mazanec, Daly, & Townsend, 2010; NAC & AARP, 2015). Many individuals with chronic illnesses, such as dementia and Alzheimer's disease, receive care from informal caregivers (Etters et al., 2008; Montgomery & Kosloski, 2009). Informal caregiving can be stressful because the caregivers are responsible for caring for their household and

trying care for others (Stephens, Franks, Norton, & Atienza, 2009). Informal caregivers, also called family caregivers, are often left to cover increasing costs and responsibilities for care because of reductions in government support and improved services for homecare (Feinberg, Reinhard, Houser, & Choula, 2011). Caregivers are an essential part of the health care system and need continuous assistance for understanding caregiving experiences.

Caregiving for a loved one with dementia is difficult. Dementia and its related disorders affect loved ones in different ways and make caring for them more difficult as the diseases progress. Adult children and spouses are usually the primary caregivers. A person having to care for a loved one's welfare, health, and safety faces heavy demands (Samson et al., 2016). Many caregivers of individuals with dementia report health problems, work disruption, and more burdens than caregivers of other conditions and illnesses (Germain et al., 2009; NAC & AARP, 2015). The demands of caring for a loved one with cognitive deficits, such as dementia, are exhausting. The symptoms of dementia cause difficulty with memory, which affects activities of daily living, and may increase behaviors such as resisting care, and caregivers face the need to spend more time managing behaviors and ensuring the safety of their loved ones (Pinquart & Sorenson, 2005). Dementia caregivers tend to develop depression and chronic physical illnesses more than noncaregivers (Bertrand et al., 2006). African American caregivers demonstrate various patterns of health-seeking behavior and responses to handling the challenges of caregiving than caregivers in other ethnic groups (Samson et al., 2016).

Caring for a loved one with dementia is challenging and can lead to various feelings of burden because of financial, emotional, physical, and social stressors (Haley, West, & Wadley, 1995; Proulx & Snyder, 2009). The effort needed to care for a loved one with dementia can take a toll on the caregiver's mental and physical well-being. Female family members and friends often take on the role of caregivers for their loved ones with dementia, along with other familial roles (NAC & AARP, 2015). Many women face the roles of working, parenting their children, and caring for a parent or older loved one. Many researchers have examined the negative physical and mental health outcomes associated with caregiving (Beach, Schulz, Yee, & Jackson, 2000; Bekhet, 2013; Dilworth-Anderson et al., 1999; Haley & Bailey, 2004). Caring for loved ones with dementia varies across culture, social class, gender, and ethnicity. Caregiver worries, multiple demands, and feeling overwhelmed increase the feelings of caregiver burden.

Caregiver Burden

Caregiver burden is a multidimensional response to the psychological, physical, emotional, social, and financial stressors associated with caregiving (Kasuya et al., 2000). Burdens in caregiving come from a caregiver's perception of stressors and factors and are associated with culture, kinship, and social environment (Etters et al., 2008). Etters et al. (2008) studied caregiving statistics correlated with caregiver burden across several cultures. The study included a review of the literature on dementia and caregiver burden, the causes of dementia-related caregiver burden, its characteristics, and interventions to assist caregivers experiencing burden. Results from the study showed culture, relationship to parent, and gender were major factors in the caregiving experience.

European American caregivers reported more stress and depression than did African American and Asian caregivers (Etters et al., 2008).

Gender impacts caregiver experiences because of cultural and kinship influences. Female caregivers reported more emotion-focused coping to be effective, whereas males reported more problems with focused strategies (Knight & Sayegh, 2010; Sterritt & Porkorny, 1988). The type of relationship between care recipient and caregiver correlates to the severity and type of illness (Hebert & Schulz, 2006; Knight et al., 2000).

Caregiver burden increases psychological and physical illnesses in caregivers (DiMattei et al., 2008). Caregiving can lead to poor health outcomes, increased stress, and a decline in physical health. Caregivers are also at higher risk of developing heart disease, cardiovascular problems, depression, or other diseases (Haley & Bailey, 2004; Schulz & Sherwood, 2008). Dementia caregivers reported having higher levels of depression than other care providers had (Schulz & Sherwood, 2008). Dilworth et al. (1999) surveyed 187 African American caregivers, and almost 20% more caregivers reported being in poorer physical health, feeling more emotionally distressed, and not receiving enough social support compared to their European American counterparts. Many caregivers report feelings of hopelessness, anger, sadness, and fear that affect their well-being (Pharr et al., 2014).

Savundranayagam and Montgomery (2010) analyzed role discrepancies and the ways they affect relationships between stressors related to illness as well as the relationship between stress and burden for spouses caring for their loved ones with dementia. Savundranayagam and Montgomery used caregiver identity theory as a

framework. Study participants completed questions that measured a variety of identity standards for caregiver roles and behaviors, assistance with activities of daily living, and burden. Analysis of data involved using structural equation modeling and revealed that role discrepancies affected relationships between behaviors and burden. Participants reported more feelings of burden when feeling overwhelmed by caregiver identity standards. When the caregivers identified their relationship between the person needing care and the amount of care given, the results showed positive feeling or justified the feelings of the caregiver.

Montgomery and Kosloski (2009) described caregiver identity and how, over time, changes in the caregiver correlated with the care recipient's health. The focus of the study was on the exchange of role identities between adult caregivers and care recipients. Janevic and Connell (2001) reviewed 18 studies and found that European American caregivers appraised caregiving as more stressful and reported higher levels of depression than African American caregivers did. Researchers who conducted a study of African American caregivers found that participants reported less stress and higher self-efficacy with managing problem behaviors and experienced less depression than did their European American comparison group (Haley et al., 1996). Some researchers have shown that African American showed more depression than did their European American comparison group (Haley et al., 1996). Other researchers have shown that African American caregivers reported lower levels of stress and burden than did noncaregivers (Knight et al., 2000). Researchers also showed that African Americans did not report

greater use of psychotropic medication or greater stress psychologically when compared to European Americans (Haley & Bailey, 2004).

The challenges of caregiving are both physical and emotional, because dementia caregiving involves using more energy and time than any other type of caregiving (Alzheimer's Association, 2015). Caregivers have to manage all aspects of care for their loved ones, which include activities of daily living and behavior problems, as well as their own challenges. Spouses are more likely to spend the most time caregiving because they live with their loved one. Many men and sons care for their loved ones; however, female caregivers comprise over 66% of caregivers in the United States (NAC & AARP, 2015).

Female Caregivers

The majority of people with dementia or Alzheimer's disease live in the community rather than in care facilities. The largest percentage of caregivers is spouses, children, grandchildren, and other relatives or friends; most are women (Alzheimer's Association, 2015; NAC, 2009; NAC & AARP, 2015). Women are more likely to take on a caregiving role than are men (Pinquart & Sorenson, 2005). Women between the ages of 45 and 65 who combine caregiving responsibilities with working full-time jobs provide most of the informal caregiving in the United States (Family Caregiver Alliance: National Center on Caregiving, 2009; NAC & AARP, 2015). Women are usually the primary caregiver and experience more primary stress than do other family members (NAC & AARP, 2015). The higher level of strain observed among daughters than among spouses is because of the multiple roles in the familial relationship (Pinquart & Sorenson, 2005).

Caregivers, who are predominately women, give up not only unpaid time, but also sacrifice their own health and hopes that could result in a higher paying job, more satisfying career, greater community service, or more enjoyable family life.

Pinquart and Sorenson (2005) reported two thirds of all unpaid caregivers are female, and they often report poorer health statuses than males. A large majority of African American families assumes responsibility and care for the elderly and other family members, and daughters are usually the caregivers (NAC & AARP, 2015). African American women play an important role in terms of complexity, intensity, and quantity of caregiving duties (Jones-Cannon & Davis, 2005). Mui (1992) examined caregiver emotional strain among African Americans and European American daughter caregivers by using a role theory perspective. Mui focused on daughter caregivers of frail older people who were at risk for placement in institutions. The sample included 581 people, of which 117 were African American and 464 were European American. The African American daughters reported having health issues, less income, and less education and being less likely to be married when compared to their European American counterparts. The African American daughters reported a more demanding caregiving role and less strain than did the European American group. The limitations noted were the use of secondary data, a nonrandom sample, the cross-sectional nature, and measurement issues (Mui, 1992).

Culture and Caregiving

Cultural norms and values impact decisions, attitudes, and actions involving family caregiving. They provide an outline and structure about providing care, which

includes who should provide care and who should access other resources in the familial network (Dilworth-Anderson et al., 2002). Many ethnic minority cultures define caregiving as behavior that is reciprocal in nature. Nkongho and Archbold (1996) conducted a qualitative analysis and revealed that 41% of respondents cited reciprocity as the reason for caring for dependent family members. The respondents noted providing care was reciprocated because of various reasons of assisting their loved one who needed care.

Pharr et al. (2014) found that cultural values and norms influenced the perception of the caregiving role and the way caregiving roles were perceived within a culture as being a choice or expected duty. Pharr et al. (2014) conducted a qualitative, interpretive, phenomenological analysis of focus group transcripts from four groups for cultural influences on caregiving (Pharr et al., 2014). The four groups represented among the 35 caregivers were African American, Hispanic American, Asian American, and European American cultures.

Filial obligation appeared to be a common phenomenon in the literature (Herbert & Schulz, 2006; Jones-Cannon & Davis, 2005; Wuest et al., 2001). Wuest et al. (2001) surveyed a sample of 15 family caregivers who cared for their loved ones and found that one emerging theme was obligatory care. Some of the caregivers indicated they felt an obligatory responsibility to provide care to their parents. Caregiver obligation indicated that providing care was primary to any other relationship responsibilities. Filial obligation formed through a socialization process of what members of one's culture expected with regard to caring for an elder parent or family member (Cicirelli, 2006).

Sanders and Corley (2003) found a common theme of familial obligation during their collection of qualitative data from 253 caregivers. This information came from a previous larger study on grief and caregiving. Sanders and Corley found that caregivers noted that their spirituality and belief in God helped them cope; many had few feelings of grief because of being grateful to be able to care for their loved one. The familial obligation led caregivers to have feelings of care for their parent that were stronger than feelings of grief (Sanders & Corley, 2003). Although many caregivers did not have good relationships with their loved one prior to diagnosis, they still felt and continued their familial obligation to provide care.

Familism appeared to be more prevalent in ethnically diverse populations, such as African Americans, Latino Americans, and Asian Americans, because of their cultural beliefs and family values. Familism is the strong normative feelings of dedication, loyalty, reciprocity, and attachment to family and familial relationships (Lim et al., 2016; Sayegh & Knight, 2010). Jones-Cannon and Davis (2005) conducted a mixed methodology project in which they surveyed 106 African American daughter caregivers on their caregiving experiences and 44 African American daughter caregivers through focus groups. Both groups reported that their cultural beliefs influenced their choices of providing care, and positive familial relationship bonds and support of family networks assisted with care and coping responsibilities, despite cost burdens and barriers to care (Jones-Cannon & Davis, 2005).

Rozario and DeRienzis (2008) studied the relationship between familism, as specified by caregivers' beliefs about their caregiving role, and psychological distress,

with a sample of African American woman family caregivers. The study involved using different approaches: a stress and coping model, a contextual model, and a sociocultural model. Rozario and DeRienzis examined the influence of caregivers' sociocultural beliefs on their psychological distress while controlling for their personal, situational, interpersonal, and psychological distress. The study findings indicated that caregivers who follow traditional familism values about their caregiving role might take sole responsibility of caring for their loved one and find some stress between caregiving tasks and resources available. The relationship between caregivers and care recipients led to a correlation between the reports of lower levels of stress and more satisfaction with the caregiving role (Rozario & DeRienzis, 2008).

African Americans

Cultural contexts outline roles in caregiving and influence caregiving responses. African American culture has strong roots and distinction that shape and affect anyone who identifies or interacts within the group. African American families focus on two cultural values: family and religion (Picot et al., 1997). Strong families are the foundation in many African American families and often provide lasting and extended kinship bonds that include aunts, uncles, grandparents, and cousins. Religion is another cultural value that is strong in African Americans. The church is an institutional structure through which its members and the community receive cultural, spiritual, social, and educational development (Picot et al., 1997).

A major concern in the African American community is the lack of education and knowledge about dementia and Alzheimer's disease. Because of these deficits, loved

ones often receive late diagnoses, which leads to delays in receiving early Alzheimer's interventions and proper care (Barnes & Bennett, 2014). African Americans are often reluctant to seek medical assistance because of a long legacy of mistrust with the medical field. Several elements have built this mistrust, including racism, poor communication skills, unethical human experiments with African Americans, and a perceived lack of empathy and compassion (Chi, Negash, & Hamilton, 2011; Fortune et al., 2013).

Such feelings highlight why research involving cultural caregiving continues to be important to the community. African American caregivers are more at risk of developing physical and mental problems because of the increased risk factors associated with the African American population. Adult women are often the primary caregivers of loved ones and often face the challenges of managing their lives with the lifestyle demands of raising a family, having a job, and caring for loved ones. Research has shown caregiving is stressful and often associated with depressive symptoms (Beach et al., 2000). In a study by Knight et al. (2000), African Americans had reported lower levels of burden than did noncaregivers because of lower levels of emotional distress. In addition, African American reported less psychological stress or psychotropic medication use in comparison to European Americans, despite difficulties accessing health care (Haley & Bailey, 2004).

African American caregivers usually include spouses, extended relatives, adult children, or close family friends (Hargrave, 2006). Researchers have shown that African American caregivers face many limitations, such as low income, underuse of services, job factors, and physical and mental hardships. Even with limitations, this culture showed

resilience and strength with familial care. One study involved using strength-based perspectives to analyze the differences between Black and White rural family caregivers (Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007). Kosberg et al. (2007) found that White caregivers were more likely to be older and married and coped with stressors by using humor and acceptance. The Black caregivers spent more time giving care, used religion and denial as coping techniques, and expressed fewer feelings of care burden (Kosberg et al., 2007).

African American caregivers must often divide their time between caring for their older loved ones and maintaining roles with their own family, such as caring for children, maintaining employment, and running a household. This has given rise to an increase of role strain and burden for those families in the sandwich generation. The sandwich generation refers to caregivers who are providing care for elderly parents and caring for their own children (Do, Cohen, & Brown, 2014). Many caregivers make sacrifices, such as reducing work hours, time with friends, or time spent participating in other activities to provide care to their loved ones (NAC, 2015).

In a qualitative study Dilworth-Anderson, Boswell, and Cohen (2007) examined the role of religious spirituality as a means of social support and coping. The purpose of the study was to understand how African Americans use their strong religious and spiritual beliefs in their roles as caregivers. Through a grounded theory approach, Dilworth-Anderson et al. showed that spirituality was an important factor in the caregiving role. The study showed that African American caregivers reported

gratification and positive feelings about their caregiving role by using their spiritual belief as a foundation of strength.

African American family caregivers caring for loved ones with Alzheimer's disease reported that caregiving is a part of tradition, and caring for family is an act of love (Sterritt & Porkorny, 1998). The four major themes that emerged from the study were caregiving as a female role, caregiving as an act of love, caregiving as a traditional family value, and social support as a mediator of caregiver burden (Sterritt & Porkorny, 1998). The exploration of the correlation between race, gender and caregiver burden was critical given the higher prevalence of Alzheimer's disease in the African American population (see Alzheimer's disease, 2015).

Knight and Sayegh (2010) explored caregiver burden, cultural values, physical health, social support, and coping mechanisms by researching problem-focused coping and emotional-focused coping interventions with caregiving. Knight and Sayegh found that emotional-focused coping (e.g., compulsive eating) did not lead to lower mental health outcomes; however, problem-focused coping (e.g., seeking advice) appeared to decrease depression and reduce caregiver strain. African American caregivers reported fewer burdens than did European American caregivers, which may be linked to European American caregivers' likelihood of caring for a spouse (Knight & Sayegh, 2010).

African American caregivers expressed more positive feelings about caregiving that did European American caregivers when dealing with the difficulty of caring for their loved ones (Knight et al., 2000; Pharr et al., 2014). African American caregivers felt a stronger obligation to care for families, had a larger social network to assess, reported

less illness, and used religion and faith supports more when compared to other caregiver groups (Beach et al., 2000). Pharr et al. (2014) explored significant differences in the cultural values and norms that shaped the caregiving experience. Pharr et al. conducted a qualitative interpretive phenomenological analysis with four focus groups: African American, Hispanic American, Asian American, and European American. Researchers have noted that African American caregivers may perceive caregiving as less stressful because they have coped with a lifetime of continuous struggles.

The cost of caring for loved ones with dementia plays a huge role in caregiving. In 2012, the estimated annual cost to African Americans for Alzheimer's and other dementia care was $71.6 billion. The families of African American women with Alzheimer's and other dementia assumed more than 60% of these costs, and close to half of the costs were in the southern part of the United States (Gaskin, Laviest, & Patrick, 2013). The economic burden of Alzheimer's disease is quite high, but no one can express the full impact of this disease in dollars. The various ways that it affects care recipients and their loved ones are difficult to quantify. Alzheimer's disease causes physical, psychological, and emotional burdens on families and caregivers by removing the memories, experiences, and wisdom that its victims can no longer share with others (Gaskin et al., 2013).

A significant number of researchers have reported that the negative effects of caregiving impact African American caregivers less than they impact European American caregivers (Knight & Sayegh, 2010). African American caregivers are strong believers of faith and religiosity, which is a compelling factor in coping. African American caregivers

often face health issues and economic concerns when caring for their families. Researchers have found that, despite the struggles, African American caregivers report more gains and rewards than do European American caregivers (Haley & Bailey, 2004; Janevic & Connell, 2001).

Summary

Although I found several studies on caregiving, a significant gap emerged regarding information about African American female caregivers and their experiences in caregiving. The African American population steadily continues to grow, and the need exists for more information to assist the growing number of caregivers faced with caring for their loved ones with dementia and Alzheimer's disease. This study involved using a phenomenological approach to determine the lived experiences of African American females caring for their loved ones with dementia. Chapter three includes information on the implementation of this study, the identification of participants, the questions asked, and the information collected and analyzed.

Chapter 3: Research Method

Introduction

My exploration of the lived experiences of African American women caring for their loved ones with Alzheimer's disease and dementia showed how these caregivers balance caregiving and their lives and includes interventions with managing the care of their loved ones. The purpose of this qualitative research study was to examine this phenomenon through the lens of attachment theory. The focus on African American female caregivers addressed a gap in the current knowledge base. A thorough detailed review of the African American caregiving perspective was overdue and necessary, especially considering this public health issue. This review and exploration of African American caregiving experiences allowed me to learn more about and reach a deeper understanding of this experience. Researchers have often compared African American caregivers to caregivers in other cultures without giving much detail into the reasons for variation and differences of outcomes (Bertrand et al., 2006; Dilworth-Anderson et al., 2002; Shurgot & Knight, 2005). The results of this study showed the ethnicity-specific ways caregivers provide care to loved ones.

The two previous chapters included a discussion on the background and purpose of analyzing the lived experiences of African American females who care for their loved ones with dementia. In this chapter, I will discuss the qualitative methods used to gather and analyze collected data. I will begin with an overview of the chapter and then discuss the research design and rationale as well as my role as researcher. I will also discuss the

setting, data collection, instruments used, and data analysis process. The principle research questions for this qualitative research study were as follows:

RQ1: What are the lived experiences of African American women caregiving for loved ones with dementia?

RQ2: How do African American women manage and cope with caring for loved ones with dementia?

Research Design and Rationale

Qualitative analysis is suitable for exploring the meanings of social phenomena as experienced by participants in an organized, scientific way (Merriam & Tisdell, 2015). Qualitative research works well with multicultural inquiry because researchers are able to examine phenomena through personal interviews and record participants' experiences. When considering the design for this study and the focus on the lived experience on African American women, it seemed appropriate to me to use a qualitative method rather than a quantitative one.

Phenomenology was a suitable research methodology for exploring the lived experiences of African American females who care for their loved ones with dementia and Alzheimer's disease. The focus of phenomenological research is on what the person experiences and the verbal representation of lived experiences (Rudenstam & Newton, 2014). Edmund Husserl formulated the concept of phenomenology as a philosophical alternative to traditional approaches of attaining knowledge about the world (Giorgi, 2012). Husserl focused on acquiring understanding of the lived experiences of others through specific language, describing the phenomenon, and having an open unbiased

mind to examine people's perceptions and life experiences (Giorgi 2012).

Phenomenology is the study of the lived experience, and researchers use it to explore

what an experience is like by describing phenomena as they appear to the persons

experiencing the phenomena (Touhy, Cooney, Dowling, & Sixsmith, 2013). As the focus

of interpretive phenomenology is to explore the lived experience, it is important to

recognize that the environment and the world in which they live influences people's

realities (Touhy et al., 2013). Researchers need to understand that links exist between

experiences and cultural, social, and political frameworks (Touhy et al., 2013).

Researchers use phenomenological inquiry to provide an analysis of how

particular experiences of a phenomenon develop to have a better understanding of

elements and to increase others' knowledge about the meaning of the experience (Beck,

2013; Moustakas, 1994). Creswell (2014) stated that a phenomenological study

examines the meaning of the lived experiences of several individuals. Phenomenological

inquiry was suitable for discerning the lived experiences of African American female

caregivers of loved ones with Alzheimer's disease and dementia.

I also considered other types of qualitative research methods for this study;

however, the focus and types of analysis were less effective in providing the information

necessary to understand this phenomenon. I considered ethnography because of my focus

on African American women and the African American culture. Researchers conduct

ethnographic studies to provide a description or interpretation of a cultural group or

system (Creswell, 2017; Merriam, 2015). After much consideration, I did not use

ethnography because of the small sample size and because ethnography usually involves collecting data over an extended period.

A second methodology I considered was case study inquiry, which involves analyzing a specific case, activity, or event that includes many people (Creswell, 2017). A case study is a qualitative approach in which an investigator explores a bounded system (case) over time using detailed, in-depth data involving multiple sources of information, such as interviews, observations, and documents, and develops a case description and case-based themes (Creswell, 2017; Merriam, 2014). A case study was not applicable because the focus of this research was not occurring over time but was something the participants were experiencing at the time of the study or had experienced as the result of a phenomenon (see Creswell, 2017; Rudestam & Newton, 2015).

Neither grounded theory, nor narrative research were suitable for this study either. The focus of grounded theory is building a theory from collected data, and it is useful for addressing concerns about how something changes over time (Merriam & Tisdell, 2015). I could have used grounded theory for this study, but I wanted to explore the phenomenon using the data collected from the participants to understand the fundamental nature of their experiences. The focus of narrative qualitative research is on one individual and their story or experiences as told by that individual (Creswell, 2017). Narrative research involves using stories as data and first-person accounts told in story form, having a beginning, middle, and end (Merriam, 2014). This type of design would not have addressed the research questions in this study.

Phenomenological inquiry was the more suitable choice for this study because it involves studying several individuals who have shared the same experience and allows the participants to share their lived experiences in their own words (Rudestam & Newton, 2015). This methodology was appropriate for this study because researchers use it to identify the essence of human experience as described by participants of the study (Creswell, 2014). The focus of hermeneutic phenomenology, also known as interpretive phenomenology, is on describing, interpreting, and understanding participants' experiences (Creswell, 2017; Rudestam & Newton, 2015). I chose the hermeneutic approach to phenomenology for this study.

Role of the Researcher

Researchers should clearly identify and describe their role as researchers to provide transparency, so readers understand how researchers impact their studies. Qualitative researchers need to acknowledge their assumptions about the research process, their professional and personal ideas, and their role as a participant (Creswell, 2017). Researchers should ensure trustworthiness, credibility, and quality by acknowledging any biases, stating their position at the beginning of the research, and thoroughly exploring all areas of the research focus (Van Manen, 2014). As the researcher for this study, it was my ethical duty to disclose that I am a licensed social worker who worked in the field of health services at a local nursing home.

I am an African American woman who has worked in the human service field for more than 20 years as a social worker. I am a licensed social worker who has worked in long-term care and with older adults and their families for most of my career. I have been

the director of social services at two nursing and rehabilitation centers in a metropolitan area in the state of Michigan. My education and training in the field of social work and health services administration prepared me to be a researcher in this field. My past positions and work experience provided opportunities to understand the phenomena of caregiving for loved ones with dementia and Alzheimer's disease. In addition to my work experience, I was also a caregiver for my beloved grandmother who had diagnoses of Alzheimer's disease and dementia until she died in 2012.

As the researcher, I served as the primary observer and collector of information from participants in this study. I asked participants semistructured interview questions and recorded their answers on separate sheets while audio recording their responses during each private interview session. After each session, I secured interview sheets, notes, and other confidential participant information in a locked safe in my home. I interpreted participants' experiences during interviews based on my personal knowledge of Alzheimer's disease. After each interview, I e-mailed or mailed each participant a complete transcript of the interview to ensure my interpretation and transcription of the information was accurate.

Methodology

The purpose of this qualitative study was to examine the lived experiences of African American females who care for loved ones with dementia. I used a qualitative phenomenological method to explore the lived experiences of African American women who care for their loved ones with Alzheimer's disease and dementia. Researchers use qualitative methodologies to study phenomena in their natural settings (Creswell, 2014).

Qualitative methodologies involve using document reviews, interviews, and participant observation data to explain and understand social phenomena (Creswell, 2017).

Descriptive phenomena are essential in understanding how to describe a phenomenon's general characteristics rather than the individual's experiences to determine the meaning of the phenomena (Creswell, 2017). Researchers directly observe, interview, and conduct discussions or provide questionnaires to participants to explore participants' lived experiences (Creswell, 2017; Rudestam & Newton, 2015). The researchers collect, analyze, and use the data to provide a description of the essence of the experience for all participants (Creswell, 2017; Rudestam & Newton, 2015). This qualitative phenomenological study involved exploring African American female caregivers in their everyday activities, which included caregiving for loved ones with dementia, to identify themes that emerged from the meaning of their lived experiences. The coping techniques, routines, culture, habits, experiences, and language of being a caregiver outlines individuals' understanding of the world.

Study Participants

The participants were a nonrandom, purposeful sample of adult African American women, aged 18 to 65 years old, who had cared for or were currently caring for a loved one diagnosed with dementia or Alzheimer's disease at the time of the study. Purposeful sampling is a process of selecting participants based on their understanding of the research problem (Creswell, 2014). I recruited participants from a metropolitan area in the state of Michigan. I worked with community agencies and physicians who specialize with working with older adults to recruit volunteer participants. The number of volunteer

participants were 10, which was an appropriate number of individuals to achieve the saturation of data needed for the qualitative phenomenological study.

I purposely selected this sampling method to gather participants who could provide an understanding of the lived experience of African American women who cared for an individual with Alzheimer's disease or dementia. This sampling method was suitable for gathering in-depth data about African American female caregivers in a convenient and timely manner. While gathering information, I learned of trends, relationships, and basic data that existed beyond this specific group of caregivers. This information may be useful for further exploration and studies that apply to the larger African American community.

Ethical Protection of Participants

The participants were African American female caregivers of loved ones who had been diagnosed with dementia or Alzheimer's disease and who volunteered to participate in the study. The volunteer participants were not subject to any known harm associated with this study. If a participant had experienced difficulty or harm associated with participating in this study, I would have provided a referral to local services. Each participant completed a consent form, and I protected their confidentiality. All transcripts, files, and audiotapes will remain stored in a locked file drawer in my home office.

Data Collection

Upon approval to begin the study, I sent out information flyers to community agencies and physician offices who allowed me to recruit from their offices in the metropolitan Detroit area (See Appendix A). The letters contained information about the

research study, the expected use of the information, and a request for their support. The information flyers contained an explanation of the study, participant requirements, and my contact information (see Appendix E). After prospective participants made contact, I verified participant criteria using the screening questionnaire and then scheduled interviews to begin data collection. Each participant received an introductory letter explaining the study and how the interviews would be conducted (see Appendix B).

Data came from participants who completed semistructured interviews. The data collection instruments were a screening questionnaire, a demographic questionnaire and a semistructured questionnaire used to help ascertain the barriers, resources, and experiences from participants (see Appendix C). Participants had the chance to describe their experience in a way that would help to uncover the nature and essence of their particular lived experience caring for their loved ones with dementia. I used an in-depth semistructured interview to gather the participants' experiences related to caregiving. According to Seidman (2013), the process of interviewing allows participants and interviewers to explore participants' experience, place it in context, and reflect on its meaning. The goal of the interview was to recreate the specific details of the participants' experiences (Seidman, 2013). The focus of the interview questions was the participants' descriptions of the lived experience of African American females who cared for their loved ones with dementia.

I made digital audio recordings of interviews using a reliable software source. Rubin and Rubin (2011) suggested using digital voice recording devices because of the ease of downloading data recordings to audio files on a computer. I used a laptop

computer and NVivo 11 computer software to transfer the interviews to the computer's hard drive for safekeeping. All participants allowed the use of a computer and digital audio recording during the interview. Back-up copies were also available if needed.

The interview technique used was semistructured, and criterion sampling offered the opportunity to identify participants of interest. Researchers use a semistructured interview technique to use standard questions with one or more individually tailored questions that will assist in probing participants' reasoning (Creswell, 2017; Leedy & Ormrod, 2010). Digitally recording interviews helped ensure accuracy. The semistructured interview is a form of interviewing and useful for collecting data when a researcher does not observe the phenomenon directly (Creswell, 2017; Seidman, 2013). I was able to study and review the feelings, perceptions, and beliefs of each participant regarding the specific phenomena based on these individual interviews. Each participant heard the same question, in the same order, to ensure no variability in the interviews, which helped to reduce bias, compare participants, analysis, and data organization (Creswell, 2017).

Interviews took place in the privacy of the participants' homes or in other locations in which the participants felt comfortable in familiar surroundings, which also helped to minimize the cost of travel. Each participant received an overview of the study and the informed consent paperwork to review and sign (see Appendix D). I encouraged and answered any questions or concerns about the study during this process. During the interviews, I took handwritten notes and used a digital audio recorder to have an audio recording of the interview to ensure accuracy. Participants received the informed consent

form to review, sign, and discuss any questions that arose. The participant then answered a set of demographic questions.

An interview can be emotionally stressful; therefore, if a participant felt uncomfortable or became fatigued, I stopped the interview. At that point, the participant had the option to resume at another time or stop the interview and withdraw from the study completely. Information was available, such as the phone number of the local Alzheimer's Association, and a listing of local dementia support groups. I made every effort to establish an atmosphere in which each participant felt safe enough to talk freely about her experiences and to share her thoughts and emotions without fear of judgment.

After all the interviews were complete, I listened to the digital audio recordings and transcribed each recording. I had copied all digital audio recordings as a safeguard using a flash drive. I used NVivo 11 for Windows to transcribe the data from participants. According to QSR International (2017), NVivo is qualitative data analysis computer software that researchers can used to handle small and large volumes of qualitative data. I created a folder for each participant for organizational purposes. Each folder contained all information pertaining to each interview conducted, including all initial correspondence (scripts and cover letters), the informed consent form, demographic data, the digital audio recording, a transcript of the interview, and the research program software. All hard copies, digital copies, and originals will remain in a locked file cabinet in my home.

Data Analysis Plan

Each participant received a random number for identification purposes to avoid bias. After data collection from the interviews was complete, the organization and review

of the data began. I analyzed the data to formulate an understanding of the information contained therein. The first step in understanding the meaning of an experience is reading a transcript thoroughly and gaining a general sense of the information (Giorgi, 2012; Moustakas, 1994).

The second step was to factor out or to identify statements in the text that were relevant to the phenomenon studied. I extracted statements or meaning units from the text and listed them separately (Giorgi, 2012; Giorgi & Giorgi, 2003). The next step involved labeling the statements as they related to understanding the phenomenon. I labeled meaningful units in the form of sensitive psychological expressions (Giorgi, 2012; Giorgi & Giorgi, 2003). The expressions represented the actions, emotions, and feelings based on how the participant experienced the phenomenon. I reframed the statements by using psychological descriptions to describe typical spoken language concerning the phenomenon.

The last step in analyzing data involved developing individual descriptions of the experience. The process used to develop group descriptions was the same. Each participant helped build her own individual description of what it means to be a female caregiver of a loved one with dementia (Moustakas, 1994; Van Manen, 2014). These individual descriptions developed by reviewing data and determining which are connections describing the meaning or theme**.** (Giorgi, 2012). I connected each participant's connections to provide a detailed description of the essences and meanings of the experience that represented the group as a whole (Moustakas, 1994; Van Manen, 2014).

Issues of Trustworthiness

To maintain credibility and trustworthiness in this study, I used reliability and validity strategies. I also used triangulation in the data analysis stage. Triangulation refers to the use of several data sources in qualitative research to develop a comprehensive understanding of a phenomenon (Creswell, 2017). The triangulation technique involved reviewing the data collected through interviews, questionnaires, and observations. I collected data in participant interviews, transcribed and analyzed the data collected, and used member checks to confirm the accuracy of the data.

Summary

This chapter included a description of the methodology used and the purpose of the research design as it related to the study. The chapter also included a discussion of the data collection procedure and analysis, as well as a brief review of the significance and purpose of the study. The findings of the study will follow in Chapter 4, and the conclusions in Chapter 5.

Chapter 4: Research Findings

Introduction

The purpose of this qualitative phenomenological research study was to explore the lived experiences of African American women caring for their loved ones with dementia and Alzheimer's disease. I collected data by individually interviewing 10 African American women caring for their loved ones. I developed each interview question with a goal of eliciting participant responses to address the research questions. The research questions guiding this study were as follows:

RQ1: What are the lived experiences of African American female caregiving for loved ones with dementia?

RQ2: How do African American females manage and cope with caring for loved ones with dementia?

Themes emerged during the data analysis to describe the lived experiences of caregiving. This chapter will begin with a review of the purpose of the study and a review of the research questions. The next sections will include a description of the study setting, participant demographics, data collection, data analysis, and the findings. I will conclude the chapter with a summary.

Setting

The setting for this research study was a metropolitan area in Michigan. The target population consisted of African American female caregivers who provided care for loved ones with dementia or Alzheimer's disease. After I received approval (Approval No. 05-16-17-0013025) from the Walden University Institutional Review Board (IRB), I

placed my flyers at the approved locations to invite African American women, aged 18 and older, caring for loved ones with dementia or Alzheimer's disease to participate in the study. Participants contacted me via phone to express their interest in the research study, and I asked further questions to ensure they fit the criteria (see Appendix A) before scheduling an interview. The face-to-face interviews took place at various locations, such as the participants' home or office, a coffee shop, or the public library. Participants were able to choose a comfortable location for their interview. Each participant received, reviewed, and signed the consent form before beginning the interview.

Demographics

Ten women participated in the study. Of the 10 participants, five were daughters caring for their mothers, two were nieces caring for their aunts, one was a spouse caring for her wife, one was a great niece caring for her great aunt, and one was a daughter-in-law caring for her mother-in-law. All 10 caregivers were caring for female care recipients, and the length of time as a caregiver ranged from 2 years to 10 years (see Table 1). The next section will include an overview of the participant demographic profile.

Table 1

Demographics of Participants

Participant	Age	Relationship to care recipient	Care recipient diagnosis	Occupation	Years of care
P00001	57	Daughter	Alzheimer's	Retired law enforcement	3
P00002	51	Niece	Dementia	Human services assistant	4
P00003	57	Daughter	Dementia	Training manager	2
P00004	60	Wife	Alzheimer's	Professional	5
P00005	57	Daughter	Dementia	Social worker	2
P00006	63	Daughter	Dementia	Religious leader	10

P00007	50	Niece	Dementia	Health care professional	4
P00008	29	Great niece	Alzheimer's	Unemployed healthcare	4
P00009	60	Daughter-in-law	Dementia	Part-time clerical	5
P00010	48	Daughter	Dementia	Government professional	8

Demographic Profiles

This section will include a brief description of each study participant. All demographic and biographical data were current at the time of the study. All participants served as caregivers for their loved ones on a daily basis. I omitted all personal information that might have led to identifying the participants in the following descriptions. The following participant profiles are a description of each participant according to my impression during the interview:

- P00001 was a 57-year-old married woman who was caring for her mother who had a diagnosis of Alzheimer's disease. She was a retired law enforcement officer and had been caring for her mother for over 3 years.

- P00002 was a 51-year-old woman who cared for her aunt who had a diagnosis of dementia. She was a human services worker who worked with mentally ill adults and had been providing care to her aunt for 4 years.

- P00003 was a 57-year-old woman who cared for her mother who had a diagnosis of dementia. She worked full time as a training manager in government services. P00003 described caring for her mother as "the long goodbye" because she saw a little of her fading away daily.

- P00004 was a 60-year-old married woman who cared for her wife of over 20 years who had a diagnosis of early onset dementia. She worked part time as a

professional while trying to ensure her loved one was cared for and safe at home.

- P00005 was a 57-year-old single woman who recently learned that her mother had a diagnosis of dementia. P00005 believed that her work in the social services field would be helpful as she prepared to provide more assistance to her mother in the future.

- P00006 was a 63-year-old married daughter caring for her mother who had a diagnosis of dementia. P0006 was the religious leader of a church and had witnessed her mother's decline from living independently to living in a memory-care setting.

- P00007 was a 50-year-old married niece who cares for her aunt who had a diagnosis of dementia. P00007 was a licensed health care professional and reported that she had assisted families with caring for their loved one but stated that nothing could have prepared her for the challenges of caring for her loved one.

- P00008 was a 29-year-old single woman caring for her great aunt who had a diagnosis of Alzheimer's disease.

- P00009 was a 60-year-old married woman who assisted with caring for her mother-in-law. She worked part time as a clerical worker and had been caring for her loved one for 5 years.

- P00010 was a 48-year-old single woman who was caring for her mother at home. Her mother had a diagnosis of dementia, and her confusion and

behaviors were getting worse. P00010 was employed in government service and reported feeling overwhelmed with caring for her mother.

Data Collection

After receiving Walden University IRB approval to begin my study, I was able to hang my flyers at the approved locations. I began receiving phone calls from interested participants and after determining they met the inclusion criteria, I invited them to participate and scheduled interviews. I used a purposeful criterion sample to identify potential participants (see Creswell, 2017). The data collection period was from June to August 2017. Ten participants took part in the study.

Interviews, focus groups, and narrative case studies are appropriate forms of data collection in phenomenological studies (Creswell, 2014). The participant interviews took place at a time and location convenient for each participant. Prior to each interview, all participants received two consent forms (see Appendix D), one to keep for her records and one to return to me. Participants reviewed the consent form and signed it before the interview began. Each participant had the opportunity to ask questions and address any concerns during the consent process. I administered both the demographic questionnaire and the consent form. Each participant received a participant number after providing sociodemographic data. The individual interviews lasted between 30 minutes and 90 minutes. There were no interruptions, and each interview went smoothly.

I digitally recorded interviews on a handheld recording device. Each participant had the opportunity to respond to each question (see Appendix D) during the interview. The interview consisted of using the questions as a guide to elicit meaningful response

from the participants. The interviews included semistructured, open-ended questions to gather the lived experiences of African American women caring for their loved ones with dementia and Alzheimer's disease. I used probes and active listening skills to keep the participants in the experience of transitioning during the interviews. Participant experiences unfolded as they shared their descriptions and stories of their lives as caregivers.

I transcribed all interviews from the digital recordings. Each participant received a copy of the transcript via e-mail, and I made a follow-up phone call to ensure accuracy. I saved the interviews on a flash drive that will remain in a locked file cabinet. There were no unusual circumstances or variations from the data collection process I previously described in Chapter 3.

Data Analysis

The phenomenological approach was suitable for interpreting the data from the interviews, which acknowledged the totality of lived experiences belonging to a single person. The purpose of the interview questions was to elicit responses from the participants from which I could collect in-depth information to address the research questions. Each participant received a random number as a form of identification to safeguard confidentiality. After each interview was complete, I transcribed the information verbatim into a Microsoft Word document for organization and review. I analyzed the data to formulate an understanding of the information that they held. The steps used in the process of discovering themes were as follows.

The first step I took in understanding the meaning of the experience was reading and reviewing each transcript thoroughly and associating a general sense of the information (see Giorgi, 2012; Moustakas, 1994). I reviewed the transcripts several times to gain an understanding and description of the participants' experiences and perceptions. I also reviewed my field notes from the interviews and read each transcript while listening to the audio recording to ensure clarity.

In the second step I reread each transcript line-by-line to ensure accuracy in comparison to the audio recordings. During this review, I factored out or identified statements in the text that were relevant to the phenomena studied. Researchers should extract identified statements or meaning units from the text and list them separately (Giorgi, 2012; Giorgi & Giorgi, 2003). Collected data yielded 604 minutes of recorded data and 2,200 transcribed lines of data. One hundred fifty significant statements emerged from the 10 verbatim transcripts. The second step involved physically manipulating the data using a variety of different methods. Initially, I identified statements with similar meanings with different colored highlighter pens. I used NVivo 11 to assist in the organization of the data and entered the transcripts into the software to obtain a more thorough review and to assist in coding.

The third step of analysis involved labeling and coding statements that related to understanding the phenomenon. I began labeling meaningful units in the form of sensitive psychological expressions (see Giorgi, 2012; Giorgi & Giorgi, 2003). The expressions represented actions, emotions, and feelings based on how the participants experienced the phenomenon. I then reframed the statements using psychological

descriptions to describe typical spoken language concerning the phenomenon. Coding is a qualitative research technique that researchers use to organize data into categories and themes that enables them to use inductive reasoning (Creswell, 2014). Codes are labels that assign symbolic meaning to the descriptive information compiled in a study (Miles, Huberman, & Saldana, 2014). Using NVivo 11, I manually coded the data; analyzed words using word trees, word frequency, and repetition; and made comparisons.

The last step in analyzing data involved developing individual descriptions of the experience. Each participant helped build her own individual description of being a female caregiver of a loved one with dementia. Researchers collect participant connections to provide a detailed description of the essences and meanings of the experience that represent the group as a whole (Moustakas, 1994; Van Manen, 2014). As the data analysis process unfolded, I identified certain thematic statements for each distinctive meaning that I discovered in the transcripts. Van Manen (1994) indicated that themes are statements or thematic statements that sum up each major portion of text and that serve as a special facet to understanding a phenomenon.

Researchers use themes to explain the essence and meaning of a phenomenon based upon participants' responses (Creswell, 2014; Seidman, 2013). Many themes emerged from the data analysis process, and I distilled them down to primary themes by using NVivo 11 functions to apply useful and meaningful names to codes and to extract directly from quotations within the interview transcript. Theme development involved analyzing the number of times participants repeated a word, which helped create codes and themes based upon the frequency and repetition of a single word.

After completing my analysis, I identified six main themes: sense of responsibility, grounded in faith, guidance for future caregivers, difficult journey, caregiver challenges, and coping strategies. The complete list of themes, the number of sources each theme came from, and the number of times participants referred to each theme in their discussion appear in Table 2. Themes emerged from 10 interviews. All participants voluntarily engaged in the process and provided additional information when asked for clarification.

Table 2

Final Themes With NVivo 11 Data Analysis

Themes	Sources	Number of references from all sources
Sense of responsibility	10	12
Grounded by faith	10	14
Guidance to future caregivers	10	18
Difficult journey	10	16
Caregiver challenges	10	20
Coping strategies	10	19

Evidence of Trustworthiness

Researchers must establish confirmability, credibility, transferability, and dependability to affirm trustworthiness in qualitative data (Creswell, 2014; Rudestam & Newton, 2015). I established confirmability and credibility using member checks and triangulation during the data collection process. Member checking helped ensure the credibility of the data by confirming the accuracy and consistency of the qualitative data using follow-up transcripts reviewed by participants 1–2 weeks after interviews took place. The participants confirmed their transcripts were accurate and commented on the findings if needed. The study also entailed triangulation in the data analysis stage.

Triangulation refers to the use of several data sources in qualitative research to develop a comprehensive understanding of phenomena (Creswell, 2017). The triangulation technique was useful for reviewing data through questionnaires, interviews, and observations. The study involved collecting data in participant interviews, analyzing and transcribing the data, and conducting member checks to confirm the accuracy of the data.

Researchers achieve transferability by providing detailed and thorough descriptions of demographics, data collection methods, and data analysis so that replication of similar studies can occur (Creswell, 2017; Rudestam & Newton, 2015). I provided detailed information of the process of participant selection and followed listed procedures for all participants during the data collection process. The details and data analysis process was well documented, as were any changes needed within the method, data collection, and data analysis. The researcher reviewed and rechecked the process throughout the study. Future researchers may be able to conduct similar studies in other settings because of the meticulous descriptions of the participants' experiences and the data collection process (Creswell, 2014; Rudestam & Newton, 2015).

The measures of dependability were achieved with the use of a digital handheld recording device (Creswell, 2014; Rudestam & Newton, 2015). I audio recorded, transcribed, and coded the initial face-to-face interview with each participant. Because the transcripts reflected the audio recordings, the data obtained were reliable. The study does not include the transcripts of the interviews, as this would jeopardize the confidentiality of all participants. I conveyed the essence of the participants' experiences

through the emerging themes, and I align them with the research questions, conceptual theory, and literature review in the following results section of this study.

Discrepant Cases

I did not identify any differences in participant caregiver responses during the study. No exceptions, outliers, or modification patterns emerged in the data. All data were indicative of the review of the literature. There were no extenuating differences in formal caregiver responses. Although there were differences in participant responses about their caregiver experiences, there were no instances in the data analysis where the data did not support the explanations given by each caregiver. Additionally, no patterns in the data challenged any of the responses given by each caregiver.

Results

This qualitative phenomenological research study involved looking at ways African American females managed and coped with caring for loved ones with dementia. The main aim of this inquiry was to develop a better understanding of how African American females provide care to loved ones in a home setting. The researcher organized the data extracted from statements into themes that captured the meaning of the women's lived experience caring for their loved ones with dementia. The task involved using NVivo 11 (QSR, 2017). The following sections contain the results of this study organized by major themes and then further divided by the responses of formal caregivers. The framework provides an opportunity to elicit and analyze essential themes from the data. I explore each theme and provide relevant quotations from each research participant. Ten participants voluntarily shared their experiences with caregiving for this study, and six

common themes emerged from the interviews: sense of responsibility, grounded in faith, guidance for future caregivers, difficult journey, caregiver challenges, and coping strategies.

The following sections include a review of the themes and excerpts of the interview content that related to the major themes. These quotations do not represent exhaustive examples of the influential factors shared during the interviews. Instead, the quotations give readers an idea of the participants' thoughts about their lived experiences regarding caring for loved ones with Alzheimer's disease and dementia.

Theme 1: Sense of Responsibility

All the participants discussed their caregiving relationship with their loved one with dementia. Each caregiver was an informal caregiver to a person in her family. Of the 10 participants, five were daughters caring for their mothers, two were nieces caring for their aunts, one was a spouse caring for her wife, one was a great niece caring for her great aunt, and one was a daughter-in-law caring for her mother-in-law. The first emerging theme was a sense of responsibility. The participants described feelings of having a sense of responsibility and commitment toward their loved one. The 10 participants' sense-of-responsibility experiences follow.

P00001 stated,

This is mom and I love her dearly. I will take care of her until one of us leaves because she took care of me. I always promised that I would never put my parent in a nursing home and I will honor that promise. Honor thy mother and father is a strong value that I believe in.

P00002 responded, "Family is a very important part of my life. I value and treasure family." P00003 replied, "What really motivated me was my determination not to put her in a nursing home. I had promised her that I will take care of here." P00004 said, "This is the love of my life. I am not going to put her in a home. I promised to care for her." P00005 noted, "She is my mother. You only get just one. She did the best she could of ensuring that my siblings and I had a good life, and I want to make sure she is cared for."

P00006 responded,

I promised her that I would never put her in a nursing home, but the memory care home appears to be more homelike, and there is a care team to help her as she declines with normal activities of daily living.

P00007 noted,

I remember that I made my aunt and my mother a promise to make sure that they are cared when they got older. I have to do this. This is my aunt, and I promised her that I would take care of her. Family is supposed to care of each other, period.

P00008 stated, "I will always be available to help my aunt as long as I am alive. As a family, we have agreed to try and care for at home until we can't anymore." P00009 replied, "I love my family. Mother is my mom, and I don't refer to her as my mother-in-law. Family takes care of family." P00010 said, "I love my mother and I will fight for her dignity and comfort to live out her days at home. She has afforded my brother and I a good life and we owe her the same."

Each participant expressed feelings of concern and duty to ensure her loved one received care. The promise of care ranged from a long-spoken promise to beliefs of

reciprocating care bestowed on the caregiver by the loved one. Analysis of the participant interviews indicated strong feelings of responsibility from caregivers to provide care for their loved ones.

Theme 2: Grounded in Faith

Another theme that emerged from the interviews was the participants' belief in faith and religion. Each participant discussed how her faith and belief in God contributed to her strength and helped her cope with her caregiving abilities. The theme emerged as participants talked about their strength and motivation to care for their loved ones. Researchers have examined the role of religious spirituality as a means of social support and coping (Dilworth-Anderson et al., 2007). Participants provided many references to strength and faith in God. A review of their responses follows.

P00001 responded, "My faith is strong in the Lord, and I know he will give the strength to see this journey through. I go to church every Sunday and pray daily, which I think helps in keeping my peace of mind." P00002 said,

I believe that it is a gift from God to be able to serve others and help them.
Something in my spirit draws me to help others, and I am good at this. I find
peace knowing that I have helped someone. My faith balances it all out.

P00003 noted,

My faith played a huge part as well. God truly has blessed me and my family. I
knew he was truly helping me in my life to get through this journey. I believe it
was the right thing to do.

P00004 stated, "I tell you, I thank God every day." P00005 replied, "I come from a strong family of women, and we have always cared for each other, especially if the other person is ill."

P00006 replied, "I thank God for my family and my friends." P00007 noted, "I draw my strength from a higher spirit. I realize that this is what I am supposed to do." P00008 said,

> I believe love and faith played a huge part in me caring for my loved one. My family is very important to me. I think that by being a blessing to others that I will continue to receive my blessings.

P00009 stated, "We have a very strong family of faith, and our trust in God carries us through the hard times." P00010 responded, "My faith in God and friends and family. Knowing my mother's faith and God and the strong beautiful woman that she is." Participants discussed how they find strength to continue to provide care and help their loved ones. Spirituality, faith, and religion were prevalent in the lives of the participants.

Theme 3: Guidance for Future Caregivers

Participants discussed several lessons they had learned from their experiences with caregiving. The overarching theme that emerged from one question on the interview was suggestions that would help future caregivers. A review of their responses follows.

The subtheme of having patience and being patient with the person needing care was evident throughout the responses. P00001 shared the following statement:

> I would tell anyone on the caregiving journey to bring patience, patience, and more patience. You never know how tough it is being a caregiver until you have

to do it. It is very tough being a caregiver. It is difficult at times but I try to

remember the good times and how beautiful and caring my mother was. I know

that her time is drawing to a close, and while she is here, I try to make days as

comfortable as possible. Try to use every resource you can find and don't be

afraid to ask for help.

P00002 stated the following:

It is very important to have patience and to know how to deal with changes.

Everyone cannot handle the stress of caregiving. Never be afraid to ask for help if

needed. I love my family and I would do anything for them.

P00008 added that patience and understanding about the disease process are helpful:

Understanding and educating oneself about dementia and Alzheimer's disease is

important. It helps to have the patience and understanding to work with older

adults as well. As a caregiver, you should always remember to take care of

yourself with getting the proper rest, care, and assistance.

P00010 summed up the idea of patience by adding that organization is also very

important: "Patience and organization is the key. I have learned to have more patience

with dealing with my mother and organizing her day. She is on a routine and that works

best for her and me."

A second subtheme that emerged from the participant responses was preparation.

P00003 described the importance of learning about the disease process and preparation:

I think it is important for anyone who has to go this journey of caregiving to

educate themselves about the disease process and try to prepare as much as

possible. Preparation begins with getting an idea of what providing care may

entail by talking to her caregivers and using community resources.

P00004 noted that preparation and organization were key: "Preparation is the key. And

organization. Plan early and get rest. Be aware of the finances and benefit package. I am

her durable power of attorney, and I am fully aware of her wishes for her care." P00007

also discussed being prepared: "Being prepared, being organized and taking care of you

are all beneficial for preparing for this task."

A third subtheme that emerged was the focus on the caregivers taking care of

themselves. P00005 stated that remaining positive and accepting help from others was

very helpful: "I would tell everyone to remain positive and focus on happy times. Don't

be afraid to accept help from others." P00006 offered the following: "To pray and

meditate on His word daily. Try to become as knowledgeable about this disease process

as you can, and don't be afraid to ask for help from others." P00009 explained that caring

for self is paramount:

> I would tell anyone who is headed on the caregiver journey to take care of
>
> yourself first. Ask for and accept any assistance from others and all people or
>
> agencies to help. It takes a village to provide care and can become very
>
> overwhelming for just one person.

The overarching theme of guidance for future caregivers developed from the data

and indicated the participants views on assisting others in the caregiver process. Each

participant discussed her thoughts about different things she had learned from her

experiences. Participants believed the information provided might help other caregivers.

Theme 4: Difficult Journey

The respondents discussed their views on being a caregiver as being on a journey. Participants acknowledged that being a caregiver is difficult and had affected their lives in different ways. For example, P00003 expressed the following:

I think it is important for anyone who has to go this journey of caregiving to educate themselves about the disease process and try to prepare as much as possible. There is a saying that Alzheimer's disease is the long goodbye and to me that phrase is true to life. God bless all caregivers.

P00001 reported similar feelings:

It's hard, but I am learning a lot about myself and my strength and faith traveling this journey. This is truly a tough job. Don't get me wrong: I love my mother with all my heart, but she is at the point where she barely recognizes me and sometimes that is tough. You never know how she is going to react from one day to another. Some days are better than others.

P00002 shared the following:

I am unable do all the things I used to do like hang out all night and day, leave and go on short trips out of the city, or be totally carefree. I have more responsibility now. In the past, I would travel a little or go out with friends. But now, I have learned to plan our days and schedule our days.

P00004 stated,

On any given day, I don't know to whom I am awakening to. For example, on a good day, she will awaken and be so sweet, stating, "I love you, and I appreciate

you for all that you do." But on other days, I sometimes don't know who she is as

it pertains to her behavior.

P00006 expressed,

> The biggest change I had to make was not feeling guilty about placing her in a
>
> memory care facility. I have always been very close to my mother, and we did
>
> everything together. But over the past 3 years; her increased care needs were
>
> becoming overwhelming.
>
> P00007 discussed the effect caregiving has on her life by stating, "It has affected

my life a lot. My life has become very hectic because I have to put her first now. I am

very concerned about her well-being and her quality of life." P00008 reported,

> This is like a job, but she is my family, and I am doing something to help my
>
> family. As a family, we try to work around our schedules so that there is always
>
> someone here to care for her. She requires 24-hour supervision and care.

P00009 stated,

> It has affected my life in many ways. It really has made me look at my own
>
> mortality and how I would like to be cared in the future. It is a chore, and together
>
> my spouse and I have to be strong together to ensure that mother is cared for.

P00010 noted that caring for her mother has affected her life:

> Caregiving is a 24-hour job because even when you are not home, you are still
>
> worrying about your loved one. I have gained weight, and I also drink a little
>
> more alcohol and beer than I used to in trying cope. I have to deal with anxiety,
>
> and I see a counselor at times to assist as well.

Participants compared their caregiving experiences to a journey, as if someone was moving. Each participant explained how caregiving has affected her life in many ways. Responses varied, but each participant noted that caregiving has affected her in different ways as she traveled her caregiving journey.

Theme 5: Caregiver Challenges

The challenges of caregiving emerged as a major theme from responses to the interview questions. African American female caregivers tend to provide care for care recipients under various health, social, and economic challenges (Chadiha, Adams, Biegel, Auslander, & Gutierrez, 2004; DiMattei et al., 2008). Each participant discussed some of the challenges and difficulties she experienced providing care to her loved one. P00001 shared the following about the difficulties of providing care:

I have shed tears because she is my mother but her memory is so poor now and her health is declining. It is sad to witness her decline like this, especially after knowing how beautiful and strong she once was. I can tell that sometimes she knows that I am a familiar face, but she doesn't remember my name or that I am her daughter. When she looks at pictures, she does not remember the people in the pictures, including her children. I believe that is the tough part of handling this disease.

P00002 shared the following about her challenges:

She needs cueing and convincing to take a shower or bathe, and she wears the adult pull-ups. We have our good days and bad days. There are times that she does not want get up or get dressed and will stay in bed all day. I take each day as

it comes. Sometimes I don't want to get out bed, so we accommodate, but it does

not usually last long, and then she is back to herself.

One subtheme that emerged was the challenge of dealing with a loved one who

hallucinates. Three participants spoke of dealing this challenge. P00003 stated,

A few years ago, she started hallucinating, such as she would hear music and see

things that were not there. I notice that she thought the people on television were

real and they could see her. She would have full conversations with them. She

would say, "Don't say that in front of them," and "Don't say stuff in front of her."

P00006 noted,

The experience of seeing your mother decline and having to provide additional

care for her is tough. Her short-term memory loss just kept increasing, and she

was becoming more and more forgetful. I realized that she was beginning to

hallucinate. She began to hallucinate and believed that there were people living

under her bed and with her in the apartment. There were several times when she

would call me over there. These people in her apartment. Also, there were times

that she would try to compensate and make up things or events because she could

not remember what really happened.

P00009 recalled,

At times she thought that the people and things which she saw on the television

was real and talked to the television like it is a real person. She stated that the

people in the television would tell her to do different things. I tried to redirect her;

however, she would insist that there were people in her room. After that, we knew

she needed closer supervision.

P00004 expressed the following:

She has her good days and bad days. There are times when she can be sweet and

kind, and then there are times when she is mean and angry at everyone. She has

been combative and will fight. She has exhibited wandering behaviors.

P00005 stated, "There are times while during a conversation she may forget the topic or

change the subject, and she often repeats herself or the same story. I know mom is going

to need more assistance down the road."

Loved ones who want to try to leave the house or open locked doors find they

must secure the home for safety purposes. For example, P00007 reported the following:

I have had to childproof the house, such as putting locks on doors up high. I put

out extra pillows because I know she likes to rearrange them and move items. It is

so hard to see someone you love who was once so caring and kind become at

times evil and mean. When she doesn't want to eat, she will push her plate away

until you move it or it goes on the floor. I have started to use paper products at

home. At times, she doesn't recognize her room, and she says she wants to go

home. I have special locks on the doors so she won't try and leave.

P00010 also expressed challenges taking care of her mother:

My mom has exhibited different behaviors over the years. Since she is very

forgetful now, the hardest part recently is getting her to relax in the evening.

About a year ago, I caught my mother trying to leave the house because she

wanted to go home. I tried to explain to her that she was at home; the home that she lived in for the past 60 years but she did not believe me. It was heart breaking trying to get her to recognize our home again. I tried showing her pictures of her and my father and of my childhood but she was not remembering. I finally had to tell her that she was staying with me for tonight and I would take her home tomorrow. She finally calmed down and went to bed and then she forgot the next day until the evening. She was sundowning. There are times that you have to really watch her. Just the other day I found the vacuum in the tub and I have found her purse in the freezer. I have had to lock different items in the house just like you would childproof a home, such as her medications, money, and her jewelry, because she would take something and lose it.

Previous research studies have shown that caring for people with dementia or Alzheimer's disease can be difficult due to the declining cognition and increased behaviors such as resisting care and difficulty bathing of the care recipient (Karagiozi et al., 2014; Shim, Barroso, Gillis, & Davis, 2013). Participants shared examples of behaviors and difficult situations involving the care recipients. The responses from the caregivers reinforced those ideas and gave insight to how caregiving affects a person's life on a daily basis.

Theme 6: Coping Strategies

Participants discussed ways they cope with being a caregiver. The coping strategies discussed ranged from not taking behaviors and combativeness personally to being thankful for the assistance of friends and family. Researchers have also discussed

various ways African American caregivers cope and manage their lives and report having more positive rewards than other ethnicities (Bekhet, 2013; Dilworth-Anderson et al., 2004; Picot et al., 1997). A summary of their responses follows.

P00001 stated,

I try not to take the negative things personal, especially when it comes to my mother's behaviors or combativeness. I tend to laugh at things more, especially when I realize she doesn't know what she is doing and can't control it.

P00002 responded,

Organization and planning activities ahead of time works well for me. I pray a lot, and I remember how my mother and aunts took care of us as children. I want to make sure she is cared for as well. I try to keep my aunt happy from making sure she has her favorite summertime snack: watermelon or a cool glass of lemonade or iced tea.

P00003 noted, "My life is so crazy and very unpredictable. Crazy has become my new normal. I did not know what was going to happen; there were days that I didn't know what would happen." P00004 replied,

You have to be creative and think out of the box. My friends help a lot because they understand what I am going through. If we go to a function or an event, they assist by keeping her busy and helping me with her behaviors.

P00005 said, "Although we are at the beginning of this journey, we are preparing for the changes to come. I plan to reach out to some of the community resources in my area for information on caregiving." P00006 responded,

I thank God for my family and my friends. I have learned how to accept help

when offered and not to worry. I have also learned how to be very patient with my

mother and allow to let her live her best life possible.

P00007 stated,

My family and friends help me cope. When I feel overwhelmed, I have a friend I

can call on, and my children often step in to help me out. Sometimes a day or two

away allows me to come back refreshed and renewed.

P00008 replied,

I manage to cope with caring for my aunt by being patient with her and working

through her behaviors. She has a very short attention span and has become very

forgetful. Even when she gets upset over something like a bath or having to get

changed, simply changing the topic or offering a snack like fruit or a peppermint

can easily distract her and she will forget about the behavior that she was

displaying. So instead of arguing with her, I let her calm down and I went to get a

popsicle. She loves popsicles. I told her that she must let me change her first, and

then she could have the popsicle, and she let me change and clean her with no

problems.

P00009 said,

I realize my normal is not her normal, and sometimes I just wait patiently to see

how things play out. I try to adjust by, and cope by, praying and meditating. I

have noticed as well that there are times when mother will have certain behaviors,

such as she can become easily agitated and refuse care or assistance. Those are

times when I have to be very patient and I usually try allow her time to calm

down and then I will reapproach her.

P00010 noted,

I just take it one day, one incident, at a time. It's hard, and I have shed many a

tear about going through this process. I try not to sweat the small stuff, as they

say. I have come to realize that I might stress and get upset over something that

my mother may not even remember that she done within the next 5 minutes. I try

to reach her and understand her on her level while maintaining her dignity.

Caregivers often face obstacles as they try to balance caring for their loved ones

with other daily demands, such as working or caring for their families. There is an

increased risk of burden or stress with these tasks, and understanding how to manage and

cope with those difficulties is beneficial. Participants shared their individual ways of

coping with caregiving and its challenges. The knowledge of helpful strategies can assist

other caregivers. Prior studies have shown that caring for a loved one with dementia or

Alzheimer's disease can be very challenging (Dilworth-Anderson et al., 2004; Wermuth,

2011).

Summary

The purpose of this qualitative, phenomenological research was to learn about and

understand the lived experiences of African American females caring for their loved ones

with dementia and Alzheimer's disease. I collected data from 10 participants by

conducting in-person interviews, transcribing them, and analyzing the data. The data

analysis resulted in six major themes that emerged from the interviews: sense of

responsibility, caregiver challenges, difficult journey, coping strategies, grounded in faith, and guidance for future caregivers. These shared lived experiences or themes help broaden the understanding of the lived experience of caring for loved ones with dementia and Alzheimer's disease. A discussion of study findings, limitations, implications for positive social change and suggestions for future research will appear in Chapter 5.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to gain an understanding of the lived experiences of African American women caring for their loved ones with dementia and Alzheimer's disease, how those experiences affected their lives, and how they coped and managed in their daily lives. My intention with this study was to acquire an in-depth understanding of this phenomenon. I was able to elucidate participants' experiences of caregiving by using the data from their responses and extracting and developing themes with which to interpret their lived experiences and meanings. An understanding of this phenomenon was necessary to gain insight into caring for loved ones with dementia and Alzheimer's disease. Research on culture-specific caregiving is critical in helping health care professionals and families provide care in the future.

The results of this study add to the knowledge base of public health and cultural caregiving. The potential implications for social change include improving public health policy, improving cultural provider-patient interactions, and improving community services for this underserved population. Chapter 5 will include a discussion of the results and their meaning as they correlate to social change. I will also discuss the 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.

Interpretation of the Findings

Research Question 1

Research Question 1 was: What are the lived experiences of African American women caring for loved ones with dementia? I used all the interview questions to paint a picture of the experiences of each participant. The first three themes described different connections and relationships between the caregivers and their loved ones and included guidance to future caregivers.

Theme 1 included a discussion on the sense of responsibility caregivers felt to provide care. Each participant had a familial connection to their loved one and expressed a sense of responsibility to provide care for them. Several participants noted that they had promised the love one that they would care for them and were fulfilling their promise. The cultural orientation of a strong filial obligation and responsibility toward providing care is strong for ethnic caregivers (Pinquart & Sorensen, 2005).

Theme 2 reflected participants' views of how the role their religious beliefs and faith played in their lives. Each participant expressed faith in God or a higher power as a way to cope with the difficulties and challenges of caregiving. When coping with the strain of providing care to a family member, African American caregivers rely on their religious beliefs. The role of religion and spirituality is pronounced in the African American culture and serves as a source of support and a means of coping to caregivers providing care to loved ones with Alzheimer's disease (Heo & Koeske, 2011).

The third theme revealed commonalities with sharing information and guidance to future caregivers to prepare them for being a caregiver. A common piece of advice was to

learn about all aspects of dementia to promote a higher understanding of the disease and to improve confidence and ability in providing direct care. Travers, Beattie, Martin-Khan, and Fielding (2013) conducted a study that revealed a person's confidence and ability to provide care increases with more knowledge and experience working with individuals with dementia.

Research Question 2

Research Question 2 was: How do African American women manage and cope with caring for loved ones with dementia? The final three themes were difficult journey, caregiver challenges, and coping strategies. Each participant described feelings about managing and coping with the responsibilities of caring for loved ones with dementia. Theme 4 included a discussion on the difficult journey of caregiving. Most of the literature on caregiving shows that caregiving can be difficult and challenging; however, researchers have noted African Americans report less stress and depression than caregivers from other cultures (Sayegh & Knight, 2010; Knight, Silverstein, McCallum, & Fox, 2000). Participants referred to caregiving as a journey because the length of time varies, and caregivers have many other experiences and encounters while providing care to others.

The fifth theme that developed in the findings revealed challenges with being a caregiver. Each participant discussed the challenges experienced as a caregiver and expressed ways of managing the difficult times. The data showed various behaviors and situations impacted caregiving in different ways. There were consistencies between the findings of this study and the current literature. Challenging situations and stressors are

related directly to the level of dependency of care recipients and caregivers' needs, demands, and experiences of providing care (Dilworth-Anderson et al., 2004; Pinquart & Sorenson, 2005; Wermuth, 2011).

The sixth and final theme was coping strategies. Each participant discussed various coping strategies for dealing with caregiving. The results from this study were consistent with the current literature with regard to caregiver coping skills. Caregivers need to stay focused on the positive aspects of caregiving and find meaning in their caregiver role (Quinn, Clare, & Woods, 2012).

Conceptual Framework

Attachment theory serves as a theoretical framework for understanding caregiver behavior and the relational experiences of caring for people with dementia (Kokkonen et al., 2012; Nelis et al., 2014). According to Bowlby's (1979) attachment theory, attachment styles formed earlier in life influence people's relationship with and ability to care for other people. Caregivers' attachment styles also affect their ability to cope with the caregiver role.

The theory lays a foundation to explain various positive and negative aspects with caregiver experiences and relationships. I interviewed 10 participants for this study, and each participant was providing care to a loved one related in some way. Of the 10 participants, five were daughters caring for their mothers, two were nieces caring for their aunts, one was a spouse caring for her wife, one was a great niece caring for her great aunt, and one was a daughter-in-law caring for her mother-in-law. Due to the level of attachment between the caregiver and the care recipient, attachment security moderated

the relationship between strain and reward in the caregiver role (Nelis et al., 2014). The next section will include a discussion on the limitations of this study.

Limitations of the Study

This study included several limitations. The focus of this study was African American women who were providing care to their loved ones with dementia and Alzheimer's disease. The participants were individuals who were African American women, 18 years old and older who resided in a metropolitan area in the state of Michigan; therefore, the results of the study were not generalizable to all African American caregivers or other races, as I only collected data from these specific participants who volunteered. I recruited a sample of 10 participants from several locations in a metropolitan area in the state of Michigan. Due to the small sample size, the results are not generalizable to all African Americans who have been diagnosed with dementia and Alzheimer's disease. A discussion of recommendations for future studies will take place in the following section.

Recommendations

Future research regarding cultural-, ethnic-, and gender-specific studies of caregiving and caregivers of patients with dementia can build on the findings from this study as well as on those from previous studies. First, researchers should conduct additional phenomenological studies to examine the lived experiences of more caregivers. As I noted in Chapter 2, research on specific cultural areas, ethnicities, or gender-specific subjects, such as African American women, is lacking. Due to the

projected increase in the next 20 years of older African Americans receiving a diagnosis of Alzheimer's disease and dementia, the need for increased care is likely to rise.

Second, future researchers may choose to widen the scope of the study by increasing the number of participants or by changing participant characteristics to broaden knowledge about African American caregivers. Future studies should target both male and female caregivers and their use of services. A more detailed understanding of caregivers and their culture can provide insight on how health care professionals can use support services to assist their families. Identifying culture-specific concerns can help with reviewing effective programs, approaches, and interventions to help and support caregivers and the community.

Implications for Social Change

The results of this study demonstrate the motivation, resilience, and strength of African American female caregivers. As evidenced by their own experiences with caring for loved ones with dementia, it is important to provide care, although it is both challenging and burdensome. The findings of this study provide a view into life experiences related to caregiving for a small number of participants. The need exists for a continued investigation of caregiving for patients with dementia that might lead to support programs and training developed to help caregivers and families. Only a few community service agencies have programs to assist caregivers and family members, but there is an increased need for these programs, as there is a projected increase for care needed for individuals diagnosed with dementia and Alzheimer's disease (Fortune et al., 2013). Researchers may use the results of this research study to develop educational

programs for culturally specific care to assist people with similar caregiving experiences.

Awareness of ethnic and cultural variations in caregiving allows health care professionals

to meet the needs of a diverse society more effectively.

The need for social work and human services support and assistance will increase

significantly because of the growing needs of the diverse aging population. The

caregiving role affects families and individuals, and social workers and health

professionals need to understand the caregiving role and how it relates to different

cultures and ethnicities. The results from this study broaden dementia caregiving research

through an exploration and examination into how African American women manage their

lives while being the primary caregivers for loved ones with dementia. Health care

professionals may use the findings to help African American families apply interventions,

use services, and manage resources more efficiently. The results may also lead to

increased knowledge and understanding of the challenges and needs of African American

caregivers and assist them with recommendations for services.

The knowledge gained from this reseach study may also help health care

professionals, caregivers, and families to learn about the resilience and coping techniques

African American women use when caring for their loved ones with Alzheimer's disease

and dementia. The results of the research in this study could be helpful to social workers

and other professionals in the human services field in providing culturally appropriate

and effective interventions for family caregivers in the African American community.

The findings in this study could also add to the current knowledge base and may lead to

increased funding in governmental resources for more Alzheimer's disease and dementia support services.

Conclusion

The purpose of this qualitative phenomenological study was to explore the lived experience of African American female caregivers caring for loved ones with dementia and Alzheimer's disease. Ten participants voluntarily shared their caregiving experiences for this study, and six common themes emerged from the interviews: sense of responsibility, grounded in faith, guidance for future caregivers, difficult journey, caregiver challenges, and coping strategies. Evident from both the study findings and the literature was that caregiving is challenging; however, caregivers have learned to manage those challenges and cope with their situations. Caregivers who had the proper information and preparation for the task of giving care were more successful.

As agents of social change, human service practitioners and social workers need to be able to work with caregivers and families from all ethnic and cultural backgrounds. The findings from this study add to the body of knowledge and the available information about dementia and Alzheimer's disease in the African American community, and human service professionals and social workers may use the findings when developing plans of care for caregivers, families, and organizations. The findings aligned with the literature, although there were a limited number of studies on African American caregivers. Therefore, this study was important because it filled the gap in the literature and added to the body of knowledge.

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Appendix A: Letter to Community Partners

Dear XXXXXXXX,

My name is Lisa Forbes and I am a doctoral candidate at Walden University. I am conducting research study on the lived experience of African American females caring for their loved ones with dementia and/or Alzheimer's disease. This research will provide insight into the caregiver experiences and give add to the body knowledge related to dementia caregiving.

Your assistance in conducting this much needed research is important. I am asking for your assistance to help identify potential candidate for the research study. I only need you to post a flyer at your agency or a note in your newsletter inviting volunteer who may interested, I am trying to recruit 12 volunteer participants who are African American females, at least age 18, and currently caring for a loved one who has been diagnosed with dementia or Alzheimer's disease. Each participant will be interviewed and data will be collected and analyzed. Participation is strictly voluntary and no monetary compensation will be offered. All information collected is strictly confidential.

For more information or if you have any concerns, please contact me at XXXXXXXX or via e-mail at XXXXXXXX

Lisa M. Forbes

Doctoral candidate

Walden University

Dear XXXXXXXX,

My name is Lisa Forbes and I am a doctoral candidate at Walden University. I am conducting research study on the lived experience of African American females caring for their loved ones with dementia and/or Alzheimer's disease. This research will provide insight into the caregiver experiences and give add to the body knowledge related to dementia caregiving.

Your assistance in conducting this much needed research is important. I am asking for your assistance to help identify potential candidate for the research study. I only need you to post a flyer at your agency or a note in your newsletter inviting volunteer who may interested, I am trying to recruit 12 volunteer participants who are African American females, at least age 18, and currently caring for a loved one who has been diagnosed with dementia or Alzheimer's disease. Each participant will be interviewed and data will be collected and analyzed. Participation is strictly voluntary and no monetary compensation will be offered. All information collected is strictly confidential.

For more information or if you have any concerns, please contact me at XXXXXXXX or via e-mail at XXXXXXXX

Lisa M. Forbes

Doctoral candidate

Walden University

Appendix B: Letter to Participant

Name of Participant

Address

Dear (Name),

My name is Lisa Forbes and I am a doctoral candidate at Walden University. I am conducting dissertation research on the lived experiences of African American females caring for their loved ones with dementia and/or Alzheimer's disease in the metropolitan Detroit area. This research will provide insight into the caregiver experiences and will add to the body knowledge related to dementia caregiving.

I understand that your time is very important to you and I appreciate your consideration to participate in this study. This study consists of a one-time interview of approximately 1-2 hours. Interviews can be held at a location of your choosing and will not require you to do anything you don't feel comfortable doing. After the interview is conducted I will email or mail you a transcript of the interview for your review, approval, and return. All information collected is strictly confidential.

I can be reached at any time. Please contact me at XXXXXXXX to schedule a date and time that we can meet. You can also email me atXXXXXXXX. I look forward to hearing from you.

Thank you so much your participation.

Lisa M. Forbes

Doctoral candidate

Walden University

Appendix C: Interview Instruments

Screening Questionnaire

Thank you for contacting me about participating in my research study about African American female caregivers who care for a loved one with Alzheimer's Disease and Dementia.

May I ask, how did you learn about this study?

And you are calling to indicate that you would like to be a participant?

Before we continue, I need to make sure you are an appropriate participant for the research study. As it states on the flyer, this study will examine how African American female caregivers who care for a loved one with Alzheimer's Disease and Dementia. In order to participate in this study, you must meet the following criteria:

- Are you an African American female?
- Are you at least age 18?
- Are you currently caring for a loved one who has been diagnosed with Alzheimer's disease or dementia? Have you been caring for this person for at least 6 months?

You have (have not) met the criteria to participate in this study.

Do you have any questions or concerns about participating in this study?

At this point, would it be ok to schedule an interview with you? What is your preference for the location of this interview?

- Ok, so your interview is scheduled for _____ at _____am/pm.   .

In preparation for the interview, I would like to send you a copy of the consent form to review. I can mail this to you or send it by email. Which would you prefer?

I will call you the day before our scheduled interview to confirm.

Before we end, are there any questions you have for me right now?

Thank you for your time and I look forward to meeting with you.

Demographic Data

1.   Name: _____

2.   Contact information: Email_____ Phone #_____

3.   Gender:_____

4.   Age: _____

5.   Occupation:_____

6.   Relationship to Care Recipient:_____

7.   Care Recipient diagnosis: _____

8.   Length of time since diagnosis:_____

9.   How long have you been caring for loved one:_____

Interview Guide

Tell me about yourself and your loved one for whom you provide care for.

Please describe how the caregiving relationship began.

Please describe the experience of being caregiver for your loved one with dementia and/ or Alzheimer's disease.

Can you tell me how caregiving affects your life?

Can you tell me how do you adjust and cope with the challenges of caregiving?

What motivates you to continue the caregiving journey?

Is there anything else you would like to share about your caregiving relationship?