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Stigmas of Alzheimer's Disease and Help Seeking for Alzheimer's Disease Among African Americans

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This is to certify that the doctoral dissertation by

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Walden University
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Abstract

Stigmas of Alzheimer’s Disease and Help Seeking for Alzheimer’s Disease Among African Americans

by

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MA, Capella University, 2016

BA, Concordia University, 1984

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human and Social Services - Gerontology

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Abstract

The purpose of this study was to examine how the perceptions of stigma of Alzheimer's disease (AD) affected the help-seeking behaviors of African American caregivers. Data used in this study were collected using semistructured interviews with 11 African American caregivers caring for loved ones diagnosed with AD. The conceptual framework of this study was guided by the stigma theory and the sociocultural health belief model. The four types of social stigmas used to assess the effects of the stigma of AD were public, self, courtesy, and structural stigma. Data were analyzed using the Thematic Content Analysis (TCA). Results provided support that the various stigmas of AD are prevalent in the lives of African American caregivers. Results suggested that stigmas of AD are major contributors to delaying help-seeking among African Americans. Stigmas associated with AD were found to be a perceptible issue in the everyday reality of African American caregivers. Being culturally aware and culturally competent on the effects of AD in African American communities has been shown to be vital to social change. Findings suggested that the stigma of AD deeply influenced the help-seeking behaviors of African American caregivers and revealed that there is a need to work on the negative issues of stigma of AD for significant change. The findings also showed that various factors of stigma of AD should be considered when planning to reduce stigmatic beliefs and behaviors associated with AD in African American communities. The results provided information beneficial to healthcare and human service practitioners, and other professionals on how the stigmas of AD affect the help-seeking behaviors for AD among African American caregivers.

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Dedication

I dedicate this dissertation to my darling daughter, for being my inspiration, showing unwavering love and support and reminding me that I can achieve whatever I set my mind to and for allowing me the opportunity to grow with her and for being my biggest champion. Thank you to my mother, Mommy thank you for your grace, strength, love, and support, and thank you to my grandmother, for being my inspirational guide. Thank you to all the caregivers for their support over the years and to all the family caregivers. Thank you to my sister for her enthusiasm and encouragement for me to join the ranks of Ph.D. holders. Thank you, Keith Gibson, Michael Norfleet, Kay Dabrio, Patricia Jones, and Sandy Dennis for being undeniably supportive friends. Thank you to those friends who I have lost, those that I have gained and continue to meet, know that you are cherished. Thank you all of those who participated in this research study, you have all provided me with a massive impact on social change which will benefit the diverse communities of caregivers and their families. It is my hope that this study will guide health and social service professionals in being more culturally aware and competent as they serve the minority communities of older adults and their families. By understanding and responding to how stigma of Alzheimer’s disease and other dementias affect the help seeking behaviors of African American populations, the health care professionals, and Human Service professionals. This study will also benefit the caregivers seeking to provide care and support to their loved one affected by Alzheimer’s without feeling that stigma of the disease will and can only repress their lives.

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First and foremost, thank you to my G-d as I greet him where the sun and sea embrace, where the lines between the water and land erase, where the boundaries between past and future collide in the sacred now. Thank you to my dissertation committee and in particular, Dr. Sandra Harris for being the first to accept the position of Chairperson of my research study, providing feedback, your insight, and guiding me through some of life’s transitioning journeys. Thank you, Dr. Tracey Phillips, for being an integral part of my educational journey. I will never forget the first day I met you both, I was inspired, I saw the possibility to accomplish this journey with and through you. Thank you for sharing your journeys with me. Thank you, Dr. Nicole Hamilton and Dr. Greg Hickman, for ushering me to the finish line. Thank you to all the professors and members of my dissertation committee. Thank you to the staff at Walden University for letting this journey of accomplishing my Ph.D. be an easy life decision. It has been an opportunity of a lifetime and I have enjoyed every moment.

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Chapter 1: Introduction to the Study

Introduction

Alzheimer's disease (AD) is a chronic, neurodegenerative disease that is common among individuals 65 years of age and older (Herrmann et al., 2017). Alzheimer's is the most common form of dementia (Alzheimer's Association [AA], 2019). Dementia is the umbrella term used to describe several progressive illnesses that affect a person's memory, thinking, behavior, and ability to perform activities of daily living (AA, 2018). According to the World Health Organization (WHO, n.d.) though some cognitive decline is a normal part of aging, increased cognitive decline and severe changes in cognitive functioning are related to the onset of AD in older adults.

A majority of the organizations and health agencies both in the United States and globally, agree that early detection and diagnosis of AD is critical, and have made it a public health priority (AA, 2019; Alzheimer's Foundation of America [AFA], 2019; WHO, 2019; United States Department of Health and Human Services [HHS], 2016). It is estimated that approximately 60% to 80% of individuals experiencing cognitive issues eventually receive a diagnosis of AD, while the remainder of this group experience one of the other dementias such as Parkinson's disease, Lewy body disease, Vascular dementia (Macdonald et al., 2017).

Alzheimer’s disease (AD) is a progressive disease and is the sixth leading cause of death in the United States, and the fifth leading cause of death among adults 65 years and older (Center of Medicare and Medicaid Services [CMS], 2016). It is also the fourth leading cause of death for African Americans (Steenland et al., 2017). According to

Wells et al. (2017), AD and other related forms of dementia are disproportionately expressed among various racial groups.

Past research has revealed that inadequate knowledge of AD and stigmas of AD are major barriers that prevent individuals from seeking treatment for the disease (Cations et al., 2018; Nguyen & Li, 2020). Stigma plays a role in defining the perceptions and experiences of AD and has been understudied (Gove et al., 2017). They stated that stigma is the most influential aspect to access and use of services and serves as a barrier to formal help-seeking when the symptoms are related to AD.

African Americans who provide care to individuals with AD often subscribe to the stigmas of AD that exist in the African American community (Epps et al., 2018; Lopez et al., 2020). These African American caregivers' perceptions of the stigmas of AD may result in delayed medical treatment. Limited information is known about how African Americans perceive and make decisions regarding care, support, and medical treatment when they experience symptoms of AD. Findings from my study could be used to promote social change by contributing information to the literature regarding how stigmas associated with AD affect African Americans' help-seeking behavior for treatment of AD.

In this chapter, I will present background information that frames the social problem that will be addressed in this study. I will describe some of the stigmas African American caregivers experience while caring for a family member affected by AD. I will discuss the problem statement, the purpose statement, the of this study, research question, definitions, methodology, and conceptual framework.

Background

Alzheimer's disease has been categorized as a public health crisis (WHO, 2018). According to WHO, historically, AD was viewed as only an aging or medical issue. Alzheimer's disease now impacts the global, national, state, and local level with a new case in the United States diagnosed every 66 seconds, and worldwide, every 4 seconds. As of 2019, there were as many as 5.8 million Americans diagnosed with AD (AA, 2020). Alzheimer's disease has brought about issues with long-term care, economic burdens on families, communities, the nation, and increased changes in the diagnosis of death among people over the age of 65 years, making it a growing epidemic (WHO, 2018).

Most people are unaware that AD is a medical disorder and that the symptoms are caused by damage to the brain (Kahn et al., 2016). They explained that this lack of knowledge about AD could lead to inaccurate assumptions regarding AD. Some of the inaccurate assumptions of AD are that it is inevitable with age (American Psychological Association [APA], 2020), that if a person has a family member with AD they will also get AD (Kahn et al., 2016), that memory loss is a natural part of aging (Steenland et al., 2015), that AD signals the end of a meaningful life (Vermunt et al., 2019), and that memory loss always signifies AD (Amjad et al, 2016). There are other assumptions about AD, such as people with AD cannot understand what is happening around them (Fukushima e al., 2016), that a person with AD is incompetent (Amjad et al., 2016), and people with AD are violent and aggressive (Kishita et al., 2019).

Alzheimer's disease (AD) impairs the cognition of adults over the age of 65 years. Adults affected by AD and their caregivers are often confronted with the many stigmas associated with AD and other related dementias (Stites et al., 2018). Stigma refers to attitudes, thoughts, and beliefs that act as barriers to health-seeking behavior for several health conditions such as AD (Howell et al, 2016; Scott et al., 2015). Alzheimer's disease and dementia-related stigma are related to fear, lack of awareness, and lack of understanding about the disease. Lack of knowledge about AD contributes greatly to AD-related stigma (Herrmann et al., 2018).

The types of stigmas that exist around AD are public stigma, courtesy stigma, self-stigma, and association stigma (Stites et al., 2018). Public stigma refers to the public endorsement of stereotypes and prejudices against people with AD that results in discriminatory behaviors toward persons affected by AD (Werner & Abojabel, 2019). Social stigmas associated with the diagnosis of AD can affect families, friendships, and other social ties (Rosin et al., 2020). Self-stigma results when a person affected by AD begins to internalize the negative attitudes and labels cast upon them by society (Howell et al., 2016). Courtesy stigma occurs when individuals who have close contact with a persona diagnosed with AD become affected by the prejudices and stigmas of AD. Exposure to and the acceptance of the various types of stigmas can have adverse effects on the daily lives and well-being of those diagnosed with AD, and the adverse effects can contribute to depression, isolation, and discrimination (Rosin et al., 2020). While there is a body of literature that addresses how stigmas affect behaviors of individuals, there is a gap in the literature regarding how stigmas associated with AD affect African Americans' help-seeking for treatment of AD. While there is some research on this topic, I was unable to find literature concerning how stigmas associated with AD affect African Americans' help-seeking treatment for AD.

Problem Statement

In this study, the research problem that I focused on was stigmas of AD and how those stigmas affect the help-seeking behavior for treating AD among African American caregivers. According to the Alzheimer's Association (2019), approximately 5.8 million Americans have been diagnosed with AD. African Americans represent more than 30% of those cases of AD, although they make up only 13% of the population in the United States. One of the major psychosocial issues surrounding the treatment of AD is the strong stigmas associated with the disease (Gregg, 2015; Herrmann et al., 2018).

The adverse impact of stigmas against AD can also extend to family caregivers of individuals with Alzheimer's (Batsch, 2015). Stigma and shame among African Americans in the United States regarding AD are barriers that prevent early diagnosis, care, support, and education about the disease (Hermann et al., 2018). Stigmas about AD could discourage caregivers from seeking treatment for families diagnosed with AD (Hermann et al., 2018). Lohmeyer et al. (2021) indicated that family members may experience the spillover of stigma, which refers to how people who do not have AD are affected by the stigma of the disease. It often affects those people who share proximity to those with AD such as family caregivers. Spillover stigma frequently leads to isolation and exclusion of the person affected by AD and affiliated individuals such as their caregivers.

Several researchers have indicated that as the population of older adults in the United States continues to grow, so will the numbers of family caregivers who care for them (Hoffman & Zucker, 2016; Williams et al, 2018; Yu et al., 2018). Approximately 80% of the care and support for persons with AD is provided by informal care from family members. African American family caregivers often experience the consequences of stigma the most (Fingerman et al., 2011; Steenland et al., 2016). Therefore, the problem that arises is that African American caregivers often delay early diagnosis and treatment due to stigmas associated with illnesses such as AD. The adverse outcomes associated with missed or delayed diagnosis and treatment of AD are many and may be problematic. Some of the outcomes that may arise with late diagnosis, or no diagnosis are, not knowing the degree of the affected persons' impairment, or not knowing the person's dementia subtype to ensure appropriate treatment (Aldus et al., 2020). According to Aldus et al. other additional outcomes may be the lack of knowledge for the disease severity and practicing of potentially harmful behavior such as driving, administering their medication, loss of responsibility of their finances. Early diagnosis of AD is important because it improves the opportunity for treatment, improves the well-being of the individual with AD and familial caregivers, and affords families and affected individuals time to prepare for future care (Rasmussen & Langerman, 2019).

Although previous research on how the stigma of AD impacts help-seeking behaviors illuminates important findings, there are a limited number of researchers who have studied AD in the African American communities. There are even fewer studies on how the stigma of AD impacts help-seeking for treatment of the disease in African

American communities. Therefore, the research problem that I addressed was how the stigma of AD affects the help-seeking behaviors of African Americans for treatment of AD.

Purpose of the Study

The purpose of this generic qualitative study was to examine African American caregivers' perceptions of how stigmas related to AD affected their willingness to seek medical help for family members affected by the disease. Alzheimer's disease is a progressive cognitive brain disorder that presents significant health issues to individuals diagnosed with the disorder (Herrmann et al., 2018). In this study, help-seeking behavior refers to the act of seeking medical help from a health care professional when faced with symptoms related to cognitive issues in older adults. Research has revealed that many African Americans have less knowledge and more stigmas about AD than their Caucasian and Hispanic counterparts (Alzheimer's Association, 2019). African Americans have experienced a wide range of attitudes toward AD, which included public, self, and courtesy stigmas (Rosin et al., 2020). As a result, African Americans were less likely to seek medical attention for older adults who exhibited potential symptoms of AD. Several researchers have indicated there is a need for more research in minority communities regarding how stigmas affect seeking help for adults who displayed signs of AD.

Research Question

I used the following research question to guide my research: What are African American caregivers" perceptions of how stigmas related to AD affect the caregivers" help-seeking behavior for older adults affected by the disease?

Conceptual Framework

I based the conceptual framework of this study on stigma theory and the socio-cultural health belief model (SHBM). I used the premises of stigma theory to explain how stigma affects individual perceptions and individual behavior. I used the premises of the SHBM to explain how culture, attitudes, beliefs, and thoughts affect help-seeking behavior for a range of physical and mental illness. Both theories were relevant to the problem because they could be used to explain how socio-cultural beliefs and stigmas about AD affects African Americans.

Stigma Theory

Irving Goffman developed the stigma theory after recognizing that people were being socially discredited, rejected, and described as undesirable based on some personal characteristic of the individual (Goffman, 1963). Goffman further contended there was a tendency for stigma to spread from the stigmatized individual with the disease to their close connections. He saw stigma as a process whereby the reaction of others destroyed the normal identity of another. Goffman further discussed how the stigmas affect behavior on the part of the individuals who hold the stigmas. Goffman posited that although stigma is typically directed toward an individual, the effects of stigmas may spill over to adversely affect those close to the stigmatized individual such as friends, family members. The major premise of Goffman's theory is that stigmas typically result in people responding negatively to those who are stigmatized. The individuals who experience the stigmas also respond negatively to being stigmatized. Premises of Goffman's stigma theory were appropriate for my research because they could be used to explain how stigmas of AD may affect African American caregivers' willingness to seek medical treatment for family members diagnosed with AD.

Sociocultural Health Belief Model

The SHBM was developed by Sayegh and Knight (2013) to describe the variables that influenced help-seeking for treating dementia among minority and ethnic older adults. The two researchers proposed the socio-cultural health belief model to explain the disparate health outcomes in the treatment of AD in older adults. According to Sayegh and Knight, they discovered that there were several barriers that prevented seeking medical treatment for dementia among minority ethnic groups. Those barriers included lower levels of acculturation, inaccurate knowledge of dementia, culturally associated beliefs about dementia (such as perceptions of memory loss as normal aging), health system barriers, and stigmas associated with dementia. The SHBM provided an empirically based conceptual framework for identifying and explaining health behaviors related to seeking evaluation and care of dementia-related symptoms among minority ethnic older adults. There are ethnic and cultural differences in AD, along with specific ethnic and cultural stigmas as they relate to AD that continues to be understudied (Bracke et al., 2019). The article concludes that there were very limited findings regarding how culture and ethnicity have influenced caregiving across ethnic groups. There are, however, sociocultural perceptions, stigma beliefs, and representations of dementia. Therefore, the SHBM was the appropriate framework for explaining how stigmas about AD may affect help-seeking behaviors related to AD among African American caregivers who provide informal care for a family member with AD.

Nature of the Study

I used a generic qualitative approach for this study. The generic qualitative approach has also been referred to as a basic qualitative approach (Kennedy, 2016). Qualitative research is used to focus, describe, and interprete a phenomenon (Baker & Edwards, 2012). Generic qualitative research is not guided by an established set of philosophic assumptions that are associated with other qualitative methodologies (Kahlke, 2014). However, generic qualitative researchers can draw on the strengths of established qualitative methodologies while allowing more methodological flexibility (Kennedy, 2016). Generic qualitative approaches are used to investigate this phenomenon, process, perspectives, and views of the targeted sample of participants (Percy et al., 2015). I employed a generic qualitative approach to examine African American caregivers' perceptions of how stigmas related to AD affect their willingness to seek medical help for family members who exhibit symptoms associated with AD.

I used purposeful and snowball sampling methods to recruit participants. Purposeful sampling is defined as the act of recruiting intentionally individuals who have knowledge or experience with the phenomenon of interest in a study (Moser & Korstjens, 2018). Palinkas’ (2015) article addressed the benefits of purposeful sampling and I used purposeful sampling to recruit participants who could provide detailed and in-depth information about their perspectives on how stigmas of AD delay their caregiving actions in seeking medical treatment for symptoms of AD among family members.

Kirchherr (2018) indicated that using the snowball sampling method to recruit participants, is often useful when potential participants are difficult to recruit for a study. They stated that snowball sampling technique is used when participants recruit other participants matching the criteria of the study. To accomplish this process, I asked participants to refer others in their social circles who may fit the criteria for participation to contact me to participate in the research. One of the criteria for participating in this research was that participants must have served as the primary caregiver in either a full-time or part-time capacity for one adult diagnosed with AD living in the United States. I recruited 11 participants to be interviewed for this study. I analyzed the data using thematic content analysis and other qualitative data analysis techniques.

Definitions

Alzheimer's disease (AD): Is a slow progressive neurodegenerative disease that destroys memory and other mental functions such as thinking and behavior (AA, 2019).

Caregiver: Refers to a paid or unpaid person who regularly looks after and assumes the responsibility for the daily care of an older adult with AD (AA, 2019).

Dementia: Is the umbrella and clinical term used to characterize the progressive decline in cognition to include memory, language, executive and special function, personality, and behavior casing loss of abilities of daily living (National Institute on Aging [NIA], 2020).

Help-seeking behavior: Any action of seeking help from a health care service or trusted person in the community. The action of seeking understanding, guidance, treatment, and general support leads to specific solutions (Soong et al., 2020).

Informal Caregiver: Unpaid individuals such as adult offspring, spouse, other family members, friends, who provide care for another person (Broese van Groenou & de Boer, 2016).

Stigma: A set of negative beliefs disqualifying an individual from full social acceptance (Goffman, 1963).

Assumptions

With any study, researchers make certain assumptions. I assumed that there are stigmas of AD that affect African Americans' help-seeking behavior for persons who exhibited symptoms of AD. I assumed that an adequate number of individuals would be willing to discuss the topic of interest for this study. I further assumed that participants would be open and honest with their perceptions of and experiences with seeking help for a family member diagnosed with AD. For this study, I assumed that participants would be willing to answer the interview questions honestly and candidly about their perceptions about stigmas of AD and caregiving for a person affected by AD. I assumed the participants would have a genuine interest in participating in this study and would not have motives other than to share their perspectives. I also assumed the inclusion criteria for my sample were appropriate for increasing the likelihood that all participants would have similar perspectives on the topic of interest. I assumed that using a qualitative approach would enable me to learn information about my participants and about the research topic of interest that I could not gather through quantitative research methodologies.

Scope and Delimitations

The problem that I addressed in this study was how the perceptions of AD-related stigma affected African American caregivers' help-seeking behaviors for treatment for symptoms of AD in family members. For this research, I focused on those participants who self-identified as being African American caregivers of an individual affected by AD. These participants resided in the United States. Participants were between 18 and 99 years of age. Many young adults have been a caregiver to either a parent or grandparent (American Psychological Association [APA], 2010). According to Edwards (2020) and Schultz and Eden (2016) the rationale for this wide age inclusion of caregivers was that caregivers could be found across the age span. In this current study, the majority of caregivers were mainly between 30 and 64 years old.

Limitations

For this study, I collected data from African American participants living in the United States in African American communities. For this study, I selected only African American caregivers who provided a minimum of at least 20 hours per week of caregiving for a family member experiencing AD. According to CDC (2017) a caregiver is considered a primary caregiver when they provide care for a minimum of 20 hours per week.

These caregivers who identified as primary caregivers were required to be caring for a family member. The focus of this study was on informal caregivers who were either providing in-home caregiving to an older adult family member who had been diagnosed with AD either before this study or during this study. I did not invite caregivers from other racial or ethnic groups to participate in this study because the results of the study may not have been transferable to caregivers of other racial and ethnic groups. The limitation of this study included the study's exclusivity to African Americans in the United States and was restricted to the age group of participants between 18 and 99 years of age. I also restricted the study to those participants whose care recipients already received a diagnosis of AD and not to those diagnosed with other forms of dementia. Results of this study may not be transferable to caregiver groups outside the targeted age group of this study.

As an African American with knowledge of the various stigmas and perceptions associated with AD within the African American communities, my data collection and interpretation of the data were not impacted by my own biases. I used reflexive journaling to manage researcher bias.

Significance of the Study

Developing an understanding of how the perception of stigmas of AD affects help-seeking behaviors among African Americans is crucial. It was a crucial first step to collecting data that could be used to provide evidence of the need for educational programs and interventions that could be used to address stigmas associated with AD and minimize their impact on the help-seeking behavior of African Americans.

Findings from this study could provide valuable information for human service professionals, social workers, and other professionals in the social sciences who work with African Americans who have been affected by AD and their caregivers. Therefore, determining how the perceptions of the stigmas affect help-seeking behavior within the African American community could provide professionals with information that would assist them in understanding, identifying, and addressing those stigmas. Information about how the perceptions of stigmas associated with AD affect help-seeking for treatment of the disease may help inform educational programs, and policies that increase awareness of and help-seeking for treatment of AD among African Americans. The desired outcome would be that knowledge and information about AD may reduce the stigmas associated with AD, and in turn, may result in African American caregivers seeking treatment for symptoms of AD in a timelier manner. The early treatment and diagnosis could lead to improved outcomes for those diagnosed with AD.

Summary

Chapter 1 contained the research question, the nature of the study, definition terms, and the conceptual framework. I provided an overview justifying the need for this study focused on how the perception of the stigma of AD affects the help-seeking behaviors of the African American population. I also discussed the assumptions, significance of the study, scope, delimitation, and limitations of this study. I also discussed possible implications for positive social change and identified potential contributions of the study to those who work in the social sciences. This study may also advance knowledge, practice, and policy related to stigma.

In Chapter 2, I will discuss the strategy I used for locating the articles related to the topic of this research, the conceptual framework, and define the different types of stigmas. I will also provide a review of the prevalence of AD, the symptoms of AD, AD and African Americans, the impact of delayed diagnosis and treatment, as well as the impact of stigma on persons with AD and their caregivers. I will also address how the stigmas o AD affects African American caregivers' help-seeking behaviors for family members who display potential symptoms of AD.

Chapter 2: Literature Review

Introduction

The purpose of this generic qualitative study was to examine African American caregivers' perceptions of how stigmas related to AD affect their willingness to seek medical help for family members affected by the disease. Research has revealed that ethnic and racial minority groups have less knowledge and more stigmas about mental health issues such as AD than their Caucasian counterparts (Ostergren, 2017). African Americans experience the highest risk of AD, yet they are the most underrepresented group in AD research in the United States (Carrillo, 2018). Following an extensive review of the literature, I found a gap in the literature regarding the perspectives of the African American caregivers and how stigmas related to AD affect their willingness to seek medical help for family members affected by the disease.

In this chapter, I will present existing literature related to this proposed study. The first section includes a discussion of the literature search strategy used to locate the literature related to the proposed topic. In the second section, I present the theories that serve as the conceptual framework that guide this study. Following the overview of the conceptual framework, I provide a concise synopsis of the current literature that establish the relevance of the problem, regarding studies that relate to the stigmas of AD. This review of literature also includes information on help-seeking behaviors of African Americans for mental health-related issues such as AD.

Literature Search Strategy

I conducted searches for relevant literature in the research databases through Walden University library. The search included literature in the following fields of human and social services: gerontology, social work, psychology, sociology, and nursing. I searched peer-reviewed journal articles, doctoral research studies, and books through the library databases. I also consulted with Walden University librarians in search of peer-reviewed articles. The databases I searched included the following: ProQuest Central, MEDLINE, EbscoHost, Google Scholar, CINAHL, PsycInfo, American Psychological Association Articles, and PsycARTICLES. I also searched other databases such as the following: Centers for Disease Control and Prevention, SAGE Journal, SocioFile, and SAGE full-text collection, PubMed, Alzheimer's Association, African American Review, Research Gate, and the National Institute on Aging. In extracting relevant literature related to this study, I used the following key search terms and combinations of search terms to search for related literature: *AD, Black caregivers, ethnic minorities, African Americans and AD, stigma, the stigma of AD, the stigma of mental health, informal caregivers of AD family members, informal caregiving, AD and caregiving, racial differences, African American caregivers, sociocultural health belief model, generic qualitative approach,* and *stigma of AD by healthcare professionals.*

I collected and reviewed over 185 research studies and peer-reviewed journal articles related to AD, African American caregivers, the stigma of AD, the stigma of mental health. For this literature review, I focused on sources published from 2016 to 2021. Older studies included in this study were pivotal to the foundation of this study.

Some of these studies dated back to 1963. I also modified the electronic search with both backward and forward reference searching of included articles and performed manual searches in books. Kahn et al. (2015) and Spurlock (2019) suggested that form of electronic search would enhance my literature search. During my extensive search of the literature, I discovered that there was very little to no current research on African Americans and their perspectives on AD and stigma.

Conceptual Framework

I developed the conceptual framework for this study using stigma theory and the sociocultural health belief model (SHBM). Goffman (1963) formulated stigma theory to explain how negative societal attitudes toward individuals result in discrediting attitudes that convey devalued stereotypes toward those individuals. The SHBM is an explanatory framework developed by Sayegh and Knight (2013) to explain differences in help-seeking behaviors for dementia among culturally diverse groups. Stigma affects people's behavior by making them more likely to hide their illness or symptoms keeping them from seeking medical help and preventing them from adopting healthy behaviors (Crowe, 2020). In the following sections I will present details regarding each theory.

Stigma Theory

Goffman introduced the concept of stigma in 1961 to explain stigma very broadly as an attitude that conveyed stereotypes, which devalued individuals based on characteristics of those individuals. Goffman formally defined stigma in 1963 as an attribute that is deeply discrediting, meaning that a person is perceived negatively by others due to having distinguishing characteristics that are viewed as a disadvantage to the person being stigmatized (Goffman, 1963). Goffman identified the following three categories of the phenomenon that frequently form the basis of stigmas: a) social impairments (race, nationality, religion, caste, and class), b) abominations of the body (physical handicaps and deformities), and c) individual character blemishes (mental disorders, alcoholism, drug addiction, criminality, homosexuality).

Goffman (1963) further argued that there was a tendency for stigma to be generalized from the stigmatized individual to individuals who have close social connections with those being stigmatized. Those social connections could be friends, family members, professionals, or others who have close contact with those who are stigmatized. Social stigmas adversely affect a stigmatized individual's ability to fit in with others who are identified as "normal." Stigmas frequently result in those who are stigmatized being treated as less than human.

Goffman (1963) stated that overall stigma includes each of the three defined stigmas that may affect the individual's behaviors worsen an individual's mental health problems and even delay or impede the individual from getting help, treatment, and their recovery. Goffman stated that stigma may affect an individual's behavior by social isolation, poverty, poor housing, and unemployment are often all linked to mental health problems. He also posited that stigma may also trap an individual in the cycle of their illness. Goffman found that the impact of stigma often included isolation, shame, hopelessness, and reluctance to ask for help or treatment, and they also experienced a lack of understanding by family, friends, or others. These findings on stigma can be degrading, demoralizing, and could lead to violence. Goffman posited that oftentimes, stigma contributes to psychosocial stress, limited social opportunities, and physical danger.

Types of Stigmas

Goffman (1963) considered stigma to be a general aspect of all social life that complicated everyday microlevel interactions between people. Broadly defined, Goffman's concept of social stigma refers to a socially construed idea of social acceptance that is often based on either individual identity or association with a person or group of individuals. According to Goffman, social stigmas results in situations where individuals who are stigmatized became disqualified from full social acceptance. Goffman also articulated that stigma results in the general management of social interactions between individuals.

Goffman (1963) posited that social stigmas resulted in individuals becoming labeled because of a distinguished difference, which can become associated with a variety of stereotyped attitudes and discriminatory behavior that denies an individual or groups full social acceptance. Those stereotypes and related discriminatory behaviors increase social inequalities and can reduce opportunities for those who were stigmatized. Stigma also refers to how society's labels and attitudes influenced those who are stigmatized and how the stigmatized individuals may come to view themselves (Kim et al., 2019).

Kim et al. (2019) posited that stigma is the number one factor that contributes to the avoidance of seeking medical help. According to Kim et al. this avoidance behavior, therefore, delays diagnosis and utilization of the health and social services interventions designed to treat symptoms of AD. The impact of stigma is pervasive. The authors also acknowledged that stigma can result in harmful outcomes for individuals which may include things such as social isolation, stereotyping, bullying, discrimination, harassment, physical violence, reluctance to seek help or treatment, lack of understanding from family, friends, and coworkers. The main types of stigmas are public/social, structural/institutional, self-stigma, and courtesy/association stigma.

Public/Social Stigma

Public stigma refers to the discriminatory and negative attitudes that others have about mental health issues (Stites et al., 2018). Stites et al. conducted a quantitative study to determine the beliefs, attitudes, behaviors, and expectations of the public toward AD. According to Stites et al. their identification of public beliefs, attitudes, behaviors, and expectations of the public toward AD were mainly assumptions made about AD. The researchers further found that the individuals with AD more often than not, often reflected on the established stereotypes about their functional abilities and disease symptoms.

Results from Stites's et al.'s (2018) qualitative study on public stigma to determine beliefs, behaviors, and expectations of the public toward AD was based on the researchers wanting to determine the attributes commonly paired with AD by the public. The findings of this study showed that when the public was informed of the condition of the person with AD, the person with AD would experience workplace discrimination and would have their health insurance limited due to data in the medical record and that African Americans would be less likely than Caucasian participants to expect that a person with AD would be excluded from medical decision making. This study on public stigma was relevant to my study because it revealed how public stigmas related to AD translated into discriminatory practices and behaviors toward individuals diagnosed with AD.

Cations et al. (2018) conducted a systematic review of research of population-based surveys in the United States, Europe, Eastern Asia, and Australia regarding public beliefs and perceptions about AD. The review compared public knowledge, understanding, and attitudes about AD in each country's surveys regarding public beliefs and perceptions about AD. The results indicated that nearly half of participants agreed that AD is a normal part of aging, that it is neither treatable nor a preventable mental disease and that AD can leave a person in a vegetative state. The authors determined that knowledge about AD prevention and treatment is largely poor but there was a slim possibility for improvement over time. Findings from this study were relevant to my proposed study because the article addressed how public misconceptions and stigmas of AD are reacted to lack of knowledge about AD.

Nguyen and Li (2020) also found in a systematic review of both qualitative and quantitative literature that limited knowledge of AD was related to public beliefs and attitudes about AD that translated into stereotyping, prejudice, and discrimination toward individuals with AD and their family caregivers. Some commonly held stigmas and stereotypes were that those diagnosed with AD were dangerous, they experienced a loss of self-esteem, and they had lower competence. In addition, Ngyen and Li found that African Americans and Caribbean participants saw AD as a Caucasian person's illness. In this review, I highlighted the need for future studies on public stigmas regarding research in various contexts and cultures. In the study findings, they confirmed negative beliefs about people with AD. Another common misunderstanding in some cultural and ethnic groups is that AD is linked to fate, evil spirits, the evil eye, lack of faith in or a punishment from God (Fletcher and Maddock, 2021). Other misunderstandings about AD include the following: a) the belief that AD is a natural part of the aging process, b) that AD is a mental disorder or disease, c) and that AD is like a second childhood which is contagious (Hermann et al., 2018). Lopez et al. (2020) also discussed public stigma and stated that this form of stigma exists in social groups and manifests at the psychological level of belief, emotion, and behavior. The authors posited that poor cognitive function significantly corresponded with stigmas associated with social isolation and social rejection. Lopez et al. further added that public stigma adds to the burden of AD by preventing individuals from securing early diagnosis and supportive services. The authors concluded that stigma when perpetuated can often result in caregiver isolation and delay in access to support and diagnostic services. In addition, the authors stated that public stigma was associated with poor quality of life in family caregivers.

Self-Stigma

Self-stigma refers to the negative attitudes that people with mental health conditions have about their illness. Urbanska et al. (2015) stated that self-stigma at an individual level is associated with personal feelings of shame, experiences of social isolation, low self-esteem, and a sense of dehumanization. People with AD may be vulnerable to internalizing society's attitudes mainly because they may be aware of the stigma toward them. These individuals are often aware of their loss and may respond to the loss with anger, frustration, and sadness, which may cause them to tend to avoid situations where they may feel they might become embarrassed about their loss (Kim et al., 2019).

Self-stigma can lead to negative effects of recovery or worsen the symptoms. Nguyen and Li (2020) conducted a systematic review of both qualitative and quantitative literature to examine the effect of self-stigma in the context of AD. The researchers found that self-stigma led to reduced hope, lower self-esteem, more difficulties at work, increased psychiatric symptoms, difficulties in social relationships, and a reduced likelihood of getting treatment. Nguyen and Li highlighted the need for future studies in public stigma and self-stigma in AD research in various contexts and cultures. They also remarked that there was a need for evidence-based and culturally competent interventions and media campaigns to change the public's perception of AD.

Institutional/Structural Stigma

Institutional/structural barriers refer to things such as policies or institutional actions or activities that either intentionally or unintentionally restrict the opportunities for targeted groups such as those with mental disorders (Lopez et al., 2020; Van Horn 2019). These discriminatory behaviors or negative attitudes are often demonstrated by the representatives of the institution. Nguyen and Li (2020) also stated that institutional stigmas had been manifested in the attitudes and behaviors of healthcare professionals. The institutional discrimination manifested by healthcare professionals had resulted from low levels of professional competence when working with patients with AD and poor service delivery, which in turn negatively affected the lives of individuals with AD and their caregivers.

Institutional or structural stigma can contribute to the negative effects because the individual may refuse to discuss the mental disorder at their job, they experience fear of retaliation or being fired if they sought mental health care or received a diagnosis. Individuals may have experienced the stereotyping within the laws of the institution and faced either intended or unintended loss of opportunities (Kim et al., 2019).

Several researchers investigated structural stigma as it relates to mental illness (Livingston, 2020; Van Horn 2019). The researchers typically agreed that institutional/structural stigmas resulted in discriminatory institutional policies and practices that affect individual-level outcomes. Van Horn (2019) stated that structural stigma affects how larger social structures and cultural contexts influenced the understanding of mental illness. The impact of institutional/structural stigmas at the individual level was not fully known as the concept of institutional/structural stigmas was relatively new. However, after conducting an exhaustive review of the literature on stigmas and mental illness, I found that Livingston (reported that structural stigma contributed to the health disparities and inequalities in healthcare by serving as a barrier that compromised the access to quality health care for those with mental problems. Though Livingston referenced mental illness and substance abuse, findings from the research were relevant to my study because structural stigma in healthcare is related to health disparities in that access and treatment for other mental health issues such as dementia.

Courtesy/Spillover/Association Stigma

Courtesy stigma, also referred to as association stigma, occurs when family members of people with mental health concerns experience consequences similar to those experienced by the person who is stigmatized (Ashworth, 2020; Epps et al., 2018; Lopez et al., 2020). This form of stigma can result in caregivers experiencing feelings of shame, guilt, and embarrassment (Epps et al., 2018; Khandi, et al., 2016), and possibly decreased caregiving and concealment of the person with AD (Lopez et al., 2020).

Courtesy stigma is particularly problematic because it can adversely affect the care and treatment of individuals who experience symptoms of AD. Results from a qualitative study by Lopez et al. (2020) revealed that participants expressed feelings of disgrace and humility as they cared for the family member with AD. The participants further indicated that they attempted to cope with the shame through a) silencing by not refusing to acknowledge or discuss their loved ones" diagnosis, b) hiding the loved one through social isolation and withdrawal, and c) avoiding contact with those diagnosed with Alzheimer's, which included the caregiver. Other research results has noted that stigma can adversely impact the emotional responses of caregivers (Epps et al., 2018; Khandi et al. 2016). Esandi et al. (2018) conducted a qualitative study using a constructivist grounded theory of the families of individuals diagnosed with AD. The researchers asked family members about their responsibilities, burdens, and perceptions of worth related to the care of the family member with AD. Several participants reported hiding family members from others due to the fear of experiencing stigma from others because of the disease and the stigma attached to the disease. Findings from a Kahn et al.

(2016) quantitative study revealed that participants negative experiences of stigmatization decreased their actions to seek medical treatment for a family member diagnosed with AD.

Cultural Stigma

Cultural stigmas refer to shared beliefs and attitudes that negatively influence the way a person thinks about themselves, others, and society (Eylem et al., 2020; Modir et al., 2020). Cultural stigma is a shared belief. It is the assumption that a person's belief or behavior can be affected by their culture. Cultural stigma can negatively affect a society's health outcomes. Stigma related to AD can demonstrate that there are stigma expectations. Stigma expectations are described as when a person believes that most individuals or communities will discriminate or devalue their being because they have AD or are related to someone with AD. According to Krendl and Pescosolido (2020), cultural stigma is a major barrier to access to AD diagnosis and treatment. Culture stigma plays a significant role in seeking AD treatment for individuals with AD or their caregivers (Eylem et al., 2020; Modir et al., 2020). Modir et al. (2020) stated that cultural stigma also impacts the individual whether individuals sought medical help or decided to not seek help. In the case of African Americans, negative stigmas about mental health disorders of any type or the treatment services associated with seeking medical help (Green-Harris et al., 2019).

Impact of Stigma Against AD

People with AD are often dehumanized by being referred to as patients, victims, cases, or sufferers. Some of these negative impacts may be self-esteem, poor mental health, isolation, and decreased quality of life (Xanthopoulou & McCabe, 2019). Both the individual affected with AD and the caregiver may be fully aware of society's view and the stereotypes about AD. Both caregivers and those affected with AD have often become concerned about the responses they will receive from others if the diagnosis of AD is made public. As a result, either the person with AD or their caregiver may delay seeking the help they require (Desin, 2016; Gregg, 2015), attempt to cover up their symptoms (Xanthopoulou & McCabe, 2019), or become ashamed of their diagnosis (Gove et al., 2016; Xanthopoulou & McCabe, 2019).

Caregivers of people with AD often experienced caregiver burden also referred to as caregiver stress (Corson, 2017). Corson stated that some signs of caregiver stress included being constantly worried, feeling overwhelmed, and losing interest in activities. Caregiver burden is referred to as the stress due to their home care situation. Caregivers also experienced negative outcomes while caring for a loved one with AD (Kahn et al., 2016). One of the main negative outcomes experienced by caregivers was the increased risk of deteriorating health problems for the caregiver.

Alzheimer's disease stigma can often lead to caregiver stress and burnout (Green Harris et al., 2017). According to Green Harris et al. this experience can result in social isolation and concealment of the person with AD. Other negative behaviors that may affect both the individual with the disease and their caregivers are avoidance, neglecting the care of the person with AD, limited social interactions with others, and failing to seek help. The authors also posited that stigma of AD can negatively affect the behavior of caregivers such as shortening the lifetime of an AD patient. The stigma of AD can also create institutionalization of the AD patient, death of an AD patient, and early mortality of the caregiver. Consequences of AD stigma can be associated with negative consequences like increased caregiver burden (Khan et al., 2016). Caregiving stress can lead to social isolation, decreased help-seeking (Abojabel & Werner, 2016; Gerain & Zech, 2019).

Relevance of Stigma Theory to This Study

Premises of Goffman's (1963) stigma theory were relevant to this proposed study because AD and dementia-related stigmas have adverse consequences for individuals and their caregivers. Lopez et al. (2020) suggested that family members of individuals affected by AD are often blamed for the condition and avoided, for fear of possible contamination which results in the caregiver being stigmatized. Stigmas against AD increased caregiver burden and may have restricted their utilization of support services for themselves and limited their access to medical services for their loved ones who show symptoms of AD (Epps et al., 2018).

Sociocultural Health Belief Model (SHBM)

The sociocultural health belief model (SHBM) was developed in 2013 by psychologists Sayegh and Knight (Sayegh & Knight, 2013). The SHBM was originally introduced in research on minority elders and their care-seeking behaviors as it related to dementia. The premise of this model was to demonstrate the various factors that would influence AD help-seeking among older adults in America's minority groups. The SHBM is a variation of the health belief model (HBM). The health belief model (HBM) is one of the most widely used models to explain health-related behaviors.

Sayegh and Knight (2013) noted in minority and ethnic groups including African Americans experienced delayed diagnosis of AD, which often led to higher levels of cognitive impairment, psychological and behavioral symptoms of AD compared to their non-Hispanic White. Results from this study showed that there were several barriers to AD care-seeking among minority groups. Those barriers included a lack of accurate knowledge regarding the causes of AD and culturally associated beliefs about AD such as their perception of AD and what to expect during normal aging and the stigma associated with AD, lower levels of acculturation, and health system barriers. This study was relevant to my study because it examined the cross-cultural differences in AD help-seeking among different diverse groups including African Americans.

Researchers have noted that barriers such as lack of knowledge, stigma, and fear were some reasons why individuals often hesitated to seek medical help for symptoms that may be related to AD (Knaak et al., 2017; Weise et al., 2018). In a subsequent study, Wiese et al. (2019) found that correcting misconceptions of AD, decreasing stigma, and bringing awareness for timely AD diagnosis, could bring about positive social change. Wiese et al., also stated that they found that many people do not understand dementia and for many, it is easier to believe the misconceptions that accompany the disease.

The sociocultural health belief model has been used to determine the disparities in help-seeking for dementia-related illnesses in minority populations (Sayegh & Knight, 2013). The SHBM provided an empirically based conceptual framework for examining sociocultural perceptions of AD among African Americans. The sociocultural health belief model was appropriate for examining African American caregiver perceptions of how AD-related stigma affects their help-seeking behavior for family members in their care who may exhibit symptoms of AD.

America's Aging Population

Globally, the population of individuals ages 65 years and older is projected to grow from 703 million in 2019 to 1.5 billion by 2050 (United Nations Department of Economic and Social Affairs, 2019). In 2018, the adult population in the United States aged 65 years and older was 52 million (United States Census Bureau: Population Projections, 2019), and the number is estimated to increase to 95 million by 2060 (Vespa et al., 2018). America's older adult population will experience a demographic shift as the population becomes more racially and ethnically diverse. Vespa et al. predicted that between 2018 and 2060 the older adult population that is non-Hispanic White will decrease from 77% to 55% of the total population over the age of 65. The older adult African American and Hispanic populations are expected to increase from 12.3 million in 2018 to 27.7 million in 2040, which will represent 34% of all older adults. (Administration on Aging, 2019; Administration for Community Aging, 2019; United States Census Bureau: Population Projections, 2019). The 2017 population profile for non-Hispanic African Americans ages 65 and over was estimated at 4,392,337 in 2016 and is expected to grow to 14.08 million by 2060 (APA, 2019).

Population aging is defined as the process by which older adults become a proportionally larger share of the total population (Skirbekk et al., 2019). Population aging is measured to inform both social and fiscal planning to measure the burden that the older adult population will present to the health, economic, and social security systems of the society. Population aging will affect America’s formal and informal social supports, economic growth, sustainability of families, the ability to provide resources for older citizens within the community, and the amount of disability caused by an increase in age-related chronic disease (Super, 2020). The importance of these aging population statistics from economists, demographers, and aging experts presents a snapshot of the trends of the challenges and opportunities clearly showing that population aging matters as it is related to aging, AD, and older African Americans (Denny et al., 2018).

Prevalence of Alzheimer’s Disease

Alzheimer’s disease is a chronic, neurodegenerative disease that is common among individuals 65 years of age and older (Denny et al., 2018; Herrmann et al., 2018). Alzheimer’s disease was first characterized and diagnosed by German psychiatrist and neuropathologist, Dr. Alois Alzheimer, who observed a 51-year-old female patient who exhibited paranoia, personality, and behavioral disturbances, language difficulties, moments of aggression and agitation, as well as memory loss (Coenen, 2016; Kumar & Singh, 2015). Dr. Alzheimer later diagnosed the patient with an aggressive form of dementia that affected her memory, language, and behavior (Coenen, 2016). Alzheimer’s is the most common form of dementia among the aging population and accounts for 60% to 80% of dementias (Qui & Fratiglioni, 2018).

Alzheimer’s disease is a growing public health crisis in the United States that has lethal outcomes (Kahn et al., 2016; Olivari et al., 2020). Alzheimer’s disease alone is the sixth leading cause of death in the United States, the fifth leading cause of death of older adults (Olivari et al., 2020). When AD is grouped with the other dementias, it becomes the third leading cause of death among all ages in the United States. Alzheimer’s disease and related dementias are the only top 10 leading causes of death in the United States with no cure or treatment (Edwards, 2020). When treatment options are referred, they address helping people maintain brain health, managing behavioral symptoms, and attempting to delay or slow the symptoms of the disease.

Olivari et al. (2020) recommended that public health programs should incorporate cognitive health strategies into existing public health programs to prepare and reduce the expected impact of AD. According to Olivari et al. the risk of dementia increases with age however, symptoms of AD should not be compared to or likened to the normal aging process. The authors posit that through public health action, there are many opportunities to improve the outcomes for individuals with AD and other dementias, and their caregivers and families. Though cognitive functioning changes during the middle stages of life this decline is not always a precursor to AD or dementia. Olivari et al. believed that through the Road Map framework and focusing on the four main areas of the framework which are educating and empowering the nation, assuring a competent workforce, mobilizing partnerships, creating new policies, and monitoring and evaluating the programs then AD in the hands of the public health agencies and their partners would experience success in addressing the public health dilemma of AD and dementia. The authors state that using this route would eliminate health disparities, increase the leverage of resources to sustain the impact and there would be the improved collaboration of multiple sectors.

The prevalence of AD is expected to increase as the number of aged 65 years and older in the United States increases. By 2030 the number of older adult Americans is estimated to reach 8.4 million and increase to 14 million by 2060 (Olivari et al., 2020). In 2018, the World Health Organization (2018) estimated that 5.8 million people in the United States and over 50 million people worldwide were affected by AD. The current rate of those with AD is expected to more than triple by the year 2060 unless prevention or cure is found (Kahn et al., 2016).

The rate of occurrence of AD is linked to aging. Of the 5.8 million affected by AD, those ages 65 – 74 years make up 1 million (17%) of the cases; those ages 75-84 years makes up 2.7 million (47%) of those affected; and individuals ages 85 years and older make up 2.1 million (36%) of the cases (CDC, 2019; Vermunt et al., 2019). Alzheimer's disease is the sixth leading cause of death in the United States according to the 122,019 official death certificates recorded in 2018 (2020 Alzheimer's Disease Facts and Figures, 2020). Alzheimer's disease is the fifth leading cause of death among older adults 65 years and older (Alzheimer's Association, 2019). Alzheimer's disease is the fourth leading cause of death for those identifying as African Americans (Steenland et al., 2016).

By the year 2050, 42% of older adults living in the United States will consist of minority group populations (Denny et al., 2018). These projections are especially important for planning a national approach to the complex issues of AD, which is one of the most common forms of dementia among the elderly. According to Medicare (2019), based on data of Medicare beneficiaries ranging from 65 years and older AD had been diagnosed in 10% of non-Hispanic Whites, 12.2% Hispanics, and 13.8% African Americans.

Symptoms of AD

Individuals who are affected by AD may experience various types of cognitive impairments such as memory loss, confusion, impaired speech and language, and difficulty with abstract thinking (Alzheimer’s Association, 2018; Brookmeyer et al., 2018). Symptoms of AD may present through cognitive decline, behavioral changes, mood changes, or other types of psychological problems (Brookmeyer et al., 2018). Symptoms of AD include short-memory loss, mood swings, apathy, and social withdrawal (Roberson, 2016). While cognitive decline and memory loss appear to be the more common symptoms, AD also has been associated with several mental health conditions such as depression and anxiety (APA, 2021).

In the early stages of AD, a diagnosis may be difficult to confirm even when the person is showing signs or symptoms associated with AD (Glover et al., 2019). However, there are specific distinctions between changes related to aging and symptoms of AD that can be determined through cognitive assessments performed by healthcare professionals (Perry et al., 2018). Researcher Brookmeyer et al. (2018) asserted that a true and correct diagnosis of AD can only be confirmed during a post-mortem examination. According to Rasmussen and Langerman (2019), although there are no modifying therapies capable of reversing the initial changes it may be possible to prevent or delay the development of AD by modifying exposure to common risk factors. Diagnosing the disease or risk of disease early in the early stages of the disease would be ideal for both the person experiencing the symptoms and their caregiver as they make choices and plan for their future and allow access to treatments meant to work during the early stages of the disease. Caregivers of individuals with memory problems should seek medical attention as early as possible to diagnose, eliminate or treat the many possible contributing factors that may cause memory loss. Memory problems do not automatically translate to AD.

Barriers to Treatment for AD

Successful outcomes for individuals diagnosed with AD begin with early diagnosis and treatment. While there is not a cure for AD, early treatment can slow the progression of the disease and improve the quality of life for the individuals diagnosed with AD and their caregivers (Rasmussen & Langerman, 2019). Despite recent advances in the treatment of AD, some barriers prevent individuals from seeking treatment of AD in the early stages. Those barriers are related to the following: a) stigmas and misconceptions of AD, b) negative experiences with healthcare professionals related to the treatment of AD, c) physician's lack of knowledge or experience in accurately diagnosing AD, and d) lack of awareness and knowledge of AD.

Stigmas against any form of mental health issues, including AD, often prevent older adults from seeking medical help (Burgener et al., 2015). Maxfield and Greenberg (2021) conducted a quantitative study to assess the relationship between perceived anticipated stigma and dementia-related anxiety. These AD-related stigmas of AD contributed to anxiety within people with AD and their caregivers. The subsequent anxiety delayed the subsequent diagnosis of AD treatment, which in turn affected the well-being and quality of life of the person with AD and their family caregivers. The study recommendations were that there was a need for studies that focused on the potential differences in AD stigma based on racial and ethnic identities. This study was relevant to my proposed study as both studies focus on how the perspectives of the stigmas of AD and the fear of these stigmas delay diagnosis and care of both the person experiencing memory loss and those who are the caregivers.

Negative reactions from healthcare professionals and providers regarding AD reinforce the negative stereotypes and stigmas associated with AD (Alzheimer’s Disease International, 2019). Herrmann et al. (2019) concluded that stigmatizing attitudes from healthcare providers also contributed to the fear of diagnosis and care of AD. Fear of AD and other dementias have become deeply ingrained in society that the diagnosis of AD is automatically viewed as a death sentence for the person diagnosed. Herrmann et al. posited that due to the fear of diagnosis and the fear of loss, the majority of older adults with dementia die without their condition ever being diagnosed or discussed with them or their families. An early and accurate diagnosis of AD might reduce the cost of misguided care related to occurrences of inappropriate use of medication, unnecessary medical and surgical interventions, hospitalizations, and emergency room visits. The early and accurate diagnosis of AD could also spare the burdened caregivers from experiences such as unnecessary depression, stress, and other negative health effects.

Additional barriers that cause delays in early diagnosis and treatment of AD are the number of physicians the patient sees for consultation and some doctors do not fully understand the diagnostic criteria for AD (Judge et al., 2019). Healthcare professionals in the community such as physicians and nurses play a significant role in AD diagnosis and care. However, very little is known about this group of professionals regarding their knowledge of AD, dementia diagnosis, or care. One research study was completed in 2019 by the Alzheimer's Association that posited that America's medical professionals are not ready for the tsunami of AD-affected individuals that will arise from the country's aging population. The Alzheimer's Association (2019) also surveyed both physicians and resident medical students and the findings were that they had only received 14 to 23 hours of AD training with an actual person affected by the disease. While 39% of the physicians reported that they were "never" or "sometimes comfortable" making a diagnosis of AD or dementia, 27% said they were not comfortable answering a patient's questions about AD and 22% of the primary care physicians reported that they had no residency training in dementia diagnosis or care and the 78% who had training, report that it was very little (AA, 2019).

Other additional barriers to delay are societal stigma, suicide risk, low public awareness of AD, diagnostic uncertainty (Judge et al, 2019), shortage of specialized diagnostic services, the reluctance of healthcare providers to diagnose when no effective disease modification options are available (Samson et al., 2016). Barriers, such as culture also lend to how a person or community defines and perceives the significance, message, or consequence of AD (Sayegh & Knight, 2013). Findings reveal that the importance of a person or group's cultural heritage knowledge can assess the various health requirements for the group.

Lack of knowledge about AD is another barrier to early diagnosis and treatment of AD (Eshbaugh & Stratton, 2016). Researchers found that family caregivers had a low level of understanding and knowledge about AD, the symptoms, prevalence, or causes of AD (Eshbaugh & Stratton, 2016; Werner & Abojabel 2019). The researchers concluded that a better understanding of the knowledge of AD and the attitudes toward AD among older adults was critical to enhancing participation in research, accelerating AD prevention and cure, and designing culturally appropriate educational interventions.

Impact of Delayed Diagnosis and Care for AD

When left undiagnosed and untreated, AD in older adults can adversely affect their quality of life and ability to age healthfully (Burgener et al., 2015; Maxfield & Greenberg, 2021). Alzheimer’s disease diagnosis is typically delayed between 1 to 3 years on average from the start of the symptoms (Helvik, 2018; Judge et al., 2019). Delaying treatments can have irreversible consequences (Crous-Brou et al., 2017). Some of the costly experiences are memory loss, lost functioning, and personality changes (Herrmann, 2018). Delayed diagnoses may result in continued participation in unsafe activities and behaviors such as driving, cooking a hot meal, mismanaging medication, and the inability to adequately manage personal finances (Gove et al., 2016). Several researchers have noted that failure to address cognitive impairments related to changes in the mental health of individuals presents an elevated risk of the individuals developing further adverse behavioral or psychological health outcomes (Bee et al., 2014; Plass-Christl et al., 2018; Thanhauser et al., 2017; Turner et al., 2019). Missed or delayed diagnosis often leads to lost opportunities for treatment and increased caregiver and patient burden (Herrmann, 2018). Additional factors contributing to delayed diagnosis of AD through the doctor are language barriers, provider factors, educational needs, consequences of misdiagnosis, attitudes toward AD (Gove et al., 2016). Failure to diagnose AD promptly represents missed opportunities to improve the quality of life for the patient, the caregiver, and society.

Alzheimer's Disease and African Americans

African Americans are particularly likely to develop AD, even after accounting for other biological and genetic factors that influence the likelihood of developing the disease (Steenland et al., 2016). African Americans are 2 to 3 times more likely to be affected by AD than non-Hispanic Whites. Additionally, African Americans represent more than 20% of the 5.8 million Americans who have been diagnosed with AD (Glover et al, 2019). African Americans also tend to be diagnosed with AD at later stages of progression of the disease (Gianattasio et al., 2019; Steenland et al., 2016). Therefore, the prognosis for African Americans with AD tends to be worse than for other racial or ethnic groups. Steenland et al. (2016), indicated that while AD is the 6th leading cause of death for all adults in the United States, it is the 4th leading cause of death for older African Americans.

Turner et al. (2019) conducted a cross-sectional exploratory study to examine African Americans' perceptions of mental health issues including AD. Results from the study revealed that stigmas against mental illness held by African Americans adversely impacted their willingness to address any signs or symptoms of cognitive issues. Findings from the study further revealed that African American's believed that discussions of any mental health issues such as depression, dementia, schizophrenia-related to family members should not be addressed outside of the family unit (Bee et al., 2014; Plass-Christl et al., 2018; Thanhauser et al., 2017).

In another qualitative study, Roche et al. (2020) studied the AD-related perceptions and experiences of those who self-identified as being African American, Black, African, or Caribbean background. The results revealed the following four themes from the data related to misconceptions about AD: a) dementia did not relate personally to the participants, b) personal experiences of inappropriate and disrespectful services, c) kinship responsibility, and d) the importance of religion in terms of one's spirituality and faith in the context of understanding and experience with AD. Religion has been considered a source of strength and healing. Results from the study also revealed that the risk of developing dementia went unacknowledged among the participants because many of the participants did not view AD as a disease that affected African Americans.

According to Roche et al. (2020), the researchers consistently found that the participants had the same attitudes toward AD and AD care. Such attitudes were often based on negative evaluations and negative experiences with health and social services. While bad experiences, service inequalities, mistrust, poor patient, and health provider relationships affected the AD attitudes of others. These negative attitudes all contributed to poor attitudes and perceptions of African Americans about AD and treatment of AD. This poor attitude heavily contributed to the delay and discouragement in accessing resources. Results revealed that this population of individuals engaged less with services despite being disproportionately affected by AD.

African Americans frequently claim they either experienced or believed they would be discriminated against when navigating the health care providers and health care system for themselves and their care recipients (Alzheimer’s Association, 2020; Gilmore-Bykovsky et al., 2018). The attitude of the majority of the African American participants also revealed that they felt it was more difficult to get excellent care for AD, medical research was biased against people of color, and believed that future cures for AD will not be equally shared with African Americans. In this same study, participants reported that they did not feel confident that they had access to healthcare professionals who had an understanding of their ethnic or racial backgrounds or cultural experience. These participants also felt that healthcare professionals were not deemed as culturally competent. Finally, the participants revealed that due to historical events, they were very cautious and conscious that they would not be used as guinea pigs in clinical research therefore they would not participate in any clinical trials in the United States.

Green-Harris et al. (2019) explored the disparities between races participating in research on AD and dementia. In particular, the researchers noted that the participation of African Americans in research on AD was very low. Green-Harris et al. argued that there were likely several factors that contributed to such low participation rates. Green-Harris et al. posited that recruitment methods and systematic biases in recruiting African Americans were not explored. The researchers found that many of the sources of resistance of African Americans to participate in research on AD and dementia involved mistrust in the healthcare system and worries of the stigma associated with AD and dementia.

Informal Caregivers

Due to the increase in the prevalence of AD in the African American community, more adult children are assuming the role of caregivers (Samson et al., 2016). More than 16 million caregivers in the United States provide informal caregiving for a person with AD or other dementia (Hogan et al., 2016). Approximately 10% to 13% of these caregivers are African American (Stojkovska et al., 2018). According to Roth et al. (2015), this type of caregiving is often referred to as informal caregiving. Informal caregiving refers to the unpaid help and support that family members or friends provide to those who are unable to function independently. The majority of African American caregivers provide either most or all care without assistance from paid help (Kasper et al., 2015). In most racial and ethnic populations, informal caregiving for someone diagnosed with AD is provided mainly by family or friends, particularly among families with lower socioeconomic status (Desin et al., 2016).

Six in 10 informal caregivers in the United States are non-Hispanic whites (61%) (AARP, 2020), 14% are non-Hispanic African Americans (Prevo et al. 2018), 17% are Hispanic or Latino, 5% are Asian American, Pacific Islander and 3% some other race/ethnicity, including multiracial (Rabarison et al., 2018). Over 57% of AD caregivers have provided care for approximately 4 or more years, and approximately 63% of those caregivers expect to continue providing care responsibilities for another 5 years (CDC, 2017). African American caregivers provide an average of 5.2 years of care (Epps et al., 2018).

The average age of the African American caregiver is 47.7 years (AARP, 2020). According to Spillman et al. (2020), 41% of African American caregivers provided help with more than three activities of daily living for family members with AD and provided medical/nursing tasks. African American caregivers provided more care to their care recipients compared to their non-Hispanic White caregiver counterparts which are approximately 28%. African Americans delivered care for approximately 37.5 hours weekly (AARP, 2020; Spillman et al., 2020). Approximately 58% of African American caregivers are meeting or exceeding the standard of high burden. High burden according to Spillman et al. is a summed-up total of the burden that caregivers of AD affected individuals become responsible for such as lack of involvement in social activities, the cost associated with reduced labor in the workforce, health deterioration which often reflects in their health-care costs and possible untreated health conditions. Activities of daily living also referred to as ADLs refer to the basic tasks that need to be accomplished for an individual to thrive such as personal hygiene, continence management, dressing, feeding, and ambulating (Edemekong et al., 2019). African American caregivers average approximately 37.5 hours per week providing care for their loved one compared to 33% of their non-Hispanic White counterparts who averaged approximately 20 hours per week (Spillman et al., 2020).

Caregiving is an activity that occurs among all generations. The percentage of caregivers in 2019 by generation are as follows ages 23 and younger at 6%, ages 24 - 39 at 23%, ages 40 - 55 at 29%, ages 56 – 74 at 34% and the eldest group of caregivers is age 75 and older (The National Alliance of Caregiving [NAC], 2020; American

Association of Retired Persons [AARP], 2020). The average caregiver in the United States is 49.9 years old with the median age for caregivers being 51 years (AARP, 2020; NAC, 2020). Studies that include caregivers’ profiles of caregivers caring for an individual with AD living at home are limited. Caregiving is viewed by many as an activity that occurs among all generations. Many of the articles refer to the older average age of the caregiver which is 79 years of age (CDC, 2019). African American caregivers who previously provided primary care to an older family member will be included in the participant search.

Knowledge Regarding Treatment for AD

Researchers Disbrow et al. (2020) posited that the lack of AD knowledge amongst African American families may be partially due to the lack of services that can inform those that need AD education. Alzheimer’s literacy is crucial for African Americans for increasing their awareness of their risk of AD, improving care, reducing disparities, and enhancing the quality of life of the people diagnosed with AD and their family members (Eshbaugh & Stratton, 2016).

Disbrow et al. (2020) sought to determine whether there were differences in the knowledge of AD and dementia between African American and non- Hispanic White family caregivers. The researchers conducted a mixed-methods study with a focus group and quantitative survey. These results found that the African American participants had a relatively poor understanding of AD and dementia in general. Even though 54% of caregivers received the majority of their information from healthcare providers, most lacked critical information regarding treatment for patients with AD and dementia or how to manage the autonomy and independence of such patients. According to a systematic review study by Rostamzadeh et al. (2020), the author's goal was to examine the lack of interest in knowledge about brain health and the risk of AD. In the literature they used, they found 26 quantitative and 6 qualitative studies that addressed at least one part of health literacy. There was evidence for the interest in AD knowledge as is related to brain health and the risk for AD.

African American caregivers may have generally low knowledge of AD (Roche et al., 2020). African American caregivers may not understand the signs or symptoms of AD, nor the characteristics, stages of progression, causes, or available resources. According to Eshbaugh and Stratton (2016), lack of knowledge of AD amongst African American families may partially be due to a lack of services, that informs those that need education. Researchers such as Eshbaugh and Stratton posited that caregivers need education on AD as well as a need for support services and care information. These researchers also suggested that there is a need for information about services and support groups for the person diagnosed with AD and their families (Roche et al., 2020). Alzheimer's disease information including studies has focused almost exclusively on the non-Hispanic White population thereby excluding minority groups (Barnes & Bennett, 2014).

Challenges and Barriers to Knowledge and Treatment of AD

Epps et al. (2018) assessed the challenges facing older African Americans affected with dementia and their families. In this study, Epps et al. found that African Americans were significantly less likely to receive information on AD and dementia from healthcare providers. The findings of this study revealed that older African Americans with AD and their families were significantly more likely to receive information on AD and dementia from friends, relatives, religious leaders, and the internet. When these older African Americans and their families received AD knowledge, health services, and support in their urban neighborhoods they experienced shame, improper housing, stigma, financial constraint, inadequate resources, transportation concerns, and a knowledge deficit were often challenged for resolution. There were no limitations mentioned in this study. Denny et al. (2018) examined the challenges African Americans had with receiving AD knowledge and treatment. The researchers claimed that African Americans were less likely to have AD diagnosed at an early onset than non-Hispanic Whites. The researchers also found that there were issues with the under-utilization of health services that may be an important factor contributing to the existing barriers to AD knowledge within the African American community.

African Americans may not experience all those services utilized by non-Hispanic Whites due to factors such as access to care, socioeconomic status, culturally competent health care providers, health insurance coverage which are key elements to the utilization and continued use of health services. According to Denny et al. (2018) African Americans have also been shown to receive a lower quality of care than their non-Hispanic White counterparts. Lower levels of quality care may also contribute to African American elders not presenting with signs and symptoms of AD at an earlier age of onset. However, older adults choosing to seek medical help later in the disease progression is often at a time of greater severity of the symptoms. The researchers of this study claimed that the lack of a significant difference in AD presentation may have been caused by the overrepresentation of 68% African Americans in this study, as there were relatively few non-Hispanic White participants. The researchers found that African American older adults and their families faced many challenges in seeking knowledge and treatment for AD. Denny et al. also claimed that AD educational programs by clinicians and academics are not physically brought to the communities they serve, instead, the professionals will wait until the community members visit their clinics and institutions.

Summary

Although there is existing literature on AD and dementia and stigma, there is still an insufficient amount of available information on African Americans and how stigma affects their help-seeking behaviors (Batsch, 2015; Evans, 2018; Green-Harris et al., 2019). Therefore, this current study may fill a gap in the existing literature by offering information about how the stigma of AD delays the medical help-seeking behaviors of African American caregivers. Given the significance of this issue, in this review, I covered African Americans and AD, the symptoms and prevalence of AD, the stigma of AD, and how stigma affects informal caregivers and those affected by AD and their behaviors. Also, covered in this chapter was the impact of the stigma of AD, the relevance of the theories I selected to guide my study, barriers to treatment of AD, the impact of delayed diagnosis, informal caregiver’s knowledge regarding the treatment of AD, and the challenges and barriers to knowledge and treatment of AD. These studies also revealed several other factors related to or that contributed to delayed help-seeking. Using the generic qualitative methodology allowed me to examine this issue of how the perceptions of African American caregivers about the stigma of AD affect their help-seeking behaviors. In chapter 3, I will explain the methodology to be used in this study, how data collection will be managed, how data analysis will take place, issues of trustworthiness, and the ethical consideration of this study.

Chapter 3: Research Method

Introduction

The purpose of this generic qualitative study was to examine African American caregivers' perceptions of how stigma related to AD affected their help-seeking behavior for older adults affected by the disease. In Chapter 3, I provide information on the research design and rationale, the research question, my role as the researcher, the methodology, the justification for participant selection, and the instrumentation to be used. I also include a discussion of the techniques used for data collections and analysis, and how I assess the trustworthiness of the collection and analysis of data. Finally, I address the informed consent and ethical considerations relevant to this study.

Research Design and Rationale

I formulated the following research question to guide this study: What are African American caregivers' perceptions of how stigma related to AD affects the help-seeking behavior of individuals and caregivers of older adults affected by the disease? For this study, I selected the qualitative method as opposed to the quantitative method. The primary focus of interest for qualitative researchers is to answer the questions of what, how, or why of a phenomenon, or to address the perceptions or experiences of the study participants (Isaacs, 2014). I did not feel that the quantitative approach was appropriate for this study because, in a quantitative approach, the participants would not be able to express their perspectives, personal feelings, experiences, or thoughts. By utilizing the quantitative approach, participants are presented with a series of survey questions and asked to select from predetermined responses most closely approximated to their own opinion (Brassil & Couch, 2019). The limited range of response options associated with close-ended question formats such as “yes” or “no” responses, multiple-choice, or true-false questions allows for the researcher to deliver detailed information from participants. According to Brassil and Couch, by using a quantitative approach it would be impossible for participants to express and elaborate on their authentic feelings and opinions.

I used a generic qualitative approach to guide this research. The generic qualitative approach is similar to the phenomenological approach in that the focus is on the responses from individuals (Percy et al., 2015). Generic qualitative researchers focus more on the participant's perspectives, attitudes, opinions of an event or issue (Kahlke, 2014). According to Kahlke, researchers can use generic qualitative studies for them to work outside of the boundaries of traditional qualitative methods. Researchers can also use the tools of several established methodologies that offer them the opportunity to develop research designs that are best suited to address their specific research questions. In this study I used the generic qualitative approach because I found it appropriate to examine African American caregivers’ perceptions of how stigma related to AD affected their help-seeking behavior for adults affected by the disease.

Research Question

What are African American caregivers’ perceptions of how stigmas related to AD affect their help-seeking behavior for treatment of AD for older adults affected by the disease?

Role of the Researcher

My role as researcher for this study was that of an active interviewer, investigator, and impartial observer. My role as interviewer established me as the primary instrument of data collection. As the investigator, I developed interview questions to guide the data collection and was responsible for the integrity and management of the design, reporting, and conduct of the study. As the role of the impartial observer, I heard and considered information without bias as my research depended on the impartiality of myself as a researcher during the interpretation of the data gathered. To collect data-rich information from the participants, I used open-ended questions and prompts. Being the primary instrument in this research, I also assumed the responsibility of designing this study, recruiting the participants, and collecting the data by using one-on-one interviews. As the researcher, I wanted to be unobtrusive and impartial in my study as much as possible. I built rapport with the participants. My role was to access the thoughts and feelings of my study participants. I did not have any personal, professional, supervisory, or instructor relationships with any of the participants who participated in this study.

Researcher Bias

According Råheim et al. (2016) I need to be aware how the concepts of positionality and reflexivity may affect both my personal and professional experience, my study topic of choice, and how I position my research question for this study. Råheim et al. suggested that it was also important to understand how my personal and professional experience may have also affected how I asked the questions in the interview sessions with the participants.

My personal and professional experiences with the topic of AD and perceptions of AD in the African American community stemmed from my experiences with my mother, who received an initial AD diagnosis 11 years ago at the age of 76 years. As the primary caregiver of my mother, I witnessed firsthand how the perceptions of caregivers grew concerning due to perceptions that AD was God's will, that the AD symptoms and behaviors were a normal part of aging and how it was safer to stay quiet and protect your loved one from the public's scrutiny and judgment by hiding. Perhaps my mother's experience as a nursing professional working in the mental health profession as a registered nurse and therapist allowed me to view mental health issues differently. I had not perceived or experienced any AD-related stigma throughout my mother's care. I did however question why other caregivers did not respond to symptoms in people in their care sooner by getting an early medical diagnosis for their loved ones. This lack of understanding people's perceptions of the disease inspired me to return to school to learn how I could contribute to social change. In my current career, I have worked with various organizations focused on the aging population and dementia where I led the programs for professionals and communities on the topics of aging, caregiving, and AD.

My perspectives, experiences, or beliefs regarding AD could have created researcher bias. Researcher bias is defined as any deviation from the truth during data collection, data analysis, and interpretation of data (Polit and Beck, 2014). Researcher bias occurs when the researcher either attempts to influence their study to achieve an outcome or when any influence such as information, activity, belief, or attitude provides a distortion in the results of the research. Researcher bias could cause false conclusions that can be misleading to the readers. Such misleading information is incorrect, false information that is communicated regardless of any intention to deceive. Palaganas et al. (2017) indicated that as the researcher of this study, I should be aware of how my personal experiences, perceptions, and subjectivity could affect the results of my research. With Palaganas et al.'s suggestion, I took the necessary action to minimize the impact of my personal research biases, I was transparent and reflexive about the process used for data collection, analysis, and findings in my study. I embraced my subjectivity by acknowledging and admitting my past and current personal experiences with the topic being examined. I used two qualitative techniques to manage and minimize researcher bias.

In the Råheim et al. (2016) study, it was suggested that I use reflexivity and positionality to manage and minimize researcher bias. Reflexivity encourages researchers to consider how their understanding, experiences, and perspectives of a phenomenon may influence the outcomes of a study. Reflexivity enables researchers to become cognizant of how their professional and personal experiences may affect data collection, data coding, data analysis, and interpretation of the data (Darawsheh, 2014; Dodgson, 2019). Researchers are advised to keep a reflexive journal to document their private thoughts and feelings throughout the research process (Anney, 2014; Cope, 2014). I employed the use of a reflexive journal throughout all stages of this research process to assist me in managing possible researcher biases related to my experiences, opinions, thoughts, and feelings related to AD, stigma, and caregiving. In this journal, I consciously acknowledged my values and examined my assumptions, goals and clarified my belief systems and principles such as my traditions, spirituality, and moral code. I used a reflective journal, so that my information would guide me in the notion of creating transparency in the research process. Cooper and Endacott (2007) and Råheim et al. (2016) addressed the use reflexivity in the research process. I kept a reflexive journal to detail my reflections, thoughts, reasons for decisions, and reactions to the data I collected. Lincoln and Guba (1986) published a guideline of what they believed should be included in the reflexive journal. Their guideline stated that there be a log of evolving perceptions, day-to-day- procedures, methodological decision points, and daily personal introspections. A reflexive journal was a tool that I used to refine my understanding of the participant's responses. I used reflexivity to identify any unfavorable personal opinions or perceptions that may have framed how I conveyed the actual words of the participants during data analysis and interpretation. Darawsheh (2014) addressed the importance of self-assessment, and I used self-assessment to monitor and evaluate the quality of my thinking and behavior as the researcher in this study. To enhance and engage in my self-assessment I continuously asked myself questions such as "Did I let my personal experience, feelings, beliefs, affect my response during the participant's interview? Have I remained neutral during the gathering of information?"

I also use positionality to manage researcher bias. Positionality is defined as the researcher's worldview on a research topic or one's stance as it relates to the social, political, historical, religious, and intellectual contexts of the study, the community, or participant group (Merriam et al., 2015; Merriam et al., 2019; Temple & Edwards, 2002). I used positionality to manage my views on shaping the scope of the research topic.

Positionality is crucial in qualitative research because researchers need to be aware of how their values, experiences, perceptions, and researcher biases affect their research. Researchers need to address these within their research through the use of reflexive statements. I managed my professional, personal, and intellectual positionalities by acknowledging my knowledge, values, and biases about AD and seeking treatment for AD. Throughout the study, I was conscious of my values, biases, experiences and how they affected the result of my study. I wrote a positionality statement of how my specific researcher biases, values, experiences, or assumptions could contribute to my research.

According to Råheim et al. (2016) on the concepts of positionality and reflexivity, it is critical that I was aware of how both my personal and professional experiences could affect how I wrote the research questions, the interview questions, and how I conducted interview sessions with the study participants. My positionality statement read as follows: my positionality in this study included both my professional experience as manager and director of programs with the Alzheimer’s Association and the Alzheimer’s Foundation of America. I have worked in the field of gerontology by providing education, care, and support to those individuals who had been diagnosed with AD, caregivers of people with AD, and professionals. I also had personal familial experience in providing the same education, care, and support. I acknowledged that I may have had a different perspective of AD and AD care due to a few factors such as my mother being a mental health professional in the nursing field and being raised in a different environment from the one I currently live in. It was important to acknowledge that I had a different viewpoint from many individuals in the African American community regarding AD. At this time, I often wondered why African Americans chose to struggle with their mental health disorders in private rather than get the medical help they needed to live a better quality of life.

After working in the field of aging and AD for several years I became more curious about African Americans and what they would do if a family memory showed signs of memory loss, confusion, and other issues related to cognitive decline. The responses I often received were either a blank stare or that they would not want to know the results. I became aware of and understood both the role and responsibility of being a caregiver, however, I did have a lack of understanding of what it is like to be an African American caregiver who did not seek medical and supportive services due to the stigma of AD. I wanted to understand more about the perspectives of African American caregivers and how stigmas related to AD may have caused them to delay getting medical help in the early stages of the disease.

According to Walden University (2019) the Walden University Institutional Review Board indicated that as I am the principal researcher of this study, I was responsible for upholding all ethical rules defined by their review board. Walden University (2013) states the by being the sole researcher, I am responsible for conducting all the interviews, collecting the data, and interpreting the responses from the participant’s interview sessions. Though I did hold some assumptions about the subjects of aging, racial and ethnic groups, and AD, I did have limited experience and knowledge of African Americans and their perceptions of AD or their medical-seeking behaviors for AD.

Methodology

For this study, I used the generic qualitative approach to examine how the stigma of AD affected the help-seeking behaviors and perspectives of African American caregivers. According to Percy et al. (2015), I used the generic qualitative studies to consider the individual’s account of their own beliefs, thoughts, reflections, or worldviews on their engagement with the environment they are a part of.

Participants Selection Logic

Sampling Strategy

I used purposeful sampling to recruit participants for this study. The goals for recruiting participants for qualitative research studies differ from a quantitative study because qualitative studies explore the participants' experiences, opinions, or perceptions on a particular topic (O’Reilly & Parker, 2012). Purposeful sampling is defined as a systematic, nonprobability method of sampling that can be used to recruit a specific group of participants who fit the criteria of a study and who are accessible to the researcher (Isaacs, 2014; Percy et al., 2015; van Rijnsoever, 2017). An acceptable sample, according to Gentles et al. (2017), is composed of participants who either best represent or have experience with the research topic of interest. Malterud et al. (2015) suggested that providing there is a clear and concise research topic and a small purposefully selected participant pool the researcher can extract relevant information for data analysis. I used the purposeful sampling method to recruit participants who could provide detailed and in-depth information about AD, their perception of AD, and stigma.

I also used snowball sampling to recruit participants for this study. The snowball sampling technique is used when participants recruit other participants who match the inclusion criteria for participating in the study (Kirchherr, 2018). I used snowball sampling to recruit from populations that are difficult to sample. Snowball sampling is a technique often used by researchers when potential participants are difficult to recruit for a study. I asked initial participants to forward information about the study to individuals in their social circles who may have fit the inclusion criteria for participation.

Inclusion Criteria of Participant

The inclusion criteria for participation in this study will be African American adults 18 - 99 years of age who provided primary care for a family member experiencing the signs and symptoms of cognitive decline. The rationale for including this wide age range is that there are many younger adult caregivers who provide care for their parents and grandparents. According to United States Census Bureau (2019), the majority of caregivers were between the ages of 30 – 75 as they entered the role to care for their spouses, parents, and grandparents. Participants must be fluent in English and have provided care to the family member diagnosed with AD for 6 months or more. African American caregivers must have also provided a minimum of at least 20 hours per week of caregiving for a family member experiencing AD. Participants must reside in the United States. Participants were excluded from participating in this study if they did not meet all of the stated inclusion criteria.

Sample Size

A total of 11 participants were recruited for this study. It is generally understood that qualitative research studies use smaller sample sizes than quantitative studies (Gentles et al., 2016). Gentles et al. suggested that including at least 10 -12 participants should facilitate gaining information of the shared knowledge or experiences of a group of people. Gentles et al. states that the primary goal of qualitative research is to reach saturation and the chosen sample size for a given study must be sufficient to achieve saturation. There are varying definitions of saturation, but saturation is generally said to have been achieved during data collection at the point where no new themes emerged from the participants (Gentles et al., 2017; van Rijnsoever, 2017). Hennink et al. (2017) stated that saturation has been achieved when the data collected is rich and comprehensive. Hennink et al. stated that researchers have determined that saturation can occur in results from a range of between 8 and 16 participant interviews. Gentles et al. also suggested the number of interviews required to achieve saturation for descriptive phenomenology was approximately 12 participants. The targeted sample size of participants was sufficient for reaching saturation based on the guidelines given regarding the sample needed to achieve saturation of data (Gentles et al., 2016; Hennik, 2017; van Rijnsoever, 2017).

Recruitment

Participants were recruited from across the United States. I contacted the directors of organizations that mainly served African American communities across the country to discuss my research project and asked permission to recruit participants from their organizations. I also used social media opportunities such as LinkedIn, Facebook, and Instagram for the recruitment of study participants. The various recruitment opportunities I contacted included directors of community organizations from community centers, adult day centers, and senior citizen centers who used bulletin boards to post activities and events pertinent to their clientele. The letter of cooperation for participant recruitment (Appendix A) was used to approach these various organizations for recruitment purposes only. The recruitment flyer (Appendix B) was created to aid in the recruitment of study participants to include the mentioned organizations and social media platforms targeting African Americans. The recruitment flyer was also posted on social media accounts of Facebook, LinkedIn, and Instagram and by the directors of community liaison staff of organizations targeting the African American population. I also posted this flyer on social media member groups that I was participating member of. In the letter of cooperation and recruitment flyer, I outlined the purpose of this study and the criteria for participation. My Walden University email address was used as the point of contact for individuals interested in participating in this study. Participants who fit the participant selection criteria of this study and were available initially contacted me through my Walden University email and the phone number listed on the flyer.

Participation

Potential participants contacted me either directly through my listed email address or a specific cell number phone number set up only for this study on the recruitment flyer (Appendix B). When potential participants contacted me by phone or email about participating in this study, I responded by asking them the screening questions (Appendix

C) to determine if they met the inclusion criteria set for this study. It was made clear that participation is on a completely voluntary basis only. After the initial screening was completed and the eligibility was established with each participant, I then emailed each participant the Consent Form (Appendix D), the Demographic Questionnaire (Appendix F), and the Counseling Resources List (Appendix J). In this informed consent, they understood that their participation was voluntary and that they were free to withdraw at any time, without any given reason, and without cost to them. Both the Consent Form confirmation and the completed Demographic Questionnaire (Appendix F) were required to be emailed back to me to schedule an interview. I then scheduled an appointment time that is convenient for them to conduct the interviews. I then emailed each participant a copy of the interview guide (Appendix E). Interviews were either held over the phone or by Zoom conference calling software.

Instrumentation

The main instrument I used to collect data for this study was the semistructured interview. Before collecting the demographic information, I provided each participant with an interview guide (Appendix E). Before the interview, I received the completed demographic questionnaire (Appendix F) via email. I printed and filed the demographic information along with the participants' informed consent to participate in the study. The purpose of the demographic questionnaire was to gain background information on each participant of this study. The questions I used provided context for the collected data. This data allowed me to describe the study participants (Fusch and Ness, 2015).

A successful interviewer must establish that the interview questions are adequate by designing questions that are, structured, open-ended, clear, concise, ethically sensitive, and relevant to the phenomenon being studied (Isaacs, 2014; Percy et al., 2015). According to Brinkmann and Kvale (2014), researchers should develop their study questions to gain as much knowledge as possible about the phenomenon. The interview protocol I used in this research study included a list of semistructured interview questions (Appendix G) that I developed.

I addressed the content validity of the instrument based on the methodological literature and the experience of my study committee for assuring the content validity of my interview questions of the subject matter to be explored. Additional instruments that were used in this study included a voice recorder. I secured written permission from each participant to record the interview sessions. A debriefing statement (Appendix H) was provided to each participant via email after the completion of the research activity. This allowed their recollections to be current. No historical or legal documents were used as a source of data. For the participants' participation in my study, I gifted them each a $20 gift card and a “thank you” card. The “thank you” card and a gift card were mailed to each participant 2-3 days after the research activity had been completed.

Data Collection

The interview questions were open-ended so that participants could provide in-depth, data-rich descriptions of their perceptions of the phenomenon (Isaacs, 2014; Percy et al., 2015). I also asked follow-up questions during the interview to encourage participants to clarify and expand on their responses about their perceptions.

I selected to conduct each participant's interview session over the telephone or Zoom conference call online platform. The choice of whether to use the telephone or Zoom depended on the preference of the participant. Telephone interviews have become an accepted approach for both qualitative and quantitative data collection (Block & Erskine, 2012; Drabble et al., 2016). Telephone interviews offer both advantages and disadvantages compared with using the face-to-face interview method. One advantage to conducting phone interviews is that most people have access to a phone (Drabble et al., 2016). Telephone interviews are also time-efficient. The use of the phone to conduct interviews can minimize cost and travel for participants and researchers (Kee & Schrock, 2019). Participants may feel more relaxed in their chosen location, and they may feel more comfortable disclosing sensitive information. Another advantage of the phone interview is that it permits greater access to participants who may reside at remote locations from the interviewer.

The absence of visual cues can result in loss of contextual and non-verbal data, which may interfere with the interviewer's ability to perceive and respond to any nonverbal cues from the participant (Oltmann, 2016). According to Farooq (2015) non-verbal cues are important because they may alert the interviewer to a participant's discomfort about a specific topic. Lechuga (2012) stated that non-verbal cues may prompt the interviewer to ask for clarification, to probe more deeply, or to request additional information. According to Farooq (2015), another disadvantage to telephone interviews is the lack of personal interactions my causes challenges in establishing rapport and keeping participants engaged in the process. Lechuga stated that such barriers may lead to the participant withholding pertinent and sensitive information. Another possible disadvantage to interviewing via phone is that there could be technological problems on either end that could negatively impact the interview experience for both the participant and the researcher.

Zoom conference call online platform offered the opportunity to interview over the internet (Archibald et al., 2019). Zoom is a web conference technology that offers video conferencing that can be effectively used for one-on-one interviews for qualitative research. Zoom offers some unique features and benefits to both the researcher and participants. Zoom is an alternative interviewing method from face-to-face, other video conferencing platforms, and the telephone. According to Archibald et al. findings suggested that Zoom is a viable tool to collect qualitative data due to it being relatively easy to use, features, data management features, cost-effectiveness, security options, and recording opportunities. Zoom offers the researcher the opportunity to recruit and interview participants across the nation who have internet.

It was imperative that potential participants understood and agreed to the terms and conditions in the informed consent form. The informed consent form provided them with information on the confidentiality policies and procedures being used in the study. The informed consent language is understandable to the potential participants. I then emailed each participant directly after the screening questions were completed and I determined that they fit the criteria for participation. For participants to provide consent, I asked the participants to send an email to me which indicated consent to participate in the research. Participants were instructed on how to give their consent by using the words “I

Consent" in the response email to confirm their agreement of participation in this study. The participants were given two days after receipt of the emailed copy to read, review and respond by email about their consent. This was also the participant's time to ask questions before responding via the email detailing each participant's consent. I then printed copies of the consent forms and emails and kept them for my records. I also informed participants to print a copy of the consent form for their records.

During this phone or Zoom call scheduled for the interview, I also reviewed with each participant the procedures I would use to protect their confidentiality, how I would use the audio recording in my research, how the data would be secured and when and how the data would be destroyed. I then proceeded to ask the series of interview questions from the interview questionnaire (Appendix G).

Each interview session was audio-recorded or recorded via Zoom conference software. Audio and Zoom conference call software recordings are considered identifiable data as they record the voice of each research participant (Cychosz et al., 2020). Identifiable data is defined as information that can be associated with or reveal the identity of a person to whom the data belongs. Participants were informed of the use of audio or Zoom recordings for the interview and each participant provided written or verbal consent before moving into the actual interview session. I also reminded participants that their interviews would be recorded. The consent form clearly stated the use of audio or Zoom recordings during the interview session. To ensure the privacy of the participant, I did not use the participant's personal information during their interview session or for any purposes outside of this research study. I removed all names and identifying details. I used alpha-numeric codes in place of names to protect the privacy of the participants during the data collection process. To ensure the privacy of the participants during the interview data collection I positioned myself in a private space in my home to conduct the interviews to minimize interruptions and ensure participant privacy. I also requested the same from each participant by either placing themselves in a private space with minimum noise or interruption. All audio and Zoom conference call recordings were filed separately from the transcribed audio and Zoom recordings of the interviews and other notes.

When any participant became emotionally distressed during the interview process, I paused the interview and offered the participant the opportunity to take a break to regain composure. I also inquired about how they were feeling and whether they were able to continue or not. Each participant was able to continue and complete their interview session. I was prepared that should a participant have required more attention such as emotional support, I would have encouraged them to contact one of several social service organizations from the Counseling Resources for Participants list (Appendix J) that I had provided to them. In the Counseling Resources for Participants list (Appendix J), I provided a list of organizations that offered free or minimal cost resources and support to caregivers of individuals who have AD. This contact referral list was emailed to each participant when I initially confirmed their participation in the study. I was also prepared that if a participant decided to terminate their participation, I would terminate the interview immediately.

Debriefing

A debriefing occurs at the conclusion of the study. Debriefing is defined as a process of informing study participants of a full explanation about the intentions of a research study (American Psychological Association [APA], 2020). By debriefing study participants, the researcher can ensure that they are returned to the condition they were before they participated in the study and no harm was done.

The debriefing process is an ethical consideration to ensure that participants have not been harmed by their participation in the study (APA, 2020). At the close of the interviews, I inquired if any of the participants had any questions for me. The participants were then informed of details that they may not have been aware of before the study. The debriefing statement was then given to each participant via email. Debriefing is important to the participation process as it provides a full explanation of the relevant background of the study at the end of the research process. This debriefing statement included information on the study and reiterated my commitment to confidentiality of the participants' information. I also provided my contact information in this debriefing statement.

I also informed the participants about transcript reviews. I used a transcript review as a process to follow up to enhance the credibility and accuracy of the information obtained during interviews (Cope, 2014). Details regarding the transcript review process are presented under the section labeled credibility. Each participant received a $20.00 gift card and “thank you” note 2 – 3 days after their interview was completed. The thank-you note, and gift card were then be mailed to the address provided to me.

Data Analysis Plan

To begin the data analysis process, I first manually transcribed the audio recordings of each participant interview into a text-based document. By transcribing this information, I was able to provide a written account of spoken words. Transcription of interviews is a necessary step in the analytic process. A written record of the interviews provided me with a document that could be referred to and reflected on repeatedly. To begin the transcribing process, I included pertinent and identifiable information in this study (Nowell et al., 2017). Nowell et al. suggested that information that was pertinent to be used was the name of this study, alpha-numeric identification for each participant, the date and time of each interview recording, the context and the setting, an audio file name using the same alphanumeric identification used for each participant, and the duration of the interview recording. I manually transcribed each participant interview audio recording verbatim.

The data collected from this study were analyzed using thematic content analysis, (Clarke & Braun, 2017). Thematic content analysis (TCA) is described as a descriptive analysis of qualitative data that is used to identify common themes in a dataset (Schreir et al., 2019). The advantages of using TCA are that it is easily grasped and quick to learn. The TCA also has fewer procedures and was a useful method to examine the perspectives of various study participants who may have generated unexpected insights and call attention to similarities and differences (Schreir et al., 2019). I used inductive analysis to determine the emergent themes from the data. Armat (2018) stated that inductive analysis is defined as an activity of allowing themes to form from the raw data. Inductive analysis is a way of analyzing text-based data in qualitative research. These themes allowed me to gain insight into how a participant perceived the phenomenon. It was imperative to conduct this study rigorously to contribute meaningful and helpful results. For research to be accepted as trustworthy, as the researcher I have demonstrated that my data analysis was conducted consistently and accurately. I first condensed all of the data I had gathered including the raw text data and created a summary format with the information. I then used inductive analysis as there were limited previous research findings on this subject matter. Inductive analysis was used to identify themes by reviewing audio recordings, verbal material, notes, and documents based on the responses of the participants' thoughts and perspectives of each question.

Following the transcription, I analyzed the data using Colaizzi’s (1978), 7- step process. This process provided me with a rigorous analysis while each step remained close to the data. The seven steps of Colaizzi’s method are presented below:

Step 1: Familiarizing. In the first step to conducting the data analysis, I first familiarized myself with the transcribed interviews of each participant by printing them and having a paper copy to read (Colaizzi, 1978). I then read and reread the interview transcripts several times to familiarize myself with the responses of each participant. Each participant’s transcript was printed so that I would have a hard copy to read.

Step 2: Identifying significant statements. The second step of the Colaizzi method of data analysis was for me to identify the central themes, patterns of keywords, and significant statements in the data. To identify significant words, statements, or key phrases across the multiple interviews, I first sorted and grouped the data by interview questions (Colaizzi, 1978). I then extracted significant statements and recurring patterns of words that appeared across the interview transcripts. Each time I found a recurring word or phrase, I would make a copy of it and the immediate context and paste it into a Microsoft Word table.

Step 3: Formulate meanings. To formulate meaning by hand, I then grouped recurring statements, phrases, and keywords that were similar in content and meaning. I then assigned a label that encompasses the meaning of the grouped words and phrases. This initial process of identifying recurring patterns of words and phrases allowed me to engage in open coding (Theron, 2015). I then determined the first round of emergent themes based on the similarities in the content and meaning across the various keywords and phrases.

Step 4: Clustering themes. In the second round of coding, I engaged in axial coding. I physically grouped and clustered the first round of themes according to common meanings or similarities of meaning (Mayring, 2014). I then engaged in data reduction by organizing and grouping the round of themes into categories of similar content. I continued the clustering of themes until no new themes were coming from the data. I then developed a code sheet for emergent themes. A code sheet is a list of codes with code definitions. This code sheet allowed me to keep track of how codes were being used to make sense of the data. In the third round of coding referred to as selective coding, I clustered the themes further to reduce the number of identified themes overall.

After the selective coding, I reread each interview and coded the emergent themes for each interview question.

Step 5: Exhaustive Description. I integrated the themes and developed an exhaustive description. For this step, I interpreted the data by writing a full description of the phenomenon including all of the themes identified in the data. I wrote an exhaustive description of participants' responses to each of the interview questions.

Step 6: Producing the Fundamental Structure. In this sixth step, I then condensed the description into a short statement explaining the findings that answered the research question.

Step 7: Verification of Findings. This step is referred to as member checking. The final step of the Colaizzi seven-step method was to share the findings with the study participants. In this final step, I contacted each participant and forwarded by email a copy of the findings to each participant. I requested each participant to review and confirm whether I had captured their perspective accurately. The participants also had the opportunity to either verify or oppose whether I had interpreted their perspectives accurately. I offered the participants the opportunity to modify information that they had shared that was interpreted incorrectly.

Issues of Trustworthiness

Trustworthiness is a concern in qualitative research because, without trustworthiness, results from the study may appear to be inaccurate and invalid (Cope, 2014). Trustworthiness enables researchers to establish the truth and accuracy of the research process and findings. In qualitative research, trustworthiness corresponds to validity and rigor in quantitative research. Rigor is defined as the quality of the research process and design (Cope, 2014; Pilot & Beck, 2014). Lincoln and Guba (1986) created a new set of key components for addressing the trustworthiness of qualitative research. There are four components of trustworthiness in qualitative research, those elements are credibility, transferability, dependability, and confirmability.

Credibility

Credibility is about establishing whether the findings of the research represent plausible information from the participants' original data (Cope, 2014). I used the transcript review to enhance the credibility of this research. I used Transcript Review Correction/Approval Email and instructions (Appendix I) to enhance the credibility of this study. The transcript review was used as a methodological approach to verify the accuracy of a participant’s transcript (Birt et al., 2016; Mero-Jaffe, 2011). Transcript review occurred when interviewees were furnished with a verbatim copy of their interview transcripts to verify the accuracy of the content, correct errors or inaccuracies in the content, and offer clarification of the content (Birt et al., 2016; Mero-Jaffe, 2011). To conduct the transcript review, I sent each participant a digital copy of the transcript from their interviews. Participants were then asked to review the transcripts and provide feedback as to whether the transcript accurately reflected their perceptions and comments. The timeframe that was set for the participants to respond to their transcript review activity was seven days starting with the date of receipt. For the participant to respond to make requested changes to the transcripts they were instructed to email me the necessary changes. It was understood that if a participant did not complete their transcript review according to the timeframe set, I would continue with the data analysis. The overall goal of transcript review was to offer the participants the opportunity to retract, reframe particular statements or add any additional thoughts that they may have had about the interview questions after the interview ended.

Participants were asked to review a Microsoft Word copy of their transcript review. Participants received their transcripts through email. The participants were informed in the email that they had 5 days from the date on the email to respond to whether the written comments reflected what they intended to communicate in their interviews. If a participant wanted to make a change to their comments, they were instructed to do so by sending me an email with the changes they felt best represented their perspective.

Transferability

Transferability is defined as the degree to which findings from a given study may apply to other contexts or settings (Anney, 2014; Cope, 2014). I enhanced the transferability of results from this study through the use of an audit trail and purposeful sampling. The use of an audit trail increased the probability that the readers could determine whether the results may be transferable to other situations and contexts. The use of the audit trail approach allowed me to maintain an in-depth record of the research. An audit trail documents all aspects of the research process including in-depth descriptions of the data analysis process, written notes on methodology, and a log of all records created and/or edited throughout the study (Cho & Lee, 2014). This audit trail provided information such as the research design, data collection and management procedures, and the documentation of the researcher's activities. It also included a detailed description of how I gathered and analyzed the data.

The use of purposeful sampling is an additional approach that could be used to enhance the transferability of results from a study (Anney, 2014). Only participants who had a connection to the research question would be able to provide meaningful information about the research question (Anney, 2014; Cope, 2014). Purposeful sampling enabled me to recruit African American caregivers who had sought care for family members diagnosed with AD.

Dependability

Dependability in qualitative is defined as the reliability of the findings and how detailed the research procedures were chronicled allowing a reader to follow and audit the process of the study (Anney, 2014). Colorafi and Evans (2016) stated that dependability may be enhanced when researchers are consistent throughout the research process. I used the audit trail to enhance the dependability of the results from this study. By using audit trails, dependability would be achieved (Anney, 2014; Cooper & Endacott, 2007). To enhance dependability both the researcher, and reader reviewed the activities as recorded in the audit trail. The audit trail included the notes, recordings, and reports used to enhance dependability.

The second technique I used to enhance dependability throughout the research process was transcript review (Birt et al., 2016). Transcript review was an important quality control process in this study (Harper & Cole, 2012). Transcript review helped to improve dependability by transcribing the interview and then asking the participants to affirm accuracy. Researchers then validate whether the transcribed information captured was what they intended to say accurately represented their perspectives (Birt et al. 2016).

Confirmability

Confirmability is the last criterion of trustworthiness that the researcher needs to establish (Birt et al., 2016). Confirmability is the degree to which another researcher may be able to confirm the results of the study (Anney, 2014). This criterion pertains to the level of confidence that findings from a study are based on the words of the participants rather than possible researcher biases. Confirmability also concerns the degree to which results accurately reflect the experiences and beliefs of the participants. Confirmability in a study was also increased by utilizing audit trials (Anney, 2014; Birt et al., 2016; Carcary, 2009; Cope, 2014; Nowell et al., 2017).

The use of audit trails provided transparency in describing the steps taken in the research process starting from the beginning of the research process through to the reporting of the findings. These audit trail records of the research were kept throughout the entire research process. The audit trail included the interview protocol, my reflexive journal, data collection, audio recordings, video sessions, transcripts, data analysis, data interpretation, and observation notes taken throughout the study to both documents for replication and also address the rationale for my analytical decisions (Korstjens & Moser, 2018; Nowell, 2017). The audit trail also demonstrated how I analyzed the study data by including early data interpretations and analysis, communication with research participants (Korstjens & Moser, 2018). An audit trail is a tool that serves to convince the research community of the study’s rigor.

Ethical Procedures

There are always potential risks associated with being in any kind of study. In this case, there were risks such as the possibility of having an adverse emotional reaction to the topic of AD. This possibility was addressed in the consent form. Ethical practices and procedures were designed to protect the participants from potential harm due to their participation in this research study (Pollock, 2012). I established safeguards from harm and protected the participants of this study by establishing trust, deference and committed to avoiding deceptive practices that would misinterpret the intention of the study and researcher (Sanjari et al., 2014). The ethical procedures for Walden University students were found on the IRB website. The IRB website provided all of the key elements to complete my study ethically. I followed all the Walden University IRB guidelines to complete my study. Participants participated and completed their interviews voluntarily.

Before conducting data collection for this proposed study, I also submitted the required documents to obtain approval from Walden University's Institutional Review Board (IRB) regarding all proposed procedures and activities related to this research project. Upon approval of my proposal, I placed the IRB approval number on each consent form which were be given to the participants before their interviews. I ensured that all recruitment information and materials complied with Walden University IRB guidelines. Each participant was informed that they had the option to discontinue participating at any time during the process.

I emailed the potential participants a copy of the informed consent form for them to read, review, and respond to using the words "I Consent" in the email responding to me with their completed demographic questionnaire. Potential participants were advised that they should print and keep a copy of the informed consent for their records. The participants were encouraged to ask any questions or discuss any concerns that they may have had during the interview. Each participant was debriefed, and each was thanked for their participation. All collected and archived data was stored and treated according to the standards set by Walden University IRB.

To protect the confidentiality of the participants, each participant was assigned an alpha-numeric designation so that their names would remain confidential. None of the participant names were kept with the interview materials. The recorded interviews and the transcripts of the interviews were stored separately from the participants' names. I secured the interview information, personal information, audio-recorded information, confidentiality agreements in a password-protected safe stored in my residence, to protect the confidentiality of the study participants for five years according to Walden University's IRB guidelines. I am the only individual who has access to this locked cabinet.

Research materials from this study will be destroyed by the researcher. These materials will be retained for 5 years after the date from completing the study and then destroyed. Research materials in the form of electronic records will be destroyed by overwriting by the use of overwriting software. To destroy written records, I will employ the process of shredding and cross-shredding. Should there be any ethical issues, I will contact my dissertation committee and Walden's IRB board.

Summary

In this chapter, I gave a detailed description of the research design and rationale, the role of the researcher, methodology, participation selection logic, data collection, issues of trustworthiness, and ethical procedures for this study. The purpose of this study was to examine the perspectives of African American caregivers of individuals affected by AD. The goal of this study was to understand how the stigma of AD delayed help-seeking behaviors in this population. I was aware of possible researcher biases and assumptions that could have been brought to the study due to my personal and professional experiences. I however engaged in the process to reduce all possible researcher biases.

In this chapter, I have discussed the methodology in depth by addressing recruitment, sampling strategy, sampling size and data saturation, and inclusion and exclusion criteria of participants. I have also discussed data collection, instrumentation, and data analysis. Semistructured interview questions will be guided by the research question: What are African American caregivers' perceptions of how stigma related to AD affect their help-seeking behavior for treatment of AD for older adults affected by the disease? I covered the issue of trustworthiness and strategies that can be used dependability, credibility, confirmability, and transferability of this study. I have also addressed ethical procedures such as the risks associated with this kind of study related to the confidentiality of the participants, correct data management, and storage. In chapter 4, I will discuss the study, demographics of the participants, data collection, and analysis process that will follow the collection of the data. The evidence and implementation of trustworthiness will also be covered. Finally, I will discuss and present the results of the data analysis of the study to understand the perceptions of the African American caregivers of older adults affected by AD and how the stigma of AD delays help-seeking behaviors in this population.

Chapter 4: Results

Introduction

In this generic qualitative study, I examined how the perceptions of the stigma of AD amongst African American caregivers affected their help-seeking behaviors in caring for older adults affected by the disease. As a researcher, my objective was to explore and understand the African American caregiver's perspective of AD and the stigma of AD and how it delays their help-seeking behaviors. In this study, I addressed the following research question: What are African American caregivers' perceptions of how stigmas related to Alzheimer's disease affect the caregivers' help-seeking behavior for older adults affected by the disease? In this chapter, I discuss the research study setting, the demographics of the participants using alpha-numeric identifier codes, and the method of data collection I use. I describe the data analysis process use I use. I also demonstrate the evidence of trustworthiness and themes that emerge from the data analysis and a summary.

Setting

A researcher who employs a generic qualitative design is seeking to understand the world views or perspectives of the phenomenon of a people (Cooper & Endacott, 2007). To secure detail-rich information from study participants, researchers need to build rapport and provide an environment that is comfortable for the participants to open up and share their information-rich stories (Rudestam & Newton, 2015). I conducted each interview session either over the phone or on the Zoom Conference software, at the convenience of the participants. Each study participant took part in one 30 to 55-minute interview session. Each interview took place either over the telephone or Zoom conference call in the security of the participant’s home. Each study participant selected the date, time, and setting they would feel most comfortable. To my knowledge, there were no other persons in the room with the interviewee, or myself, during the interview sessions. To my understanding, there were no professional or personal connections that may have influenced the participants, their knowledge of the study, or my interpretations of the data shared. To ensure the confidentiality of each participant, I identified them as participants and used alphanumeric identifiers with an accompanying number for each participant (e.g., Participant 1 AAC1, Participant 2 AAC2, Participant 3 AAC3, etcetera).

Demographics

The data collection process consisted of collecting basic and useful demographic information from each participant. This information included age, race, gender, caregiving status and length, age of the care recipient at time of diagnosis, relationship to the care recipient, and direct caregiving hours. Each of the participants of this study met the inclusion criteria of being African American, being between the ages of 18 and 99 years of age, and having participated as a primary caregiver of a family member who had been medically diagnosed with AD and residing was at home.

I used the purposeful sampling method because my inclusion criteria were specific to African American adult caregivers. These caregivers had to fit the criteria of informal caregivers. An informal caregiver is a person who is not receiving pay through a healthcare organization or agency. Informal caregivers of persons with AD are usually either a spouse or adult children providing home support and supervision for a loved one with memory loss or cognitive impairment. Each caregiver participant met the inclusion criteria of the study through self-identification. Each of the 11 participants began caring for their recipient after the age of 18. One participant had an executive background, two had academic backgrounds in human services, three were working as social workers, one was a university professor, three were retired, and one was a stay-at-home partner and small business owner. Seven participants identified as female and four identified as male. Of the 11 participants in this study, five had never been married, three were divorced and the remaining three participants were married at the time of their interviews. Participant ages ranged between age 21 and 70 years old. The average age of the participants was 50 years. To honor the confidentiality of each participant I used a unique identifier. The identifier was in alphanumeric format. For the remainder of this study, I refer to each participant by their assigned unique identifier.

Demographic Profile of Participants

For the demographic profile of the study participants, I provide a brief biographical and demographic description of each. During this study, each participant either previously or currently provided care for a loved one with AD who is residing in their respective home. None of the care recipients lived in assisted living facilities or nursing homes. I have removed all the identifying information from each participant.

Participant 1

Participant 1 (AAC1) was a 42-year-old woman. She was a bank executive who was also the primary caregiver for her 71-year-old mother who was diagnosed at age 68. She was the eldest child in her family. She was single and had a bachelor’s degree. She had been caring for her elderly mother who had been diagnosed with AD for 3 years. AAC1 had her mother living with her in New York. Participant AAC1 spent approximately 28 to 42 hours a week caring for her parent.

Participant 2

Participant 2 (AAC2) was a 52-year-old woman. She was a licensed clinical social worker and was employed full-time. She had a graduate degree. This participant was divorced and resided in Florida. She had been caring for her 82-year-old parent for the past 2 years. Her parent was diagnosed at age 80 years. The participant spent approximately 56 hours per week caregiving for her parent.

Participant 3

Participant 3 (AAC3) was a 63-year-old man who was married. He had an advanced college degree and resided in Florida. This participant worked full-time as a college professor. The participant had been caring for his parent for over 6 years. His parent is now 87 years of age and was diagnosed at age 81 years. The participant spent approximately 48 hours providing caregiving duties for his parent. The participant’s spouse did not share in the caregiving responsibilities.

Participant 4

Participant 4 (AAC4) was a 65-year-old woman who was married. She has an advanced college degree and was retired. This participant was retired and reentered the workforce part-time. She was the wife of the caregiving recipient. They had been married for over 45 years. The couple resided together in Georgia. Her husband was 75-years old and was diagnosed at age 70. The participant has been caregiving officially for approximately 5 years since the official diagnosis. The approximate amount of time spent caregiving was around 28 to 30 hours per week.

Participant 5

Participant 5 (AAC5) was a single woman aged 42 years. She had a bachelor’s degree and worked full time as a social worker. She resided in Massachusetts. She had been caregiving for 2 years for her grandparent. Her grandparent was 77 years old and had been diagnosed when she was 72 years. This participant spent approximately 20 to 25 hours per week caregiving.

Participant 6

Participant 6 (AAC6) was a single woman aged 62 years. The participant resided in Texas. She had a bachelor’s degree and was retired. She cared for her 88-year-old parent. Her parent was diagnosed at age 79. She had been her parent’s caregiver for over 9 years. The participant spent approximately 40 hours per week caregiving for her parent.

Participant 7

Participant 7 (AAC7) was a 37-year-old woman who resided in North Carolina. She was married. She had an associate degree. The participant worked part-time as a social worker. She was the granddaughter of the care recipient, who was her grandmother. The care recipient was 74 years old and was diagnosed at age 71. She contributed approximately 28 hours per week to provide care for her grandparent. The participant’s spouse minimally shared in caregiving duties such as transportation assistance.

Participant 8

Participant 8 (AAC8) was a man who was 53-years old and divorced. He was a resident of New York. He was the son of the care recipient. He had a bachelor’s degree and worked full time. He had been providing care for his parent for 2 years. His parent was 78 years old and was diagnosed at age 73. He provided approximately 40 to 42 hours a week of care.

Participant 9

Participant 9 (AAC9) was a male caregiver who was aged 70 years. He was divorced. The participant resided in Florida. He had an advanced graduate degree. He was a retired college professor. He had been providing care for his sibling (brother) for over 3 years. His sibling was 70 years old and was 69 when he was officially diagnosed. The participant provided approximately 30 to 35 hours of care weekly.

Participant 10

Participant 10 (AAC10) was a 60-year-old single female caregiver who resided in New Jersey. She had an associate degree and worked full time. The participant provided care for her sibling. The approximate time allocated to caring for her sibling per week was 45 to 50 hours. The participant’s sibling was 77 years old and was diagnosed at age 75.

Participant 11

Participant 11 (AAC11) was a 21-year-old single man who resided in New York. He completed high school and was currently employed. The participant had been providing care for his grandparent for over 1 year. The participant provided approximately 40 to 50 hours of care for his grandparent. The care recipient was 78 years old and was diagnosed at age 75.

Data Collection

Upon receiving official approval from the Walden University IRB (IRB Approval Number 08-20-21-0659067), I proceeded with the collection of data for this study. This IRB approval allowed me to move forward with recruiting and gathering information from the study participants. The data collection spanned 4 weeks from August 2021 to September 2021. As the sole researcher for this study, I was permitted to recruit 11 participants who met the following criteria: (a) African American, (b) between the ages of 18 and 99, (c) an adult who was the primary caregiver, (d) who provide care or were providing care for a loved one living in at home in the community, (e) who's care recipient had been formally diagnosed with AD. Initial introductions with each participant and discussion of informed consent were held over the telephone. After my initial introduction, I discussed the informed consent and the need for the participants to understand and agree by responding to the email using the words "I Consent" in the email before the official interview session. In my discussion with each participant, I also informed them of the purpose of the study, the benefits and risks of participating, and the procedure for reporting disclosure of suspicions of elder abuse, and confidentiality during the study.

During this time, I also provided each participant with a list of counseling resources (Appendix J) and the demographic questionnaire (Appendix F). The Counseling Resources Guide provided participants with information such as free helpline services, caregiver support groups from organizations that specialize in providing AD education and caregiver support, and care and were staffed with either licensed clinical social workers or dementia specialists. Though the participants were from various states, the guide consisted of only those organizations that could engage and support those requiring help and information on AD. I selected these national agencies because they have a connection to services that are at the local level. Upon completion of the demographic questionnaire (Appendix F) they were returned to me in the consent email. After providing this information, I allowed time for the participants to ask questions and closed with a reminder that to participate in this study the consent needed to be communicated to me using the words "I Consent" in the return email to me by using my Walden University email. The deadline date was September 5, 2021, before participating in this study. During the interview session, I also reviewed the interview guide to collect meaningful words expressed by each participant. With each participant, I also secured permission to record their interview sessions. Each participant's interview was conducted without interruption. My data collection procedure did not deviate from the established plan that I presented in Chapter 3. I did not encounter any unusual or unexpected situations during the data collection process.

For this study, I conducted individual interviews by telephone or through the Zoom conference call system. I used a spreadsheet, journal, and a digital recorder including the recording over Zoom to gather the interview data. Throughout these 4 weeks, I conducted eight phone interview sessions and three Zoom interview sessions. Telephone interviews spanned between 35 to 45 minutes, and Zoom interviews were between 30 and 55 minutes. I approached each interview with semistructured interview questions. I asked each participant the same set of interview questions during their interview session. I used semistructured, open-ended questions to gather data. By using this form of gathering data I was able to promote and collect data-rich responses of the African American caregiver's perspectives related to how the stigma of AD affected their help-seeking behaviors from diagnosis to care and support for their loved one. During the interviews, each participant was able to voice their perspectives. Each participant experienced some emotional responses when answering some of the questions. For example, two of the 11 participants showed signs of slight emotions as they discussed noticing the changes in their loved ones, and about the caregiving responsibilities that they had to perform for their loved ones. At the sound of distress, I asked each participant if they were okay, however, each participant responded "yes" and preferred to continue with the interview session. There were no more distress signal interruptions during the remainder of the interview sessions. Each participant was informed that the interview time would be between 30 to 60 minutes, however, each interview was completed in less time than they were scheduled for. The average length of the interview sessions was between 35 to 55 minutes in length.

Each participant was debriefed (Appendix H) at the end of their interviews. I then confirmed each participant's responses from the audio recordings to document them. After the debriefing and the research activities were completed, I thanked each participant and mailed them a "thank you" card and gifted each participant with a gift card with a value of $20.00 three days after the interviews were completed.

Transcription of each of the participant's audio recordings and Zoom recordings was completed immediately after the identifying information was removed and replaced by the unique identifiers. Upon completion of the transcription of each interview response, I conducted member checking by emailing each participant a copy of their transcribed interview for them to confirm the accuracy of the information as I understood it. They each confirmed, by email, that the transcribed interview information was accurate. None of the participants had additional information, nor needed to clarify or modify information from the transcribed record. To continue to protect the confidentiality of each participant, the data was saved on a single USB drive which was then placed in a secured safely with a lock, in my home office where I am the only person who has access. The safe is not shared with anyone else. The information will be retained and remain protected in this location for five years from the completion of the study.

Data Analysis

For this study, the generic qualitative approach was appropriate. I also employed an inductive approach to the data analysis. The approach was appropriate for the interpretation of the data collected from the study participants and the themes that emerged from the data. For the data analysis process, I used Colaizzi's (1978) seven-step method as defined in Chapter 3. According to the Colaizzi method, it was crucial to read the interview transcripts for descriptive data and group them into categorical themes until we exhausted the process where no new themes emerged.

The tables were created in Microsoft Word to organize the categorized axial codes, open codes, and keywords and phrases. In the case of any disclosure of sensitive or identifiable information disclosed by the participants, I redacted the information to maintain the confidentiality of the participants, and anyone related to the study. In each of these interviews, I sought to gain an understanding of each participant’s perspectives and worldview on the stigma of AD, how it influenced the delay of their help-seeking behaviors, and how it contributed to the quality of life of their loved ones. The objective of the semistructured interview questions was to evoke and obtain rich data in the form of responses that would inform or answer the research question. To have data to analyze, I conducted interview sessions that spanned from 35 minutes to 55 minutes. Each of the participants responded with detailed accounts on their perspectives on how they experienced AD as a caregiver and how their perspective of AD delayed their help-seeking behaviors for their loved ones. The data collected for this study consisted of eleven individual interview recordings of the selected participants that were later transcribed verbatim. The total data covered approximately 392 minutes of recorded time from the participants' recorded sessions resulting in 1506 lines of transcribed information. For accuracy and organization, I transcribed the participant’s interview recordings verbatim using Microsoft Word software within the first 24 hours after the recording was completed. I then manually coded each similar repetitive word and highlighted phrases. As mentioned previously, to analyze the data, I used the seven stages of Colaizzi’s s thematic analysis as stated in Chapter 3 to analyze the data gathered (Colaizzi, 1978). Colaizzi’s seven thematic analysis steps are a) familiarizing, (b) identifying significant statements, (b) identifying central themes, (c) formulate meanings- open coding, (d) cluster themes- axial coding, (e) exhaustive description-integrate data, (f) produced fundamental structure, (g) verification of findings.

For each participant's interview recording, I repeatedly listened to them and read and reread the transcripts several times each so that I had a clear and concise understanding of what the participants wanted to convey (Colaizzi, 1978). According to Braun and Clarke, (2006) repeatedly reading, along with listening to the audio recordings will give rise to the data immersion. Colaizzi (1978) stated that it was crucial to have the researcher read the transcripts to find descriptive statements and then group the statements into themes that were categorized until there are no new emerging themes. I positioned myself in such a way that I was able to give undivided attention to the study participant's accounts and expressions connected to their perspectives on AD, the stigma attached to AD, and their response to seeking early medical help. During this open coding process, each of the interview questions introduced emergent themes.

In the second stage of the analysis, I was able to start the initial coding by use of the frequently used words and statements. In stage three, I probed for themes. I used the initial codes that were relevant to the research question and grouped them into themes. I then used axial and selective coding. Through axial and selective coding, I was able to code portions of the text related to the themes. I created tables in Microsoft Excel to format the categorized axial codes, open codes, keywords, and phrases. I removed any themes that were not relevant or supportive to answering the research question. By refining the themes, it formed a logical pattern that assisted in forming the data-relevant themes. I then reviewed and revised the data to ensure that no emerging themes were missed. In step five the emerging themes were named and described. In step six I then summarized the description into short statements that explain the findings that answer the research question. The last stage involved constructing a report which included choosing examples from the participant's transcript to illustrate elements of the themes. In step seven I shared the findings with the study participants for them to review and confirm that I had captured their perspective accurately. If a participant shared any form of sensitive or identifiable data such as their loved one's name, I removed the identifiable or sensitive information to continue to protect the identity of the participant and those closely connected to them or the study.

After the data analysis process, I was able to identify three prominent themes that informed my research question. The three themes were: (1) Caregiver Perceptions of the Disease and Caregiver Role, (2) Caregiver Perceptions of Reactions from Others, (3) Caregiver Perceptions of Stigma.

Evidence of Trustworthiness

For the researcher to evaluate the trustworthiness of their study, I needed to evaluate the details of the study including the ethical conduct of the researcher toward the study participants (Rallis et al., 2007). The findings of my study were based on what I understood to be truthful responses expressed by the study participants. I ensured that I pursued the inclusion criteria set in Chapter 3 to be able to evaluate four key components of data trustworthiness. The four components are credibility, dependability, confirmability, and transferability of the study.

Credibility

The first component of data trustworthiness was credibility. When study participants confirmed the interpretations of the research findings and it then further allowed for the readers to use the findings to make informed decisions that resulted in credibility (Noble & Smith, 2015; Tracy, 2010). I used purposeful sampling to recruit participants who had critical information to participate in the research. During my interview process, I recorded, in my reflexive journal, all of my thoughts, feelings, questions, and observations so I could acknowledge any possible researcher biases. I also used transcript review by providing the study participants with a copy of their transcribed interview for them to review if I had accurately understood their perspectives. All documents related to the study were maintained in an audit trail.

Transferability

According to Amankwaa (2016) and Tracy and Hinrichs (2017), when the researcher chronicled the phenomenon with meaningful details, the reader would then determine the scope to which the study findings were capable of being conceptualized in broader terms for other settings. To enhance transferability and for readers to intently connect with this study, I used thick descriptions to describe the findings of this study. I detailed how the participants were recruited to participate in this study and how the data was collected, coded, and analyzed. Additionally, I maintained an audit trail of all participant’s audio recordings, interview notes, and my reflexive journal that contained my perspectives, reactions, reflections, and experiences of the research process and the consolidation of the ideas about my data collection process.

Dependability

Results of the study are considered dependable when the study findings are consistent and repeatable (Amankwaa, 2016). The researcher’s goal is to verify that the study findings are consistent with the raw data I collected during the interviews. To enhance the dependability of the study findings, I maintained an audit trail that contained research material that pertained to this study. This material consisted of the informed consent form, interview protocol, audio recordings, transcribed interviews, notes, interview transcripts, and other materials relevant to the study. All materials for this study have been stored in a secured location where only I have access to them. To be able to acknowledge any concerns in the study, I relied on the feedback from my dissertation team as my dependability auditor.

Confirmability

Research confirmability refers to the degree to which the study findings reflect the accounts of the participants and can be confirmed by other researchers (Nicholls, 2017). I maintained the audit trail of documents and materials collected, coded, and analyzed by securing and safely storing them in a private location where only I had access to them for the set amount of time of 5 years before they are appropriately destroyed. I have also recorded all my thoughts, feelings, questions, surroundings, and observations of participants in my reflexive journal while I was collecting data. I have also integrated multiple sources of information such as the literature addressing the topic in Chapter 2, the conceptual framework, and the findings from this study.

Results

The purpose of this study was to examine how the stigma of AD affected the help-seeking behaviors of African American caregivers who cared for a loved one affected by AD. The study objective was to examine how the existing stigma of AD influences caregiver responsibility, prolonged/delayed diagnosis of AD, understanding the disease and health disparities to both the caregivers of care recipient may have been affected due to their perceptions about AD and the stigmas about AD. The primary method of examination into the perceptions of African American caregivers of AD loved ones was based on the research question. The patterns that arose as themes in the process from data collection to coding and then to themes provided credibility that informed the research question. The research question for this study was: What are African American caregivers' perceptions of how stigmas related to AD affect the caregiver's help-seeking behavior for older adults affected by the disease?

The table of axial, open codes, keywords, and phrases introduced the results for each of the interview questions. There is a brief description of the three major themes including sub-themes relevant to the interview questions related to examining the research question that accompanies each table. The findings were organized around the perceptions of the stigma of AD and its effect on the participants' help-seeking behaviors. Each theme evolved after considerations of the transcribed data. The themes that informed the research question are (1) Caregiver perceptions of the disease and caregiver role, (2) Caregiver perceptions from reactions of others, (3) Caregiver's perceptions of stigma.

The research gaps identified that there are minimal studies in the examination of the cultural perspectives, beliefs, experiences, and backgrounds of African Americans as it relates to the stigma of AD and how it delayed their help-seeking behaviors. The analysis of the data revealed the perception of African American caregivers" on how stigmas related to AD affect their help-seeking behavior for older adults affected by the disease.

The perceptions of the African American caregivers fell into the following three major themes as per the data analysis: Theme 1 – Caregiver Perceptions of the Disease and Caregiver Role, Theme 2-Caregivers Perceptions from Reactions of Others, Theme 3-Caregiver's Perceptions of Stigma.

Theme 1 - Caregiver Perceptions of the Disease and Caregiver Role

The first major theme "caregiver perceptions of the disease and caregiver role" further comprised two sub-themes as described here: (a) learning about the disease and (b) challenges when seeking assistance. As shown in Table 1, the perceptions of the caregivers included comments, feelings, and perceptions of their caregiver experience for a person with AD. Some of the caregiver perceptions included the length of time that passed before the diagnosis, learning about the disease, understanding the disease and knowledge of AD before and after the diagnosis and during their caregiving journey.

Subtheme 1: Learning about the Disease

This analysis described the views of the participants in terms of their learning about the disease. The views of the participants were described as symptoms (signs) of Alzheimer's in loved ones, duration (timeline to diagnosis), knowledge before having a loved one with Alzheimer's, and factors in the change of knowledge about AD. Participants got their knowledge and learning about symptoms of AD from their loved ones. Sub-theme one identified seven categories.

The seven categories are not knowing normal aging and AD changes, fear of negative views of others resulting in stigmatizing behaviors against them and their loved one; fear of others' views (judging), duration of time from seeing the changes in their loved ones, the delay in their loved one's diagnosis to when the AD diagnosis took place, revealed factors in the change of knowledge about AD, challenges in caregiver's roles and solutions/actions to overcome the caregiver's stress.

The first initial category of the first sub-theme, learning about the disease, was not knowing normal aging and AD changes as it described the perception of the African American caregivers in terms of being judged by others. One participant stated,

> I really just thought they were just a normal part of aging like forgetting where things are, forgetting name, mixing up recipes, losing keys and getting lost when she would drive her car to visit friends or go to the grocery store.

One participant shared their knowledge level about the disease as “Little bits of information and experiences”, whereas another stated “I noticed some signs that something was wrong perhaps about three years prior to my grandmother moving in with me and my husband but didn't know it was Alzheimer's disease”, “I didn't know anything”, “I had only known little bits of information and experiences from friends whose parents had been affected by the disease” and,

> I didn't know anything other than information from a few friends that had gone through the same thing with their family members, and they had had a rough time especially when they thought they would have support from family, friends, and their church family.

The second category under this sub-theme was fear of negative views of others resulting in stigmatizing behaviors against them and their loved one. For this category there was only one statement that was specific to this category where the participant stated "I just felt the need to keep the diagnosis a secret to protect us from the harsh realities. Unfortunately, I was right about some with the judgements".

In the third category was fear of others views (judging) where one participant stated "I also worried about what others may think about my mother and I when we go out together." This experience resulted in worry for the participants when others judged them. Other participants also stated, "I felt disconnected and isolated", "I found that people were very fearful of the behaviors attached to the disease" and "the stigma of the disease is very common."

The fourth category in this sub-theme was duration of time from seeing the changes in their loved ones, the delay in their loved one's diagnosis to when the AD diagnosis took place by stating "for months", "seven years", "three years", "two years", "five years", and "one year and "a year and a half".

For the fifth category the data identified revealed factors in the change of knowledge about AD. The following factors were identified by the data analysis, shown in Table 1, that the change of knowledge of caregivers about AD came from nonprofit organizations who were able to help with information about the caring for loved ones. Participants stated such comments as "attended educational workshops on Alzheimer's", "get my knowledge from the local clinic social worker and the internet", "knew about it through friends who had been caregivers for their own loved ones”, and “non-profit organizations are able to help me with information about the handling of loved one.”

This sixth category also addressed the challenges in caregiver’s roles, where participants mentioned the following challenges that played a major role in their perceptions such as understanding AD behavior, caregiver stress, siblings weren’t supportive, keeping the individual protected from harming himself, stigma of AD, non-cooperation of health professionals, lack of knowledge of health professionals, and constant isolation. While describing the challenges, in Table 1, the data also included types of caregiver stress where participants shared the various types of stress experienced as they learned about the disease, such is the case of one participant who mentioned that “some of my challenges as a caregiver is just making sure he doesn’t wander off, he doesn’t hurt himself at the gym, and sometimes I get angry about the situation”. One participant described that understanding a loved one’s behavior is a big challenge, further adding to the comment, “while taking on this caregiving role of caring for my mother who has Alzheimer’s disease was first fully understanding her behaviors and what triggered them and understanding when the stages of the disease changes”.

Subtheme 2: Challenges When Seeking Assistance

The second sub-theme was challenges when seeking assistance. This sub-theme revealed two categories which are: available informal assistance and available professional assistance. This category revealed the experiences and perceptions as explained by the caregivers in their quest for seeking assistance and care for a loved one. As shown in Table 1, the caregivers shared their perceptions on the types of assistance systems they had to choose from. The data analysis information shared the perceptions of caregivers about the challenges they had when seeking assistance.

In sub-theme one, category one the first support addressed was the challenges of seeking assistance through available informal assistance. The participants shared their views about the information and assistance available to them. Participants mentioned the following available informal assistance, social assistance from the church group, advice from the caregiver group, emotional assistance from siblings, family, and friends, and not having much assistance from family and family. While sharing their views about the available informal assistance, one participant described their view that their siblings try to support them emotionally and they also received social assistance from their church. Participant’s exact words when addressing seeking assistance were “I do try to stay connected with my church group because they try to include both my mother and I in group events and my mother enjoys it.” On the other hand, one participant gave the opposite view by saying that “to be honest it’s just been me and her alone you know the other family don’t really have time” whereas another stated “My siblings try to support me emotionally, however, they have neither contributed to the care time or financially for our mother’s care”.

As shown in Table 1, there were additional challenges in seeking assistance. The second support identified in category two was available professional assistance. Participants had mentioned and shared points of view about available professional assistance as follows, (a) A trained caregiver from a health care agency, (b) Not enough assistance or services available for older adults, (c) Clinics in the neighborhood, (d) Senior community centers, and (e) Adult Day Center. One of the participants revealed that it was a very challenging experience and there was a shortage of healthcare professionals trained in AD. Another of the participants declared that in their caregiving journey they had faced non-cooperation and lack of AD knowledge from health professionals which leads to nightmares for caregivers. The participant further added that "being able to get information from doctors and other health professionals is very messy", while another stated "because the stigma of Alzheimer's disease is a very real". While another of the participants expressed that they "faced discrimination because of the said illness" whereas, another participant mentioned that the "supports in my community are minimal however at the adult day center we have been using the services of the doctor, nurse and social worker", "We both found that the services of the clinic were more genuine and there were more African American professionals with experience in Alzheimer's disease", "I did notice that there are a lot of doctors who don't want to or cannot give a diagnosis of Alzheimer's", "When we get to the doctor or clinic you can see the fear in the staff's body language and they seemed a bit reluctant to work with us", and "my grandmother's doctors, care manager and social workers were not very helpful when it came to sharing the knowledge about the disease because they did not know". While sharing views on the available professional assistance, several caregivers mentioned clinics in the neighborhood, availability of senior community centers, availability of trained caregiver from a health care agency and adult day center. One participant did share opposite views by saying that "I feel that there are not enough supports or services available for older adults, minority older adults or caregivers of people caring for people with Alzheimer's dementia" while another participant stated, “we have changed doctors several times because we were unable to find one that had been trained in Alzheimer’s disease”.

Theme 2 - Caregiver Perceptions of Reactions from Others

The second major theme caregiver perceptions of reactions from others further comprised two sub-themes as described here: (a) social stigma from the public and stigma of AD in healthcare professionals. As shown the perceptions of the caregivers about others included comments, feelings, and their perceptions of their caregiver experience while caring for a person with AD. Some of the caregiver perceptions about others included the comments stated in the data collection process. It was important to hear information concerning the public’s knowledge, concerns, beliefs, and sources of information about AD and Alzheimer’s caregiving. In the data analysis it revealed that most adults were aware of AD but lacked specific knowledge about the disease.

Subtheme 1: Social Stigma from the Public

The under the major theme caregiver perceptions of reactions from others revealed information about the feelings and perceptions of the general public and healthcare professionals as perceived by caregivers of a person with AD. The stigmatization of AD and the comments of others including healthcare professionals were important issues facing these caregivers and delaying their help-seeking behaviors.

The first sub-theme was social stigma from the public. This sub-theme revealed two categories. The initial statements from participants were identified in the data analysis under this sub-theme. Category one was fear of negative reactions and attitudes attached to AD diagnosis. It focused on the public” reactions and attitudes attached to AD diagnosis and AD caregiving. In this category, participants shared comments that were either directed to them directly or about what they heard of the disease and the stigma of the disease such as “My fear was that people would humiliate and hurt him because the disease had progressed”, “I also heard how mean people can be to people with this disease and how fearful people were of the behaviors of Alzheimer’s”. Another participant shared that they, and “keep your mother inside the house so people don’t see her behavior”, “I heard things about people with Alzheimer’s disease like they were crazy and filthy, dangerous and mean and useless”, and “I just felt the need to keep the diagnosis a secret to protect us from the harsh realities. Unfortunately, I was right about some with the judgements”, “others have commented that I should feel ashamed that I might have contributed to my grandmother’s deterioration. This was very painful”.

The second category in this sub-theme one, focused was “misunderstandings and misconceptions about AD and AD caregiver role”. Misconceptions about the disease can often lead to stigma. The statements that represented this category were “Others have commented that I should feel ashamed that I might have contributed to my grandmother’s deterioration this was very painful”, “Ah, I have also heard how people in my own African American community feel negatively about people with any mental health issues and they don’t want to be associated with you or your loved one”, “Many explained they had a lack of understanding about the disease and questioned why a person would to be a caregiver of a person with Alzheimer’s instead of placing them in a facility. some made comments about how the perceived that most people with Alzheimer’s disease are dirty, smell bad, and that I would become as crazy as my mother”, “Because my husband was perspiring and smelled of sweat that he smelled bad and doesn’t take a shower, then I also was nasty because I take care of him and don’t bathe him enough”, “People have commented that I am a bad wife because they view me as being impatient and harsh with my husband and they feel that because of this I am the cause of him deteriorating”, and “Some people have made ignorant comments that they are afraid my grandmother’s disease is contagious. People have also told me that I don’t take good care of my grandmother.”

Subtheme 2: Stigma of AD in Healthcare Professionals

In this second sub-theme stigma of AD in healthcare professionals, caregivers had certain expectations from the healthcare professionals such as doctors and nurses were to have less prejudice or discrimination and misconceptions about AD dementia. The data analysis revealed that there is AD stigma among doctors who are perhaps non-neurologists and some nursing staff. Initial statements from participants were identified in the data analysis under this sub-theme.

The second sub-theme, category one was perceptions about AD discrimination amongst healthcare professionals where participants shared comments that were either directed to them directly or experiences that they had with doctors or nurses such as “both the doctors and the nurses we have approached seem like they would rather avoid the conversation of the disease as though it was a death sentence and so we went to a neurologist instead”. Whereas another participant stated, “I think they were reluctant to diagnose my husband perhaps it was their own fear of not being sure”. Another participant and “I had heard people such as healthcare professionals, family and friends will discriminate against us”.

The second category in second sub-theme focused on healthcare professional's responses impacting help-seeking and standard to care. Participants disclosed their perspectives with statements such as "I felt as though his doctor was resisting and not wanting to commit the time to do the cognitive test. So, I was not happy, so I had to force the issue to get it done. Hmm it's now been five years since my husband's diagnosis, and we have changed doctors several times because we were unable to find one that had been trained in Alzheimer's disease", "The physicians in our community do not seem to know much about dementia or Alzheimer's disease. They also do not know much about African Americans. Though trying to get a knowledgeable doctor on the matter it caused my grandmother to get an even further delayed diagnosis. The doctor said, "what were you expecting she's 70 years old her brain will go and she will be like a baby again". I was mortified to say the least had to insist on the doctor to tell me her diagnosis", and "I did notice that there are a lot of doctors who don't want or cannot give a diagnosis of Alzheimer's. I understand from them that they, they don't know what the next steps are after the diagnosis so they would prefer not to or that they don't want to give a death sentence."

Theme 3 - Caregiver Perceptions of Stigma

The last and third major theme reflected stigma when participants shared their views about their perception of stigmas related specifically to culture and offered suggestions for and from African Americans. This third major theme is comprised of two sub-themes (a) stigma as a barrier and (b) stigmas related to culture. Sub-theme "stigma as a barrier revealed two categories: "barriers contributing to delay of AD diagnosis" and “lack of culturally focused brain health and AD knowledge in the community”. In Theme 3 the perceptions of the caregivers included comments, feelings, and their perceptions about AD in the community. There was both the focus on lack of knowledge about AD including culturally influenced beliefs as major barriers to delaying having a loved one’s memory assessed.

Subtheme 1: Stigma as a barrier

The third theme discovered in the data analysis revealed the theme of Caregivers Perceptions of Stigma. The data analysis suggested that the caregiver’s perception of stigma was that it negatively affected their response to seeking medical help for their loved ones. Their fear of discrimination against them or their fear of enacted stigma against them may have contributed to the development of negative feelings about themselves and their loved ones with AD.

In sub-theme one, category one focused on barriers contributing to delay of AD diagnoses. Delayed diagnosis due to stigma can lead to negative health outcomes. Other barriers resulting in delayed diagnosis may be patient and caregiver attitudes, communications, educational deficits, and health system resources. The participants stated their feelings of shame and embarrassment such as “They also informed me that I would experience shame and embarrassment as the disease progresses”. The perception of a healthcare community that is rejecting, can make it more difficult for the caregivers and families of people with AD to take part in effective interventions to create more supportive and understanding communities. Such statements as “I also heard such things as their doctors didn’t want to give them a true diagnosis and not being open with them about it" and "my grandmother's doctors, care manager and social workers were not very helpful when it came to sharing the knowledge about the disease" and "I had heard people such as healthcare professionals, family and friends will discriminate against us, I will lose my friendships and I may get isolated" and "Both the doctors and the nurses we have approached seem like they would rather avoid the conversation of the disease as though it was a death sentence and so we went to a neurologist instead" suggested this. This perceived stigma may negatively influence the mental and physical well-being and quality of life of both the caregiver and their care recipient was revealed in statement such as "Just being able to get information from doctors and other health professionals is very messy" and,

> You know just dealing with caregiver stress can create many problems but the worst of all of these challenges would be the beliefs of those who surrounded us whether it be the doctors the nurses the social workers friends or families just society in general makes it so much harder to care for a person with Alzheimer's disease and myself.

Alzheimer's disease stigmatized individuals are often unwilling to seek services and social interactions due to the widely held misconceptions about the causes and nature of AD situations. Participants made such statements as "I have on a few occasions canceled his participation at doctors' appointments and social invitations just to not have to experience the reaction of others" and "I avoided seeking help from anyone including the doctors and other health care professionals because I didn't want my mother nor I to be called crazy".

In sub-theme one, category two the main focus was on lack of culturally focused brain health and AD knowledge in the community. This can lead to client dissatisfaction. This lack of knowledge in the African American caregiver community can often lead to a lack of effective communication with services and supports and may lead to lower quality of care and influence the delay of early diagnosis. Alzheimer's disease knowledge amongst caregivers can reduce health disparities and positively influence the quality of life and care. The participants shared information on the knowledge they had on brain health and AD before their caregiving role. Participants stated,

> Reality is that I only knew of the name of the disease but not much else… There was no information that was readily available….. I searched for other outlets that may share information with me about the disease and how it affected an African American,

"I had only known little bits of information and experiences from friends whose parents had been affected by the disease", "I did not know very much about Alzheimer's disease or dementia. I had to learn on the job of being a caregiver", "I did not know the details that one should know to identify the disease of about the stages of the disease", "I had never heard of Alzheimer's disease until the diagnosis", "Information on the disease is not readily available plus there is the stigma of the disease so most people including us did not really want to be associated with it",

> I don't think I knew that much about it except that it's something that is common in older adults and and that it affects your perception of the world but I didn't even know that Alzheimer's was so progressive it may seem ignorant but I really

> just didn’t know a lot about it so I’ve had to just cope and deal and take care of her,

and “My grandmother’s doctors, care manager and social workers were not very helpful when it came to sharing the knowledge about the disease because they did not know.”

Subtheme 2: Stigmas Related to Culture

The data analysis identified the following initial codes related to the perceptions of the stigma of AD amongst African Americans as (a) Shared negative beliefs about the disease, (b) Experience shame and embarrassment as the disease progresses (c) Isolation and social rejection, (d) Caucasian person’s disease, (e) People with Alzheimer’s were mentally incapable of thinking, (f) People in the healthcare system need to be culturally competent, (f) Don’t heavily rely on family and friends to support, (g) People sympathize but don’t support.

The data analysis revealed information that most participants shared negative beliefs about the disease. In category one of sub-theme two, the focus was on the socio-cultural beliefs of AD. Social, cultural, and family influences can shape the beliefs and attitudes and impact a person or group’s health and help-seeking behaviors. Participants further added that “warned me of the loneliness, isolation, and social rejection we would both experience of the stigma of the disease in our community”, “people with Alzheimer’s were mentally incapable of thinking”, “it’s a “white person’s disease”, “black people do not put our parents in nursing homes”, “some even stated that this disease was more of a white American illness”. Participants gave the recommendations by adding the statement “those people in the health care system also need to learn about the disease and be culturally competent for right now they are not”.

In sub-theme two, category two which was focused on religious beliefs giving meaning to life’s occurrences while influencing stigma. In this category, religion tended to have traditions and moral values intended to explain how a person’s earthly behavior may be punished on earth. Religion in the African American culture is very important in their lives and is a source of resiliency. Religion is deeply ingrained in the culture and their community life. Religion is considered as part of the culture where one expresses spirituality both personal and inward. Participants shared comments directed toward them regarding their loved ones affected by AD as “I’ve also heard that we need to pray more and God is punishing us”,

> Some of the older ones brought to my attention that God was dishing out what to my mother what she deserved, while some said that she probably had some enemies who practiced witchcraft on her or that someone had the evil eye in the church,

“I felt that God had betrayed us., “They did surprise me when they said it was God’s punishment and needed to repent to be forgiven”, “I hear people say that God was going to bless me for taking on this role as caregiver, I was too young to give up my life and that I should get some religion in my life” and “They emphasized things like did your mother upset someone and they worked voodoo on her, or god was punishing her for something she did.”

Summary

In this chapter, I presented the findings of the eleven interviews focusing on how the stigma of AD affected the help-seeking behaviors of the African American caregivers caring for a loved one diagnosed with AD. For the participants of this study, I offered a safe and effective way to participate in the study while providing them privacy. I encouraged the participants to be open and as honest as possible in their responses. Several participants had similar results and shared their efforts of being a caregiver of a person affected by AD. In this chapter, the study analysis revealed the perceptions of African American caregivers about AD and how the stigma of AD affected their help-seeking behavior as they cared for their older adult loved ones resulted negatively in their caregiving help-seeking behaviors. In this chapter, I also analyzed the data that presented three significant three themes and six sub-themes identified in this data analysis. The three themes were caregiver perceptions of the disease and caregiver role, caregiver perceptions of reactions from others, and caregiver perception of stigma. The sub-themes were about learning about the disease, challenges when seeking assistance, social stigma from the public, the stigma of AD in healthcare professionals, stigma as a barrier, and stigma related to culture. It also revealed how they had encountered and endured challenging and often difficult Alzheimer's caregiving perceptions and experiences of others throughout their caregiving journeys. Together, these beliefs and experiences ultimately shaped their perceptions and their caregiving orientation as it related to brain health, AD, health and wellness knowledge, outlook, and outcomes. The findings revealed that the perceptions of African American caregivers who have experienced the behaviors and actions connected to the stigma of AD were deeply affected by the behaviors of others that could negatively influence how they care for their loved ones affected by AD.

Regardless of cultural influences, perceptions, and challenges in AD caregiving, several of the participants in this study had a positive caregiving journey though they had some negative experiences from others related to the stigma of AD. They responded to the negative impact of the stigma of AD in caregiving by providing the care that they could. Each of the themes generated in this study detailed the understanding of how the perception of AD amongst the diverse cultures of African American caregivers can negatively impact their help-seeking behaviors, at times to the detriment of both the caregiver and their loved one. Integral to the fabric of the interviews, was a persistent and abiding commitment of love and care provided to their loved ones. The lack of knowledge regarding AD and the perception of the challenges brought about by the stigma of AD can often make an already difficult experience even more challenging. The data also revealed not only the negative perceptions about AD and the prevalent beliefs and stigma associated with AD but also the barriers to getting help, the challenges to the support systems, the stigma and discrimination associated with AD, the lack of knowledge about AD, and normal aging, the lack of knowledge in cultural competency and compassion of the healthcare providers and the breakdown or lack of informal and professional supports. Lastly, the data highlighted how misunderstood African Americans felt in accepting the role of caregiver of a loved one with AD, often by close family and friend because of their misunderstanding and fear of the disease.

In Chapter 5, I presented my interpretation and implications of the findings. I also presented and described how professionals and practitioners may apply the findings to help this studied group of African American caregivers and others with their experiences. I also described the limitations of this study and recommendations for further study of this study on the stigma of AD and how it affects the help-seeking behavior of African Americans.

Chapter 5: Discussion, Recommendations and Conclusion

Introduction

The purpose of this generic qualitative study was to examine how the stigma of Alzheimer's disease affected the help-seeking behaviors of African American caregivers of loved ones diagnosed with AD. Although there has been prior research on the stigma of AD, and prior research on African American caregivers, there was limited to no research examining how the influence of the stigma of AD affected the African American caregivers' help-seeking behavior when caregiving for a loved one diagnosed with AD.

I collected information on how the stigma of AD may have delayed African American caregivers from seeking medical help for their loved ones. I also examined how the AD diagnosis for a loved one may have shaped the participant's perceptions on AD, and negatively influenced the opportunities for early diagnosis, care, and support, and how culture influenced the stigmatizing beliefs about AD. I recruited each of the participants of this study using the purposeful sampling strategy in conjunction with snowballing sampling.

In this research study, I employed the generic qualitative approach incorporating Colaizzi's (1978) seven stages of thematic data analysis. This study was based on one research question. I used semistructured interviews to carefully examine and understand this particular social phenomenon. To collect the perceptions of the study participants, I used semistructured interview questions to extract deep and rich detailed information on how they experienced the AD caregiving process and how the stigma of AD influenced their help-seeking behaviors.

The objective of this study was to introduce a new perspective and broaden the existing knowledge of how the stigma of AD can delay the help-seeking behaviors of African American caregivers of the loved ones affected by AD. I used one research question to guide this study: What are African American caregivers' perceptions of how stigmas related to AD affect the caregivers' help-seeking behavior for older adults affected by the disease?

In Chapter 4, I discussed the collection of data, analysis of data, and research findings were described. Upon completing the data analysis, I identified three themes (a) Caregiver perceptions of the disease and caregiver role, (b) Caregivers' perceptions of reactions from others, (3) Caregivers' perceptions of stigma. Findings from this study revealed that participants who had loved ones who had been diagnosed with AD experienced both intrapersonal and interpersonal challenges as a result of the diagnosis of AD and the stigma of AD. The data further showed that each participant had a difficult time with the diagnosis of AD and maintaining their social connections as they provided care for their loved ones. Results in this study also revealed that despite their challenging experiences with the diagnosis of AD, the stigma associated with AD, and the care of their loved ones, they were able to maintain interpersonal experiences and shared positive caring relationships.

Several major themes developed from the data gathered and analyzed. I used the data I collected and analyzed to identify three major themes. These dominant themes that emerged from this study supported the premises of the stigma theory and the socio-cultural health belief framework, both of which postulate that stigma of AD has persisting negative influences and effects on both those African Americans affected by AD and their caregivers.

In this chapter, I provide my interpretations of the findings, discuss the limitations of the study and the benefits of participation. I offer my reflections and recommendations for practice regarding how it would expand the field of gerontology and human services, further research, implications for positive social change, and the conclusion.

Interpretation of the Findings

The outcomes of the literature review in Chapter 2 revealed that the behaviors related to any of these stigmas of AD whether public stigma, self-stigma, courtesy stigma, or structural stigma, can complicate and negatively influence the perceptions of African American caregivers and affect their help-seeking behaviors when in the caregiving role. Throughout these interviews, culture, lack of AD knowledge, and fear of the stigma of AD were constant concerns. Cultural influences and beliefs were significant factors in caregiving. The culture was the center point of each participant’s actions including during their emotional times during the interview. It was important to focus on the understanding and awareness of cultural influences and how the stigma of AD can affect their caregiver roles.

Moreover, African Americans with AD symptoms have been found to be diagnosed at a much later stage than other races and ethnic groups and have been found to be at increased risk of delayed care and support. In this chapter, I describe the key findings of the major themes for this study and discuss how these findings relate and expand on previous research.

Caregiver Perceptions of the Disease and Caregiver Role

During the interview sessions, I asked each participant how they learned out about their loved one's AD diagnosis. The data revealed that participants learned about their loved one's diagnosis either through formal diagnosis or through informal channels/measures. Several participants shared that their loved ones permitted the healthcare professional to share their AD diagnosis with them or chose to disclose their diagnosis directly with the participants, or the participants mistakenly discovered the medical documents detailing their loved one's diagnosis of AD. Many of the participants who discovered their loved one's AD diagnosis through formal channels had seen the changes in behavior over a period of time, however, they accepted the changes as normal aging changes.

Findings from this study supported previous research findings, which showed that AD can have various contributing factors and showed that AD accompanies other disorders such as mood and personality disorders. Previous studies have explained that individuals with AD oftentimes presented with other disorders and that the AD diagnosis was expected. The findings also revealed that neglect can be viewed as discriminatory behavior when participants disclosed about others assuming that their loved ones were being neglected of adequate care especially in relation to their appearance, medications, behavior, or diet. It also revealed that there were significant emotional reactions associated with the stigma of AD. There were mainly negative emotional reactions from caregivers. The negative emotional reactions focused on lack of understanding of the disease, discrimination, and the other challenges caused by the stigma of AD. The lack of understanding often stemmed from others not understanding the various challenges that come with caring for a person with AD and the misconceptions about the disease leading to stigmatizing behaviors. The feelings related to the lack of understanding and the misconceptions of AD were often strong and pervasive. Pity was also revealed by the caregivers when they reported the feelings of others. Others pitied them because of their caregiving challenges.

In each interview, I asked the participant to share their views on when they discovered their loved one's diagnosis of AD. Participants stated how their loved one's diagnosis confirmed that there was an extensive concern for memory loss and other cognitive declines they had witnessed prior to the diagnosis. One of the main points in the analysis was that the AD diagnosis was accurate and affirmed the participants' thoughts that there was a problem with cognitive decline. The information gathered revealed to the participants the accuracy of the AD diagnosis that allowed them to explain their loved one's inconsistent and concerning behaviors. The information also revealed the participant's fear of the stigma of AD toward them.

Findings from this study revealed that participants felt the AD diagnosis affirmed and validated the AD-related behaviors that others characterized as uncontrollable, scary, and unstable. Participants said their loved ones with AD often showed symptoms of memory loss, depression, anxiety, change in orientation, and other changes in behavior. Furthermore, data findings showed that African Americans initially presented later into the disease prior to getting the diagnosis. Evidence suggested that AD symptoms include various types of behaviors. Upon reviewing participants responses, many described their loved one’s behavior according to the signs and symptoms of AD. This description has been identified consistently in earlier literature.

Participants expressed negative experiences that led to their negative perceptions of the disease and their caregiving experiences. Participants revealed that they did not know the symptoms of AD although some of the symptoms were happening right before them. Many were unaware that the changes varied from person to person and believed that the changes were normal in the aging process. Participants described their acknowledgment of the changes and how they extended delays of their loved ones' diagnosis, care, and support. The concept of caregiver burden focuses not just on the responsibility of being a caregiver but also on the emotional, mental, physical, and financial influences. Data revealed that timeframes spanned from “for months to 7 years.” Some of the challenges that were experienced ranged from finding “informal and formal assistance” in or near their own communities, being able to secure AD knowledgeable professional care, AD educational information, and resources, challenges with family and friends assisting them with the care of the loved ones, issues that also created significant challenges were the comments and beliefs of others, the stigma of the disease and being able to provide a better quality of life for themselves and their AD affected loved ones. Many did not understand or know of the options that were available and they did not feel that there was consistent AD information awareness specific to their needs or culture to manage their new reality. Data revealed that learning and adjusting on their own about their challenges of activities of daily living challenges with behaviors and understanding that they needed to create a plan and find opportunities for help were all challenges that

10 of the 11 participants experienced. The solutions they created were personal. For a couple of the participants, they managed their new reality by hiding from society, for others they struggled to remain close to their nonaccepting communities.

In the second subtheme, challenges when seeking assistance, the majority of participants were critical of the services and supports available to older African Americans and their caregivers. Only one participant was pleased with what their state and immediate community had to offer. Overall, the participants were displeased about the level and quality of support services, healthcare professionals, and care options available to them. The participants shared similar efforts about their care and support challenges in the communities and also questioned the quality of care provided to their loved ones. The data also revealed that amongst African American caregivers there was still a longstanding distrust of the American healthcare system and that discrimination in healthcare and stigma of mental illness was very much prevalent. According to Keefe (2010), distrust often disclosed in the interviews can reveal that the participants are very much aware of the stigma of AD and the health disparities in the African American community. According to Keefe, there are healthcare professionals with prejudices that may contribute to the delays in the care and support and could create bias and discrimination that is rooted in the minority communities. African Americans still felt a sense of suspicion and lack of trust toward healthcare professionals and care institutions (Sue & Sue, 2016).

This study also revealed that African American caregivers encountered significantly more barriers in healthcare assistance including their own cultural influences. Though each participant understood the need for social support systems as a critical and necessary factor for older adult African Americans especially with those with AD, they associated all these support systems with negative associations attached to them. It was also evident that healthcare professionals were unable to provide care or support due to bias, lack of cultural competency, lack of AD knowledge, or stereotyping of the patient and illness.

Caregiver Perceptions of Others

In these caregiver perceptions of reactions from others, participants offered opinions about their perceptions of others’ feelings about AD and the social stigma surrounding AD. The subthemes were social stigma from the public and stigmas of AD in healthcare professionals. Participants shared negative views about AD. They shared that they experienced people telling them not to expose their loved ones with AD to other people. While others shared that as the disease progressed people would attempt to convince them to place their loved one in a facility. They also mentioned that others with a lack of AD knowledge warned them that people with AD were crazy, filthy, dangerous, mean, and useless. Other participants are focused on the healthcare system and how cultural competency would be a requirement and another ascertained to seek support. The data revealed that the stigma of AD also runs high amongst healthcare professionals at various levels.

Caregiver’s Perceptions of Stigma

This theme revealed two subthemes: Stigma of AD as a barrier and stigma related to culture. Overall research has suggested that due to the changes in America’s demographic and ethnic make-up, compared to Caucasians, African Americans are experiencing a higher prevalence in AD. These studies have revealed that the high prevalence rates are due to factors that included late medical diagnosis, misdiagnosis, lack of AD education, cultural influences and differences in beliefs, health care disparities, and the stigmas of AD.

In theme three, participants shared their opinions and recommendations for those who shared a similar culture. It was important to consider how the contributors to the stigma surrounding AD prevent many African Americans from getting help. Stigma may even make it more difficult for African Americans to get professional help. The stigma of AD was shown to be a barrier to seeking medical help. In this community, the responses revealed that there is a prevalent stigma that implied that AD including other mental health problems is seen as a sign of weakness. This attitude toward AD also seems to have reinforced the belief that AD-affected loved ones should be hidden from others. Cultural beliefs about AD are often formed through experience, beliefs, formal education, religion, and cultural traditions. Communications in the format shared of stories between family and friends also play an important role that contributes to the stigma of AD.

The belief is often that any mental health-related issues mean that the person is unable to function in society. Behaviors of AD-affected individuals often tended to perpetuate the belief that they are also violent. These types of beliefs often reinforced that AD is shameful. According to the participants, ideas about AD that may reinforce stigma include their beliefs, about consequences such as do they feel that untreated AD has consequences, treatment such as how much does the person think the disease can be managed or can’t be helped, timeline refers to beliefs about the illness being chronic, acute or cyclic, identities such as if the person affected or caregiver belief that the symptoms of AD are a normal part of aging, and cause such as whether the symptoms are from character issues, personal weakness or spiritual deficiency. In this study, there were several cultural factors, societal pressures, and stereotypes that may influence stigmatizing beliefs about AD in the African American community. Participants made statements that reflected that AD was viewed as either or both a personal and moral defect.

Theoretical Perceptions

In discussing the three themes that emerged from this study, it was important to understand that the themes supported the study regarding the theories that were chosen to support the research. The two theories that were selected for this study were the stigma theory and the socio-cultural health belief model. The importance of discussing the theoretical and conceptual frameworks was to show that they were used well together. They each provided the researcher the support to explain the relevance and need for this study in the field. The theoretical framework is the frame I used to interpret the data and confirm the gaps in knowledge and provide the justification needed to conduct my study. Though stigma is a complex concept, it occurred at several levels such as individual, societal, interpersonal, and institutional. Goffman (1963) defined stigma as a circumstance when an individual is disqualified from society. The concept of stigma fully excluded the individual from full social inclusion. Culturally noteworthy conceptualizations of stigma are important for further research. In applying the stigma theory to AD, it was important to consider the various stereotypes that applied to this study such as public stigma, courtesy stigma, self-stigma, structural stigma, and the implications to African American family caregivers. Due to significant brain dysfunction and the memory and functional loss associated with AD, it is further destroyed by the common social constructs associated with AD. The social constructs of African American AD affected individuals, and their caregivers increased the dehumanization of those diagnosed. The perception was that AD diagnosed individuals and their caregivers had not forgone their quality of life. In a broader aspect, perceptions of AD were attached to the "incompetence", "being burdensome" to one's family and the healthcare system, "inability to contribute to society" and on the path to "eventual death" (Gaugler et al., 2020). Previous studies have agreed that there are significant gaps in the knowledge of AD in the minority ethnic populations in the United States. It is understood that the public understands more of the general information of AD but lacked knowledge about the specifics of AD. In the African American communities, the perception was that there are even bigger gaps in knowledge about AD both in general and specific information. Due to the misunderstandings of AD, public stigma may have significantly influenced the daily lives and outcomes of both the persons affected by AD and their African American caregivers. Public stigma is shown to have irreversible consequences for those identified with AD. Also, in public stigma, we needed to understand that there is often confusion with mental illness and AD. Often there is a greater stigma when mental illness is accredited to a person's behavior. However, due to there being an overlap in the symptoms of mental illness as in schizophrenia such as delusions, unpredictability, and violence, the person who had been diagnosed with AD experienced an increase in AD stigma due to the perceptions (Cahill et al., 2015). In one systematic review, the researchers found that the public's knowledge of AD found that AD was often believed to be a normal part of aging and there was a lack of knowledge about AD. Both the terminology and misunderstandings of the symptoms related to AD may have prevented diagnosis and increased stigma of AD.

Structural stigma also referred to as institutional stigma contributed to the unwillingness of both the individual receiving an early diagnosis and the African American caregiver from ensuring early diagnosis, care, and support through community services because of the fear of the consequences of AD diagnosis and the stigma of AD attached to AD. Their concerns also included the negative outcomes on their medical insurance and the possible discrimination from the healthcare professionals and their employers. They were also hesitant that an AD diagnosis would remove them from decision-making in medical circumstances for themselves. Structural stigma is often attached to an individual's financial insecurity.

Courtesy stigma also referred to as family stigma takes place when discrimination, prejudice, and stereotypes are attributed to an individual who has been linked to a labeled group such as in the case of the African American family caregivers of loved ones diagnosed with AD. Family stigma initially arose when negative attitudes, behaviors, emotions, and perceptions had been directed toward the family caregiver of the AD diagnosed individual as it has been activated by the public (Park and Park, 2014).

Self- stigma also known as self-stigmatization is described as when collectively shared stereotypes are represented an individual's identity. It is self-devaluation that is predicted by a stigmatizing attribute such as AD (Eriksson, 2019). This stigma focused on the repercussions on the individual due to internalizing negative stereotypes and applying them to oneself. This behavior often led to worse psychosocial outcomes for the African American caregiver.

Stigmatic perceptions of self and others regarding a person's caregiving role of a loved one with AD are prevalent in the African American caregiver community. Being perceived by others, whether family, friends, professionals, or others as crazy, dirty, useless or other derogatory descriptions has been one mechanism causing social stigmas. Goffman (1963) posited that labeling of another such as the labeling of the caregiver as a "neglectful caregiver" is also a stereotype attached to the stigma.

According to the study participants, these perceptions of emotional, carelessness, labeling, and irresponsible caregivers, though unrelated to their effort, did not minimize their love and time invested in this role of caring for their loved ones. They believed that those perceptions were deeply rooted in the lack of AD knowledge by others caring for a loved one with AD. Goffman (1963) argued that those who have been labeled in a manner inconsistent in their view of themselves may suffer serious consequences. They may even attempt to adopt different strategies to reduce the conflicting information.

The socio-cultural health belief model (Sayegh & Knight, 2013) when applied to this study, the data analysis revealed that there was consistent evidence that African American older adults with AD and their caregivers tended to present later for diagnosis and had greater diagnostic delays and higher levels of behavioral and psychological symptoms, and cognitive impairment during their initial medical assessment or testing. In this study, African American caregivers and loved ones with AD experienced several systematic barriers associated with culture that affected their timely diagnosis that also contributed to their AD care-seeking. In this study, I identified three themes that also contributed to the barriers that included lower levels of AD acculturation and knowledge, that there were culturally associated beliefs about AD such as both the person affected by AD and their caregiver's perception of memory loss is a normal part of aging, healthcare and health system barriers and stigma associated with AD. This SHBM framework provided an empirically-based framework for example the cultural difference in care-seeking among the African American diverse group. This framework revealed how cultural influences, health behaviors, and health-related quality of life have been influential in the African American community and how it has negatively influenced their care-seeking behaviors.

Given the rise to the detection and perception of AD in the often-marginalized minority populations in the United States, it is critical that I examined how AD intersects and affects the African American caregivers. The further influence of race, culture, and ethnicity and its likelihood on the effects of the stigma of AD is important for research. Both racial and ethnic minority groups in the United States are greatly underrepresented in early AD testing and research. According to the data analysis of this study, it showed that the aim of early AD detection among African Americans is important, especially if there is a future with the realization of prevention, a cure, or disease-modifying treatment that will reduce the number of AD cases in the African American community. It is imperative to understand the burden of AD-diagnosed designation on the African American population and to include its potentially stigmatizing consequences. The personal outcomes of AD diagnosed individuals and their caregivers revealed that the stigma surrounding AD is likely to dissuade African Americans and African American caregivers from getting diagnosed and learning about AD.

Burden of AD Diagnosis

In the interviews, I asked the participants about their challenges in AD caregiving. Three major themes emerged from the data analysis, of which of the participants shared their experience in becoming caregivers of a loved one with AD, the AD perceptions of others, and the perceptions of the stigma of AD as they related specifically to the African American culture. The findings illustrated that it was important to help African American caregivers cope with the issues of AD and to provide positive adjustments through securing knowledge of AD and employing specific intervention strategies to reduce the stigma of AD in the African American communities and in both informal and formal assistance.

Whether early or late diagnosis, diagnosis of AD was seen as the time which an individual would become labeled or stigmatized with the diagnosis of AD. It is important to understand that the negative stereotypes associated with AD affected not only the African American individuals diagnosed by AD but also the African American caregiver. These stereotypes can be taken as personally relevant when there is an official diagnosis of AD or being at risk for the disease. Most often at this time of being labeled or diagnosed, it is the start to predicting the stigma of AD from others. Other stereotypes of AD that were commonly included perceptions of being a burden to one's family and the healthcare system, being incompetent with the inability to contribute to society, and being on a faster path to death. Both the diagnosed loved one and the caregiver experienced negative caregiving behaviors such as keeping the diagnosis a secret, limiting social interactions, constant isolation, and not seeking medical help for fear of being judged or discriminated against.

Emotional burdens brought about the emotional costs carried by African American caregivers. This emotional burden often started long before the loved one actually received a formal diagnosis of AD. These caregivers had to balance their loved one's needs, their own care, the demands of their jobs and emotional stress associated with the AD illness of their loved one, and exhaustion. The intangible costs on people affected by AD and their families and caregivers are usually not covered in the economic analysis of the effects of AD.

Another hidden consequence of AD is the financial costs that often extend way beyond the affected person and the professional healthcare system. In addition to this are also the indirect costs such as the billions of hours estimated for informal care often provided by caregivers of people with AD. Participants in this study reflected that though they would have liked to use the private services and supports including adult day centers and transportation they could not because it added a significant cost, and many were unable to employ these opportunities for their loved ones. In the end, these poor coping mechanisms may have led to what we refer to as harmful psychological, social, and financial consequences (Link et al., 1989).

The negative outcome of AD also presented structural or institutional discrimination. This institutional discrimination can lead already labeled individuals or groups to experience major disadvantages such as the questions about the confidentiality of the individual’s early AD diagnosis being documented in the individual’s health record and issues with workplace care accommodations for the caregiver. This structural discrimination may possibly cause fear in the person diagnosed with AD and their caregiver, thereby negatively influencing their engagement in clinical trials or other future opportunities to experience structural discrimination such as insurance coverage and being in the workplace. By applying the stigma theory to AD, it was important to first acknowledge that AD is an age-related disease. In the Western world, old age is not associated with being a gift. Old age is, however, associated with negative perceptions, often referring to aging to not being able to function independently and not being able to care for themselves much like the perceptions of AD. In the United States, there has always been the fear of losing one’s independence, individuality, personal sovereignty, and productivity as these are central to good and capable living in the United States. AD and the stigma of AD have become symbolic in the fear of losing these characteristics that are most prized in American society. The concept of normal aging and non-normal aging as it relates to AD comes into play, with those individuals who have been diagnosed with AD who fall in America’s society as not normal.

Outcomes of the Stigma of AD

In the gathered data of this study, the stigma of AD has shown to be a complex concept. The stigma of AD has presented itself at several levels in this study. The levels the stigma of AD presented itself in this study at the individual, family, social, interpersonal, and institutional levels. This study has also encompassed relevant stigmas such as public stigma, self-stigma, courtesy stigma, and institutional stigma. Goffman (1963) defined stigma as "a situation whereby an individual is excluded from full social acceptance" due to their differences. According to Goffman, this same individual would then be reduced in the public's mind from a whole and normal person to one who had been recognized as an impaired or diseased one and those associated with them such as family caregivers will experience the same by association. The stigma of AD is often surrounded by the fear of the unknown about the disease and the negative responses according to the beliefs about the disease. The stigma of AD more often than not, prevents people from seeking an early diagnosis or any diagnosis at all, seeking medical treatment when symptoms present themselves, making plans for their long-term care, legal and financial future, benefitting from available treatments, participating in clinical trials, or giving themselves the best quality of life when they are able to do so. The stigma and lack of awareness also negatively affect research pertaining to AD (Gregg, 2015). Stigma and the lack of awareness often present significant obstacles to the well-being and quality of life for those affected and their families. Stigma, lack of awareness, and misconceptions associated with AD are widespread and profoundly affect the care provided to and isolation felt by people with AD and their families. People with AD are often isolated or hidden due to the stigma of AD or the negative reaction from neighbors, family, or friends to their behavioral and psychological symptoms. Stigma and lack of awareness and understanding of the disease adversely affect not only the life of the person affected by AD, but also their caregivers and the community (Kahn et al., 2016).

Stigma can lead to discrimination. Hermann et al. (2018) indicated that stigma and shame among African Americans in the United States regarding AD have resulted in barriers that prevent early diagnosis, care, support, information, education, and participation in clinical trials and research about the disease. Stites et al. (2018) argue that concerns about discrimination and overly harsh judgments about the severity of the symptoms are often the reasons for not seeking help. Additional harmful effects of stigma may be lack of understanding by family, friends, co-workers, healthcare, and social service practitioners, minimized opportunities, bullying, and harassment or social isolation. The stigma of AD may also be an obstacle to education and prevention.

We must also include how media and the medical field in the United States portray aging and AD and its negative outcomes. They both have the power to positively or negatively influence the perceptions and the public stigma surrounding AD and aging, both together and separately. Often people are portrayed in the later stages of the disease when they have lost most of their faculties, as opposed to in the early stages of the disease when they are still quite able to participate in society’s activities and still desire to participate in society’s norm of productivity.

Another issue is that AD can generate stigma is the problem within the community of the possible confusion between AD and mental illness and the causes and symptoms of AD. Alzheimer's disease shares many of the characteristics of mental illness such as depression and schizophrenia. Due to both illnesses having overlapping symptoms such as violence and unpredictability during the later stages of the illness, there is a great possibility that this confusion may increase the stigma of AD. Many still believe that AD is a mental illness. Finally, in the study data, the participants often misconstrued those symptoms of AD were a normal part of aging and there was a lack of prior knowledge regarding when the symptoms were not presenting as a "normal" part of aging but instead as AD. This acceptance of AD as normal aging is especially high in both the African American communities and other minority ethnic groups. By misunderstanding the symptoms related to AD it may prevent or delay diagnosis, help-seeking behaviors and increase the stigma of AD.

Effects of Alzheimer's Caregiving

As noted in the responses to the interview questions, caring for a loved one with AD has posed many challenges. The person who is affected by AD experiences many losses especially during the middle to later stages of AD. Some of those losses can be loss of orientation, loss of the ability to understand, loss of communication and personality, losses in judgment and so many more. These losses can bring about some of the greatest challenges for caregivers as African American family caregivers must often and are expected to help their loved ones to manage these issues. These challenges also require increased supervision and personal care as AD progresses. As the disease progresses, family caregivers experience the burden of increased physical and emotional stress, even depression can be a great factor. The burden of AD also brings about or exacerbates health issues, depleted finances, and income. This is often due to the disruptions in employment and pays on frequent healthcare visits and other services for the loved one affected by AD and themselves. There is also the stress of care transitions when having to admit a loved one into residential care. This can affect the family caregiver’s emotional and psychological well-being. The caregiver’s physical health is also negatively affected. Many experienced declines in their own health bringing on increased susceptibility to disease and health complications. These familial caregivers also experience an increased risk of dying due to AD caregiving. The burden of AD caregiving can also result in the overstressed caregiver being so distressed that there is the likelihood of the loved one with AD to experience abuse. Another consequence of AD caregiving is the caregivers' emotional and social well-being and higher levels of burden, stress, and strain often due to the increased discrimination and stigma of the disease that is both perceived and experienced by them.

Limitations of the Study

Several limitations in this study have been recognized. The first limitation was the sample size. In Chapter 3, I discussed the recruitment process for this generic qualitative study to be 11 participants. This sample size was limited to only African Americans who were identified as primary caregivers of loved ones diagnosed with AD. Additionally, this study very specifically does not represent caregivers of other racial or ethnic groups. This was because no other race or ethnicity could be representative of this sample population. This sample size was sufficient for transference but not suitable for a general population of caregivers of loved ones diagnosed with AD. The sole purpose of this study was to examine how the stigma of AD affected the caregiving behaviors of African Americans caring for loved ones with AD.

Upon conducting a thorough review of the literature, I discovered that I was unable to identify any studies that focused on how the stigma of AD affected the help-seeking behaviors of African American caregivers of loved ones affected by AD. As this qualitative study is unique, the transferability of the findings of this study may be limited. Additional research would be required to expand on this qualitative study to impart further examine how the African American caregiver is negatively affected by the stigma of AD and how this stigma of AD influences their response and delays their help-seeking behaviors.

Recommendations

The data analysis results revealed three themes and their relevant sub-themes that captured the personal perspectives of the caregiver's experiences in adjusting to their loved ones" diagnosis of AD. This data analysis has led to the following recommendations. The first general recommendation is promoting discussions about AD in the African American communities. It is critical for African American caregivers to recognize the effects that cognitive decline can have on their family relationships, health, and well-being of loved ones, on their interpersonal relationship abilities, and their own health. Findings from this study could extend empirically-based research evidence to human and social services providers, social workers, counselors, and clinicians about knowing and understanding what can delay help-seeking amongst this population and inform on what is missing from interventions that target African Americans.

The most significant recommendations that arose from the study's data during the interview sessions were (a) African American caregivers, (b) health and social service care and support professionals, (c) raising awareness and knowledge about AD amongst African Americans, other minority ethnic communities and healthcare professionals, and (d) future research. It is necessary that African Americans and other racial-ethnic minorities are afforded information, care, and support that speaks directly to them, without the stigma attached. It is also necessary that clinicians, health, and social service professionals expand their knowledge and understanding of AD and AD in the African American communities and other racial-ethnic groups and aim to understand the implications of the disease within the racial and ethnic groups. Transferability may not be generalized to other populations outside of the African American caregivers caring for loved ones diagnosed with AD.

A significant number of the literature review focused on the negative and adverse outcomes of the stigma AD for the general public, however, did not include African Americans. The literature review however highlighted that there was a scarcity of research on the African American population and AD, and the stigma of AD as it relates to African Americans. Below, I have focused on the most significant recommendations that arose from the study's data.

Recommendations for African American Caregivers

African American caregivers involved in caregiving for their loved ones who have been diagnosed with AD, should consider reflecting on the components that may likely disrupt their family relationships and need for support and care such as cultural, social, and community. Seek interventions such as social assistance that are specific to the African American group to improve caregiver knowledge, improve quality of life and health, reduce caregiver burden, and that is outside of the family and friend structure. Seek coping mechanisms from other African American caregivers who have shared circumstances such as informal networks, professional healthcare intervention programs, and community-based social support programs. Participate in clinical trials and research. Partake in AD awareness campaigns. Volunteer to learn and educate other African Americans on the various aspects of AD.

Recommendations for Healthcare and Social Service Professionals

It is vital that health and social service professionals should have some awareness regarding the perceptions of AD, care, and support that are common among people from other minority racial and ethnic groups, in this study specifically African Americans. These professional groups in healthcare and social service professions should seek and develop ways to normalize the routine of help-seeking and advance the discussion of what the symptoms of AD are. It is critical to consider an individual’s beliefs about AD, as a way to accelerate the reduction of discrimination and stigma that are associated with AD and help-seeking. In the African American caregiver community and general African American communities, it should not be considered that failure to seek initial help would mean that the individual would not benefit from a diagnosis or opportunities for future support, or that people from the African American community “look after their own”.

Healthcare and social service professionals and providers, community and religious leadership should consider how to connect with “grassroots” organizations and local cultural groups as a way to reach members of this racial and ethnic group and possibly to include them in seeking their advice on how to increase help-seeking amongst those in their communities.

It is also recommended that policies be developed to increase brain health and AD education and coordination between primary care physicians and other healthcare and social service providers including an improved system to share and disseminate knowledge about available local services and supports. It is also recommended that efforts should be made to build trust between medical practitioners and the healthcare system in the United States. This is because some people from the African American communities and other minority ethnic groups lack trust in America's healthcare system. This could be addressed through awareness campaigns about brain health and AD for people from African American communities and from other minority ethnic groups.

Because African Americans find it difficult to seek medical help in the case of symptoms of AD, I would also recommend that African Americans should have access to a free care navigator or coordinator. This navigation/coordinator system should be free of charge and easy to access. It is also recommended for AD and aging organizations that while striving to promote brain health, AD, normal aging literacy they would also ensure that their own procedures and practices are straightforward, understandable, diverse, and inclusive. Certain medical practitioners such as primary care physicians and medical students should be required as part of their licensing to have AD training both practical and advanced to be able to give a diagnosis, educate on the stages of the disease and make referrals to specialists, services, and support. Another recommendation is for health agencies to conduct outreach to community leaders to promote positive understanding and attitudes about seeking help and support. This would inevitably create grassroots knowledge.

Recommendations to Raise Awareness and Knowledge of AD Amongst African Americans

It is also recommended that there need to be culturally appropriate means of communication and appropriate channels developed and utilized to reach both individuals with AD and their caregivers from the African American community. Included in these channels and communications there should be materials, face-to-face and audio-visual approaches geared toward the minority ethnic groups. Another recommendation would be that when using AD awareness-raising materials that are targeted at African American communities, we should include images that reflect the typical life in that community. Images should be an example that African Americans can relate to. Another recommendation is that African Americans should be involved in both the creation and development of culturally appropriate messages and materials.

There should also be efforts included to build trust within the African American communities prior to and as part of any proactive awareness-raising initiatives or campaigns All awareness-raising materials are to describe the progression of AD and stress the potential benefits of support in the many issues that may arise. Another recommendation to removing the stigma of AD should be that there should be more research carried out about the perceptions held by people within minority ethnic groups about AD, care, health, and support. Assistance to healthcare professionals to close the gap between African Americans and other minority ethnic groups through education on changing of attitudes, skills and knowledge and skills pertaining to cultural competency. Cultural competence education should be required for current and continuing professionals in the healthcare sector. To date cultural competence education, though a blend of several medical and nursing education programs has not yet been standardized and universal in content (Horvat et al., 2014).

Support services from social workers and human service professionals can assist African American caregivers with locating local community-based social assistance, cultural awareness, and education workshops for informal caregivers. Social workers and human service professionals and clinicians can add cultural values to AD care and support. They can offer support and encourage supportive guidance and care in disease familiarity, copying skills, respite care, education all based on the cultural needs of the individual and their family.

Recommendations for Future Research

For future research, it is recommended that additional research is necessary to provide a more in-depth scope of this study. From generation to generation, the African American family and other minority ethnic groups have been culturally instilled to take on the role of a family caregiver, especially for their older adults. From the perspectives of the study participants, there is a need for cultural AD awareness and an understanding of how culture can influence both their perspective and experience of being a caregiver of a loved one with AD. Due to the limitation of the scope of this study and the use of the preferred qualitative methodology, I would suggest that additional information be used about this topic to further validate the outcomes of this study. The sample size of 11 African American caregivers acting as the primary and often only caregiver of a loved one diagnosed with AD. The future outcome of the studies could be generalized by comparing them to another racial or ethnic group of caregivers to compare the outcome of how the stigma of AD delays or influences their help-seeking behaviors.

In this qualitative study using the generic approach, data was captured using semistructured interview sessions. The perspective of the participants which was brought on by their lived experiences provided validation for the unknown about how the stigma of AD affected the help-seeking behaviors of African American caregivers of loved ones diagnosed with AD.

The African American caregivers who participated in this study were in a variety of demographics. Future research studies should focus on the population of minority ethnic groups of the United States.

Social Change Implications

Results from this study could benefit healthcare and social service professionals, change policies, and create meaningful and effective interventions that include the African American experience when it comes to help-seeking behaviors that affect AD caregiving. Because of the findings from this study, geriatricians, gerontologists, human and social service professionals, social workers, therapists, primary care physicians, community-based social practitioners, community leaders, and policymakers may strengthen and reassure family members among the African American communities as a resource to expand AD awareness through education and other awareness interventions to reduce the stigma of AD in these underserved communities. Additionally, these findings may be used to inform the development and implementation of culturally competent and culturally responsive awareness, educational programs, and other targeted interventions for African American caregivers caring for a loved one diagnosed with AD. It will also encourage those who have not been diagnosed but are showing the signs and symptoms of AD to use the appropriate services for early detection and diagnosis, care, and support. Ultimately, participants suggested that more research in the area of AD stigma and African Americans was needed and that more culturally sensitive educational, supportive, and treatment interventions for African American caregivers were needed. Social change can occur by promoting AD education, awareness, and the effects of AD on the African American caregiver. This social change implication could be enlightening for the African American caregivers who struggle with the AD diagnosis, signs, symptoms, and stigma.

Given the knowledge of examined information and gaps in the literature of this study topic, African American caregivers of loved ones diagnosed with AD are often in extreme need of care and support. Given the lack of knowledge of AD amongst the study participants, there should be the promotion of brain health and AD and restructuring positive narratives around brain health and AD help-seeking to encourage healthy help-seeking behaviors. It is essential that African American caregivers recognize how the stigma of AD can negatively influence their help-seeking behavior. Findings from this study could extend empirical-based research evidence to health and social services professionals, social services workers, counselors, community leaders, policymakers, and clinicians about the harmful consequences of delayed AD diagnosis and how the stigma of AD creates harmful outcomes for African American people affected by AD and their caregivers. Social service workers and professionals could utilize AD knowledge as interventions in the event they encounter an African American caregiver or African American older adult affected by AD who struggles with securing formal and informal care and support as a result of the stereotypes and stigma of the disease. My implication for social change is to create, disseminate valuable information to the health and social services professional and educate healthcare professionals to bring awareness and enlightenment to African American caregivers, and encourage healthy personal, interpersonal, and institutional outcomes for African American caregivers.

Additionally, results from this study could help both health and social service workers including social workers who are familiar with a culturally sensitive approach to understanding how the stigma of AD influences the help-seeking behavior of African Americans caring for loved ones and can contribute to later-stage diagnosis problems. A further social change could occur by promoting awareness of the effects of the stigma of AD on African American caregiving. The social change implication could be insightful and enlightening to African American caregivers who struggle with the importance of practicing positive help-seeking behaviors both for their loved ones and for themselves.

Participants in this study were responsive and displayed openness and respect to the importance of their cultural beliefs and values but also to the support they needed from family and friends diagnosed with AD. Despite their dedication to care and support their loved one diagnosed with AD, these African American caregivers expressed the critical need for cultural understanding, awareness, and support to be able to continue to provide care and support for their loved ones. Also, there needs to be a show of compassion, trust, and openness of those in the health care field for those who are members of culturally diverse populations such as African Americans. Moving forward the importance of guidance specific to the African American community for the development of community diversity and social support programs that are education-based. Additionally, the development of more interventions and supportive programs aimed at culturally diverse caregivers of loved ones affected by AD needs to be prioritized. Intervention opportunities should include self-help coping strategies, community support groups, educational and testing conferences, workshops, and opportunities for affordable short-term respite support.

Other implications would be for the field of gerontology. The tsunami of older adults affected by AD is expected to be challenging for people of all ages, but particularly devastating to those who are the caregivers to their loved ones. In 2019, there was an estimated 5.8 diagnosed AD cases reported in the United States with an estimated 30% represented by the African American community. Of these estimates, older adult African Americans make up a small portion of those diagnosed, because African American older adults are not getting formally diagnosed for their symptoms in the early stages due to various reasons mentioned in this study. This non-help-seeking behavior of both the older adults and their caregivers has raised concerns in the research community and the gerontological field, regarding the need for increase and improvement in services necessary to support older adults and their caregivers. Many of these supports and services require the assistance of social workers, human services professionals, clinicians, community leaders, and other service providers trained to work in the field of aging and AD. This research study is challenging the way the traditional training, interventions, and knowledge has been controlled. It is important to recognize the importance of training clinicians, social workers, and other professionals with the necessary skills to work effectively with other professionals and to support the needs of the communities. It should be our mission to ensure that both new and current healthcare and social professionals are proficient in necessary competencies including cultural competencies that are essential for community and population oriented, patient-centered collaborative, and interprofessional practice. The tsunami of older adults with AD in the United States is coming and our professionals are not yet fully prepared to provide support to these individuals especially those who are African American or of other racial-ethnic groups who are affected by AD.

The goal of this study is also to gather together community leaders, educators, and policymakers seeking to strengthen interprofessional practice among clinicians, social workers, and human services professionals. This research is an emerging area of study that really needs to be highlighted and calls on the professions in gerontology to review our approaches to interprofessional education, proactive education, and research and to add to and strengthen information where necessary. Though there is existing research on the stigma of AD, there is limited research on how the stigma of AD negatively affects the help-seeking behaviors of African American caregivers of loved ones affected by AD. As a researcher, I aim to raise the profile of this research area by leading this special issue.

Conclusion

Alzheimer's disease is not an inevitable outcome of aging, however, the risk of AD increases greatly with age. Those with AD experience a double stigma. The stigma of AD comes from not understanding and fear of the disease. The stigma around AD is a significant issue in many diverse racial and ethnic communities. This stigma can be a barrier to African Americans who may have encountered cultural values of family reliance, emotional restraint and shame, and embarrassment when seeking a diagnosis, care, or support. The socio-cultural aspect of caring for a loved one in the African American community who has been diagnosed with AD often presents unique challenges causing physical, emotional, social, financial, and psychological burdens. Despite the sociocultural influences such as beliefs and traditions, taking personal responsibility for caregiving for a loved one has become an increased risk of the African American caregivers becoming secondary patients. This problem then interferes with the care recipient not being able to complete their care at home as intended. Therefore, the data captured in this study has been pertinent to this research study for social change for the examination of how the stigma of AD affects the help-seeking behaviors of African American caregivers caring for loved ones with AD. The African American caregivers who participated in this study shared what their socio-cultural norms were and what was expected of them in addition to the caregiver burden and lack of both informal and formal assistance that are necessary for quality of life for both the caregiver and the loved one affected by AD. From the participants" personal perspectives, it was understood that though one's culture was important and significant in their caregiving process, having access to community-based supports, and services with knowledgeable and culturally competent representatives were critical.

The aspect of living with AD is rarely discussed in the African American popular culture and could perhaps be made more prominent in order to reduce prevalent public stereotypes of AD and the stigma of AD in the African American communities. Therefore, it is critical for the quality of care and quality of life for there to be a strong support system to ease the caregiver burden. This strong support system will garner trust and reduce the stigma of AD in the African American communities. Having a strong support system is critical for positive social change and may allow African Americans who are influenced by culture to experience some validation while caring for their loved ones with AD.

Unlike America’s general caregiver population, African Americans, and other racial and ethnic groups, experience cultural influence and a great deal of AD stigma that both influence how they care for and support their loved ones and increase their caregiver burden which in term makes their own health vulnerable. It is therefore critical that community stakeholder collaborates in bringing together a comprehensive plan that positively affects the African American caregiver community and reduces the stigma of AD to develop a sustainable network of support and care services easily accessible for both the care recipient and the caregiver. This study finds that the stigma of AD amongst African American caregivers can be mitigated with identifiable and planned interventions.

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Appendix A: Letter of Cooperation

Dear Ms. de Levante Raphael,

Thank you for providing the information we requested about your study. I apologize for my delay in getting back to you.

We are in receipt of your study proposal and objectives of your study and would like to work with you to have our members participate in this worthwhile study. We are positive that we have members who may fit your participant profile and would likely be interested in participating. We will post your study on our organization website and also on our social media and notify you as soon as it is done.

We thank you for this opportunity. We look forward to learning the results of your research. If there is anything we can do to help in furthering your recruitment of participants, please let me know.

Kind regards,

XXXXX

Executive Director

Appendix B: Online/Email Recruitment Flyer

Interview Study Seeks African American Caregivers Caring for Family Members Affected by Alzheimer's Disease

Caregivers, would you like to share your perceptions and experiences of Alzheimer's disease or dementia?

Hello Caregivers, there is a new research study exploring the ***"Stigmas of Alzheimer's Disease and Help Seeking for Alzheimer's Disease Among African Americans"*** that could gather information that could inform African American caregivers and older adults affected by Alzheimer's disease. This study will also help healthcare providers, gerontologists, social workers, policy makers and local leaders understand about Alzheimer's disease in the community.

The purpose of this study is to examine African American caregiver's perceptions of how stigmas related to Alzheimer's disease affects their willingness to seek medical help.

For this study, you are invited to describe your experiences and perceptions of Alzheimer's disease. This interview is part of the doctoral study for Donna de Levante Raphael, a Walden University doctoral candidate. Interviews will take place during the week of XXXXX via phone.

About the study

- One 30 – 60 minutes phone interview that will be audio-recorded
- As a "Thank you" for fully participating in the study you will receive $20 gift card
- Participating in this study will be voluntary.

Eligibility to Participate

- Identify as African American/Black between ages 18– 99 years
- Fluent in English (speaking, reading, and writing)
- Currently or previously served as the primary caregiver for an older adult affected by Alzheimer's disease
- Have a minimum of 6 months or more experience serving as a caregiver (current or past) for a loved one medically diagnosed with Alzheimer's disease
- Be a resident of any part of the United States
- Provide more than 20 hours per week of care for the care recipient
- Care recipient must have a formal diagnosis of Alzheimer's by a healthcare professional
- Care recipient must reside at home in the community

For more information contact:

Donna de Levante Raphael at donna.delevanteraphael@waldenu.edu, or call or text Donna de Levante Raphael at XXX-XXX-XXXX two weeks from the date of this letter. The Walden University IRB Approval Number for this study is XX-XX-XX-XXXXXXX

Thank you

Appendix C: Screening Questions

1. Are you an African American/Black?
2. Do you currently serve as caregiver or previously served as caregiver for an older adult family member affected by Alzheimer’s disease?
3. Are you between the ages of 18 and 99 years of age?
4. Has the older adult received a formal diagnosis of Alzheimer’s disease?
5. Are you fluent in the English language (speak, read, and write)?
6. Do you reside in the United States?
7. Does your care recipient reside at home in the community?
8. Are you the primary caregiver?
9. Do you provide more than 20 hours per week of care?
10. Do you have at least a minimum of 6 months of caregiving experience with this care recipient?

Appendix D: Interview Guide

Thank you again for agreeing to participate in this study. Your time and willingness to share your perspectives on such a sensitive topic is greatly appreciated. The purpose of the study is to determine how stigmas related to Alzheimer’s disease affects the help seeking behaviors of African Americans. You have been recruited because you match the criteria for this study. All information you will share with me today will remain confidential. Your personal information will not be shared in any way. The results from the interviews will be presented in aggregate from. No names or other personally identifying information will be includes in the results.

This interview will run approximately 30 - 60 minutes and will be audio recorded so that all details of you comment will be captured. The audio recording of the interview will be transcribed into a text-based document. I will email you a copy of the text version your interview for you to verify whether the transcript accurately reflects your comments given during the interview. You will have 3 calendar days from the date of the sent email to make corrections, approve, and return any corrections in the transcript to me via email. If you do not wish to continue with this interview you may stop it at any time without consequence.

The interview will begin with a few demographic or background questions about you as a participant. The information from the demographic questions will be used to describe the caregivers who participate in the study. The interview questions are designed to draw information from participants regarding beliefs and thoughts about of Alzheimer’s disease African American caregivers of loved ones affected by Alzheimer’s disease. Do you have any questions before we proceed? Do you consent to participated in this research?

Appendix E: Demographic Questionnaire

This demographic screening questionnaire is conducted by the researcher, Donna de Levante Raphael. The researcher is a doctoral student at Walden University. As a volunteer participating in this study, you have the right to not answer any question due to personal reasons.

Email address: ___________________________________
Telephone number: ______________________________
Mailing Address: _________________________________
Race (   ) (Participant must identify as African American, African, Caribbean, Black or Biracial to participate in this study.)
Age: _______
Gender (Male/Female)
Marital status (Single/ Married/Separated/Divorced/Widowed)
How long have you been serving as caregiver? ______________
What is your relationship to the person affected by AD:

- ( ) Husband
- ( ) Wife
- ( ) Daughter/Daughter in Law
- ( )Son/Son in Law
- ( ) Sister
- ( ) Brother
- ( ) Other Relative, Specify:___________
- ( ) Friend
- ( ) Neighbor

What is the current age of the care recipient? ______________
What was the age of the care recipient when diagnosed with AD? ______________
Are you residing with the individual affected by Alzheimer's disease? (Yes/No)
How many direct caregiving hours per day do you provide to your care recipient with Alzheimer's disease?

- ( ) Less than 1 hour
- ( ) 1 – 3 hours
- ( ) 4 – 6 hours
- ( ) 7-9 hours
- ( ) More than 10 hours

Education level completed:

- ( ) Less than High School
- ( ) High School
- ( ) Associate Degree
- ( ) College: (Bachelor) (Advanced Degree)

Unpaid hours of caregiving per week: ___________
Employed: (full-time/part-time, retired, unemployed)

Appendix F: Interview Questionnaire

1 How did you discover that your loved one had Alzheimer’s disease?

2 How long was it from seeing the signs and symptoms of AD to getting a diagnosis?

3 Describe your experiences of with getting medical care for your family member with AD

4 What were your thoughts about your loved one’s diagnosis of Alzheimer’s disease?

5 What signs or symptoms did you see prior to the discovery of Alzheimer’s diagnosis?

6 What were your thoughts about the diagnosis of Alzheimer’s diagnosis?

7 What did you know about Alzheimer’s disease before you became your family member’s caregiver?

8 What have you heard from other African Americans about your role as a caregiver for a person with Alzheimer’s?

9 What kind of comments have you heard within the community regarding individuals with Alzheimer’s?

10 describe how your knowledge of Alzheimer’s disease has changed.

11 What kinds of challenges have you had in your caregiving role for your loved one with Alzheimer’s disease?

12 How have you overcome those challenges?

What kind of informal support do you have (family, friends, church) for caring for your family member with AD?

What kind of professional resources are available to you and your loved one with Alzheimer's in the community (community resources, physicians, social workers, care managers, elder care lawyers, adult day centers, transportation)?

What recommendations would you offer to other African Americans who are caring for their loved one with Alzheimer's?

Appendix G: Debriefing Statement

Again, I thank you for your participation in this study. I greatly appreciate your cooperation. If you have any questions regarding the study, please feel free to contact the researcher at this time email: donna.delevanteraphael@waldenu.edu.

It may have been difficult to respond to the kind of questions you were asked and your generosity and willingness to participate in this study has been greatly appreciated. Your input may contribute to the advancement of the field of health and social service research. At times you may have found some of the questions in the interview emotionally upsetting. If responding to any of the interview questions led you to feel distressed and you would like to speak to someone about your feelings or thoughts, please contact one of the following services on the **Counseling Resource page** that I have emailed to you. I will send you a summary of the results after the research has been completed.

Finally, thank you again for participating in this research. Your participation has been greatly valued.

Sincerely,

Donna de Levante Raphael, MS
Walden University, PhD Candidate

Appendix H: Transcript Review Correction or Approval Email

Subject: **(AAC#) Interview Transcript Review for Correction/Approval**

Dear Study Participant,

I wanted to thank you again for agreeing to participate in this research study Stigmas of Alzheimer's Disease and Help Seeking for Alzheimer's Disease Among African Americans. As a participant of this study, I invite you to review this transcribed copy of your interview. Attached is a copy of your audio or Zoom recorded interview in written form. I ask that you verify whether the transcript accurately captures your responses during the interview. Please provide feedback as to whether your responses were accurate or if you need to modify information provided. **(See attached Participant Transcript Review Instructions).** Once you have conducted a complete overview of your interview, please email the edited/approved copy back to me at **donna.delevanteraphael@waldenu.edu**. Please note that you will have seven days from the transmission of this email to respond to this request. Once this study is completed, you will be emailed a 1–2 page summary of the study findings.

Sincerely,

Donna de Levante Raphael, MS,

Walden University, PhD Candidate

Appendix I Participant Transcript Review Instructions

1.You will receive an email/letter entitled “(AAC#____) Interview for Correction/Approval”. This email/letter will contain a researcher-transcribed version of your audio-recorded interview and you will be given the opportunity to review your interview as the researcher has transcribed it.

2.Once you have reviewed your transcribed interview, as a participant of this study, you will be given the opportunity to approve or correct any part of the interview that you feel needs modification or retracting.

3. Study Participant on Making Corrections to Researcher’s Transcription of Data

- If your transcript/translation of the interview requires any correction, please make any corrections, by using of a different color font.

4. Return the Participant Transcript Review Approval/Corrections back to the researcher

- Please return your approved interview transcription to me via email to donna.delevanteraphael@waldenu.edu**.**

Sincerely,

Donna de Levante Raphael, MS

Walden University, PhD Candidate

Appendix J: Counseling Resources for Participants

Resources:

Alzheimer's Association
www.alz.org
888-272-3900
Provides disease education, support groups, personalized care consultation online or in person, free 24/7 Helpline

Alzheimer's Foundation of America
www.alzfdn.org
866-232-8484
Provides disease education, care consultations, free Helpline, and support groups

Alzheimers.org
www.alzheimers.gov

Community Living Connections (Area Agencies on Aging/AAAs)
www.waclc.org
855-567-0252

Alzheimer's Disease Education and Referral (ADEAR)
Nia.nih.gov/Alzheimers
800-438-4380
Offers Alzheimer's disease information by phone or online for individuals with Alzheimer's or other dementias and their families

Administration on Community Living
Alzheimers.gov
Offers support to individuals with Alzheimer's or other dementias and their caregivers by increasing access to community resources

ALZConnected
Alzconnected.org
Online community that connects individuals facing Alzheimer's disease and provide online support

Community Resource Finder
Alz.org/CRF
Provides local programs, resources, and support services

Caregiver.org
Offers support for family and friends who provide long-term in-home care

Aging Life Care Association
Aginglifecare.org
Helps to locate geriatric care managers

Eldercare Locator (Administration on Aging)
Eldercare.gov
Connecting older adults and their caregivers with local services, resource referrals and contact information for state and local agencies on aging.