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Caregivers' Perceptions of an Early Diagnosis of Alzheimer's Disease in African Americans

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Abstract

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MS, Delta State University, 2007

BS, Delta State University, 2005

Dissertation Submitted in Partial Fulfillment

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Abstract

Alzheimer’s disease (AD) is significantly more prevalent among African Americans than within the general population, but rates of early detection are lower in the African American community. Researchers have demonstrated that both pessimistic Alzheimer’s-directed health beliefs, and negative perceptions of the effectiveness and the accessibility of medical care act as barriers to care seeking by African American family members of individuals with the disease. Recent research into causal judgments made by potential caregivers about individuals with undiagnosed AD suggests that gender bias and errors in attribution may constitute covert barriers to both lay and professional interpretations regarding the need for cognitive assessment. This study used grounded theory to investigate whether African American family caregivers hold integrated, gender-distinct beliefs about causal attributions of their family member’s cognitive decline which may contribute to a delay in care-seeking behaviors. The health belief model was used in conjunction with the attribution theory as the conceptual framework for understanding the data. Purposive sampling of geriatric and memory clinics, and a church was used to recruit eight family caregivers who participated in in-depth interviews. The results indicated that there is a significant lack of caregivers’ knowledge and understanding of AD regardless of gender, and that this lack is linked to delays in diagnosis. These results may be used to support the development of a new theory of family caregivers’ knowledge and understanding of AD. The social change implications include decreasing delayed diagnosis through increased educational awareness, community outreach programs, and universal mandatory cognitive testing of AD for at-risk individuals.

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Dedication

This dissertation is dedicated to my beloved grandmother Minnie L. Harris who was diagnosed with Dementia in 2005 and made her heavenly entrance in 2013. She has always been my role model and hero because she experienced so many health issues and challenges in her life and God always kept her safe in his hands. With my grandmother diagnosis, I noticed a disease that changed the person I have known for 30 years of my life at that time and transformed her into someone who was very vulnerable and unable to live alone and maintain her independence. After battling with this chronic illness for 8 years, she still stood strong at 82 years of age without an intense progression as some individuals have experienced. She still possessed her charismatic personality, yet sometimes was unable to remember things that just happened. I am thankful that she still recognized her children and grandchildren and was able to communicate with us on a regular basis. On July 6, 2013 my granny went on to continue her life in heaven and she no longer has to suffer from Alzheimer's disease or any other chronic illness. I miss her so much and will always love her. She always told me the importance of education.

Since this research will not directly impact my grandmother's life, hopefully it will help others to come that are susceptible to developing Alzheimer's disease. I love you grandmother. Also, I would like to dedicate this research study to my grandfather Theodore Dowdy who passed away in 1997 from prostate cancer, he is now my angel in the sky and I know he is very proud of his granddaughter. He will always hold a special place in my heart. I love you both forever and always.

Acknowledgments

First, I would like to thank God who is my savior and the reason that I have been able to fulfill this dream. He has given me the desires of my heart to complete such a task that will not only be a great accomplishment for myself but will allow me to help others.

Secondly, I would like to thank my mother who has always inspired and encouraged me to be the best that I can be and to never give up and always trust God to see me through any challenging situation. She is my rock and support throughout my entire educational journey. To my grandparents, I love and miss each of you dearly and I thank you all for always loving and supporting me in all my endeavors. To Dr. Robinson, thank you for being my heaven sent angel to see me through to the end of this journey. I thank Dr. Green for serving on my committee and assisting me throughout this journey too. Thanks to Dr. Thron and the research team for their valuable feedback and support. I truly express thanks to every mentor that inspired my interest in science and my previous chair Dr. Mary for assisting me with portions of my dissertation. I would like to thank my participants for their time and information that built this study. Thanks to my partner Eric for always supporting me and giving advice countless times during this process. I thank my brother, family, and friends that have supported me through words, advice, laughter, and prayer. I am very grateful for all of your time, commitment, love, and diligence. I have obtained a lot of knowledge and experiences throughout this time that will continue to direct me into more awesome endeavors. Once again thank you all very much. I sincerely love you all.

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Chapter 1: Introduction to the Study

Introduction

Alzheimer's disease (AD) is an important public health concern because of its rapid yearly increase of over 5 million people, and because its numbers are projected to double by 2020 (Alzheimer's Association [AA], 2014a). African American caregivers often lack knowledge needed for an early diagnosis in their patients. African American caregivers are often unaware of early signs and symptoms to look for in their aging family members although they have heard of the illness (Hughes et al., 2009; Clark et al., 2005). African Americans have a higher risk of early onset of AD than other ethnicities because of several risk factors related to age, underlying health conditions, genetics, and family history (AA, 2014a; Hughes et al., 2009; Clark et al., 2005). The most significant barrier for African Americans in early diagnosis of AD has been closely linked to individual health beliefs and a lack of knowledge among both at-risk patients and family caregivers (Hughes et al., 2009; Clark et al., 2005).

The findings of this study contribute to social change by providing African Americans at risk for AD, their family caregivers, and healthcare providers better ways to identify AD early-on. The results can be used to assist with proper planning for the patient's overall care including long-term healthcare, the management of their finances and property, and the appointment of a person to make decisions for the patient before the symptoms of the disease progress (AA, 2015b). This chapter presents background information on AD, a problem statement, the purpose and significance of this study, its theoretical and conceptual frameworks, and its delimitations, limitations, and assumptions. I will discuss the importance of this study further in chapter 2.

Background

Chronic diseases such as AD have become one of the top 10 causes of death in the United States. Alzheimer's disease is one of the most devastating chronic illnesses, affecting millions of elderly individuals and families across the world (AA, 2014a). African Americans are at a higher risk of developing AD than Caucasians because late diagnosis and their greater risks for hypertension, diabetes, heart disease and strokes (Leung et al., 2011; Hughes et al., 2009; Clark et al., 2005). Women over the age of 65, especially those in racial minorities, have become more prone to developing AD because of their longevity compared to their male counterparts (AA, 2014a; Vina & Lloret, 2010). There is a paucity of data that compare and contrast the effects of AD development in African American males and females (Hughes et al., 2009; Luchsinger, Tang, Stern, Shea et al., 2001). The literature examining AD in African Americans has tended to focus on the disproportionate burden of the disease among this group. Thus, one area of study that I addressed was the identification of gender biases and attribution errors as covert barriers among African American family caregivers that result in delayed diagnosis (Holmes & Alder, 2005).

Individuals often lack adequate knowledge about AD which may contribute to a delay in their loved one's diagnosis. Some in the African American community believe that a change in cognition in an elder is a normal part of aging (Leung, Finlay, Silvius, Koehn, McCleary, Cohen, & Drummond, 2011; Griffith & Lopez, 2009; Hughes et al., 2009; Clark et al., 2005; Mahoney, Cloutterbuck, Neary, & Zhan, 2005). African American family caregivers often delay seeking a medical diagnosis for their family members mainly because they lack adequate knowledge of early AD signs and symptoms. In addition, poor physician-caregiver relationships also lead to delays in AD diagnosis among African Americans (Connell, Roberts, McLaughlin, & Carpenter, 2009a; Clark et al., 2005; Manly, Touradiji, Tang, & Stern, 2003). It has further been found that African American caregivers do not become knowledgeable about AD until after their loved one's diagnosis (Hughes et al., 2009). Responding to these issues, my study promotes social change within African American communities so that family caregivers can recognize the symptoms and signs of AD early and hopefully prevent a delay in diagnosis. The ultimate goal of this study is to implement more education and public awareness about AD for African American caregivers and healthcare providers in order to provide quality care for sufferers.

Problem Statement

Alzheimer's disease (AD) is a progressive, degenerative disease that initially impairs and ultimately destroys cognition (AA, 2013; Leifer, 2009). According to the Centers for Disease Control and Prevention (CDC), 5.3 million people in the United States currently suffer from AD. Although early-onset AD may be present in individuals in their 30's, 40's or 50's, the majority of cases occur in persons age 65 or older (AA, 2013). The incidence of this disease is projected to increase greatly over the next decade as the generation of baby boomers enters the age groups at highest risk for incurring the illness (CDC, 2013). While AD strikes both males and females and manifests across races, elderly African Americans are twice as likely to present with AD as Caucasians, and are more likely than Caucasians to present with significant cognitive damage in all age groups (AA, 2012; Connell, Roberts, McLaughlin, & Carpenter, 2009b; Hughes et al., 2009).

Researchers have determined that a significant factor contributing to the more advanced cognitive impairment found among African Americans is a greater delay in medical diagnosis (Hughes et al., 2009; Leifer, 2009; Souder & Terry, 2009; Mosconi et al., 2007; Clark et al., 2005; Bullock & Hammond, 2003). This delay is noteworthy because although current medical science can neither cure nor substantially slow the progression of this disease, treatments exist that if administered in the early stages of the illness, can prolong the period of higher level mental functioning and extend the quality of life for both the sufferer and their caregiver (Buckley & Schub, 2012; Mosconi, et al., 2007).

Researchers have demonstrated that the detection of AD among African Americans is often delayed because the family and sufferer do not recognize the need to seek medical care (Griffith & Lopez, 2009; Hughes et al., 2009; Clark et al., 2005; Shadlen, Larson, Gibbons, McCormick, & Teri, 1999). A series of investigators have examined the factors that contribute to this, and have identified socioeconomic status, family beliefs regarding Alzheimer’s disease itself, family beliefs regarding the potential for discrimination by the medical system, family beliefs about the effectiveness of medical care interventions, and family concerns about the cost of care as important barriers to pursuing a medical assessment (Griffith & Lopez, 2009; Hughes et al., 2009; Clark et al., 2005).

Wadley and Haley (2001), however, provided suggestive evidence that gender bias and a fundamental attribution error may serve as yet-unexplored barriers to family-based judgments of the need to pursue a cognitive assessment. The intent of the Wadley and Haley investigation was to examine the influence of labeling or not labeling a set of circumstances as an illness. The researchers developed fictitious scenarios of Alzheimer's sufferers in which study participants were presented with information on eccentric patient behavior consistent with cognitive impairment. When the scenario contained an established diagnosis of AD, the participants were more likely to respond with compassion for the patient and to attribute the eccentric behaviors to the illness. When there was no established AD diagnosis, participants were significantly more likely to attribute causality for eccentric behaviors to personality traits or character flaws and to respond in a judgmental fashion to the patient's plight. In addition, the researchers found that fictitious undiagnosed male AD sufferers were judged more harshly than their female counterparts.

Although attributions have yet to be directly explored as potential barriers to the early diagnosis of Alzheimer's disease, a case study by Griffith and Lopez (2009) found that African American family members attributed the cause of cognitive missteps on the part of an afflicted family member to either a normal part of aging or as a demonstration of craziness. Similar *de facto* attributions have been cited in the work of Leung et al., 2011; Griffith & Lopez, 2009; and Wadley & Haley, 2001. Attributions are potentially powerful barriers to care-seeking behavior on the part of family caregivers because of the ease of committing the other-directed fundamental attribution error (FAE): a cognitive bias in which the negative behavior of another individual is significantly more likely to be credited to internal agency than to extenuating circumstances (Wadley & Haley, 2001). Further, when the other-directed FAE is applied to a negative behavior, the observer is likely to experience negative emotions toward the perpetrator of the behavior. Finally, when a behavior is judged to be especially egregious, the other-directed FAE heightens the tendency of the observer to respond harshly to the perpetrator. These three characteristics of the other-directed FAE suggest that if family caregivers are responding to the early symptoms of Alzheimer’s with the other-directed FAE, then it can set the stage for continued and escalating negative judgments as the symptoms of cognitive impairment progress--a process that could significantly delay care-seeking behavior.

The gender bias detected by Wadley and Haley (2001) is a unique distinction that has not been explored relative to African American family caregivers. Investigations into gender differences are scarce and concern the potential biological differences between males and females to determine if one gender is at higher natural risk for AD (Werner, Goldberg, Mandel, & Korczyn, 2013; Sinforiani et al., 2010; Clark et al., 2005; Wadley & Haley, 2001). If gender bias does exist among African American family caregivers, it could contribute to differential patterns of attribution-driven delay that may place males at increased risk for late diagnosis.

With respect to the extension of attribution bias and gender bias to the provider setting, medical sociologists researching the lay referral system have established a link between family beliefs and a lay diagnosis of the problem that may potentially bias how symptoms are reported to medical professionals (Long, 1994; Donabedian, 1973; Koos, 1954). These researchers identified a conceptual pathway by which family caregivers' attribution-driven interpretation of the problem influenced the diagnostic process and the inclination of the physician to initiate cognitive testing (Long, 1994; Donabedian, 1973; Koos, 1954). If gender bias is embedded in the lay interpretation of the problem (Wadley & Haley, 2001), then it would also indirectly influence the diagnostic process. In their research into the bias associated with the impact of frequency on the decision-making process, Khaneman and Tversky (1974) suggest a further mechanism through which gender bias could influence the medical encounter. They examined how the availability heuristic prompts decision-makers to use frequency of occurrence as a decision rule in considering solutions to a given problem (Khaneman & Tversky, 1974). Because the majority of African American AD sufferers are female (Clark et al., 2005; Hughes et al., 2001; Luchsinger, Tang, Stern, Shea, & Mayeux, 2001; Tang et al., 2001), it is possible that attribution bias is compounded by the frequency bias in the medical encounter, once again increasing the potential for African American males to be at higher risk for diagnostic delay. There was thus the need to study the dynamic interaction of beliefs, attributions, and gender distinctions that may serve as additional barriers to the early diagnosis of AD, and how the perspectives of family caregivers may influence the judgment of the medical provider. I addressed this need in my investigation.

Purpose of the study

In this study, I used grounded theory to investigate whether African American family caregivers hold integrated gender-distinct belief sets and make causal attribution errors that contribute to a delay in care-seeking behaviors. The intent of this investigation was to develop a unified understanding of the influence of family members' cognitive barriers in order to support the development of a new theory of the lay interpretation of the meaning and consequences of the early signs of mental impairment in elderly African Americans. Understanding whether attribution and gender biases contributed to the delay in diagnosis of AD in African Americans was fundamental to identifying the totality of perceptual barriers facing the African American community relative to the early diagnosis of AD. I explored the expression of these biases in conjunction with the variables identified as perceptual barriers by previous researchers (Griffith & Lopez, 2009; Hughes et al., 2009; Clark et al., 2005; Paton, Johnston, Katona, & Livingston, 2004; and Wadley & Haley, 2001), to understand if a unique cognitive pattern exists that better explains why African Americans are at a higher risk for a delayed diagnosis of AD than the elderly of other racial/ethnic backgrounds. My emphasis on gender distinction helped further clarify cognitive patterns within the African American context and illuminated whether and the extent to which African American males are at a greater risk for a delayed diagnosis than are African American females.

To accomplish the study intent, I used in-depth interviews with semi-structured questions to gather data from African American family caregivers regarding their beliefs, attributions, and perceived barriers, because these constituted the lay interpretation of the symptoms exhibited prior to the diagnosis of AD. This sample consisted of families with female AD sufferers and families with male AD sufferers. I recruited participants whose family members were at all stages of cognitive decline at diagnosis in order to determine if cognitions and biases differed between those families who received an earlier diagnosis and those who received a later diagnosis of AD for their family member.

The results from this study informed behavioral and educational interventions I designed to decrease the delay in AD diagnosis in African Americans. They also helped determine whether public health interventions should be tailored to account for differential cognitive patterns toward male and female AD sufferers. The findings contribute to positive social change by indicating the need for interventions to ensure early recognition and treatment of AD in the African American community, to improve the quality of life for AD sufferers and their family caregivers, and to allow for proactive planning for the patient's lifestyle changes before the disease progresses.

Research Questions

RQ1: To what extent do caregiver perceptions of the value of obtaining a diagnosis of Alzheimer's vary by gender of the affected family member?

RQ2: To what extent do caregiver perceptions of the accessibility of medical care vary by gender of the affected family member?

RQ3: To what extent do attributions directed toward the affected family member vary by gender?

RQ4: To what extent does the lay interpretation of the need to seek medical care differ by attributions?

Theoretical Framework

Health Belief Model (HBM) and Attribution Theory

The health belief model (HBM) was created by U.S. public health social psychologists in the 1950's. The social psychologists desired to know why individuals were not partaking in accessible health screening programs and not implementing preventative health behaviors in their daily lives (Carpenter, 2010; Hughes et al., 2009; Turner, Hunt, DiBrezzo, & Jones, 2004; Abraham, Sheeran, & Johnston, 1998; Glanz & Rimer, 1997; Hochbaum, 1958). In Chapter 2, I provide more details concerning the origin and implementation of the HBM and its constructs.

There is a need for early detection and screening for AD to decrease disease burden (Hughes et al., 2009; Leifer, 2009; Clark et al., 2005). The HBM is examining beliefs related to screening behaviors and early detection. According to the HBM, people are more likely to participate in preventive health behaviors if they identify themselves to be susceptible to a particular condition (perceived susceptibility), identify the situation to have potentially serious results (perceived severity), think that there will be positive outcomes from taking the course of action (perceived benefits), and believe that if actions are taken, the barriers will outweigh the benefits (perceived barriers) (Glanz & Rimer, 1997, pp. 13-14). In addition, I used the model to assess perceived self-efficacy that reflected the family caregivers' perceptions of their abilities to identify AD signs and symptoms correctly. The aim of this study was to identify barriers to accurate and early diagnosis of AD among African Americans from the perspectives of family caregivers. The explanatory theory of HBM helped me obtain the perspectives of family caregivers' personal experiences with early detection in diagnosed patients with hopes to enhance social support services and educational awareness of AD. The challenges that African Americans encountered with health issues were extremely significant, and the HBM provided ways to formulate positive changes within their lives (Hughes et al., 2009).

The attribution theory initially developed by Heider (1958) has been used by other researchers who have adapted some of its concepts further (see Chapter 2). In this study, I used the concepts of attribution theory to explore ways to identify the causal reasoning of individuals relative to the early signs and symptoms of AD in a family member. My use of the attribution theory also enabled me to propose possible ways to understand how causal reasoning impacts the decision to seek medical care for the affected family member. Several investigators have explored laypersons' and caregivers' causal attributions regarding patients with AD, HIV, learning disabilities, challenging behavior, addiction, and cancer (Switzer & Boysen, 2009; Weigel, Langon, Collins, & O'Brien, 2006; Polk, 2005; Williamson et al., 2005; Cobb & Chabert, 2002; Follet & Hess, 2002; Tarrier et. al., 2002). The researchers' results marked a distinction between both internal and external attributions, and validated a consistent tendency for participants' use of the FAE in assigning negative behaviors to cognitively impaired individuals.

In this study, I used the health belief model (HBM) and attribution theory as a theoretical framework to support the development of a new theory of family caregivers' knowledge and understanding of AD. The HBM and attribution theory individually cannot adequately account for the observed behaviors that delay AD diagnosis in African Americans. By combining the HBM constructs and attribution theory, I was able to determine definite perceptions that contribute to the family caregiver’s decision to seek care for a cognitively impaired loved one. Researchers’ examined literature that described the effects of the HBM constructs and attribution theory in which another individual was observed as displaying both unexpected and adverse behavior than the observer’s perspective. (Adekeye & Adeusi, 2011; Abraham et al., 1999; King, 1983). There has not been an examination of how the HBM and attribution theory may be used to determine barriers and biases that may contribution to the delay of AD in African Americans. My use of the HBM and attribution theory offers possible ways to understand how health beliefs and causal reasoning impact the decision to seek medical care for the affected family member. As a result, I have a better understanding of the patterns of cognition that can lead to a delay in the diagnosis and treatment of AD.

Nature of the Study

This was a qualitative study that used a grounded theory approach. Qualitative research is reliable for understanding barriers to early diagnosis of Alzheimer’s disease in African Americans and how this understanding may be used assist family caregivers and healthcare providers with better techniques to help the at-risk group (Hughes et al., 2009). The methodological approach for this study included the collection of primary data from eight family caregivers using semi-structured questions to gather information about biases and barriers to early diagnosis in diagnosed African Americans. In Chapter 3 I offer more details concerning the research methodology, design, procedure, interview protocol, data collection and analysis, and ethical procedures.

Definitions

In this study, I used several terms to describe the illness and persons involved in the research study.

Alzheimer's disease (AD): A common type of dementia which affects the neurons in the brain and causes plaques to form resulting in initial memory loss in hippocampus region of the brain (AA, 2014a; U.S. National Library of Medicine, 2012).

Attributes: Explicit judgments made to determine the reasoning for a given outcome (Weiner, 2008).

Early diagnosis: A diagnosis of Alzheimer's disease before symptoms start (varies from each individual) which may allow treatment to target disease before irreversible cognitive decline occurs (AA, 2015c).

Family caregiver (FCG): A family member (typically a husband, wife, daughter, or son) that is responsible for taking care of an elderly person or child that is sick or disabled (American Psychological Association, 2015a). Family caregivers are normally older adults.

Healthcare providers (HCPs): Offer medical services for AD patients in aspects of diagnosis, treatment, educational resources, specialist referrals, and psychological therapy (U.S. National Library of Medicine, 2015).

Lack of knowledge: When one is not aware or familiar with a certain topic or condition (such as Alzheimer's disease), which may affect their personal situation and outcome (Hughes et al., 2009; Clark et al., 2005).

Mild cognitive impairment (MCI): a condition associated with the first stage of AD, which may affect cognitive decline with memory, language, judgment and thinking skills which is not considered normal aging (MAYO Clinic, 2015; AA, 2014a).

Primary care physicians (PCPs): Provide care to patients initially before any specific disease diagnosis confirmation, in addition to, continuing care for other illnesses (U.S. National Library of Medicine, 2015).

Psychological stress: A thought process within the brain due to an emotional disturbance that causes mental episodes (American Psychological Association, 2015b).

Assumptions

Below I outline several assumptions relating to AD that I made over the course of this study.

- A pool of at least 15-20 volunteers was required to select at least seven to 12 participants for the study.
- Participants explained their caregiver experiences openly and honestly during interviews to provide accuracy during the study. I ensured that participants understood the purpose of this study and sought to contribute to social change by communicating material that I used to develop recommendations for AD health awareness programs, interventions, and further exploration.

Scope and Delimitations

The limitations of this study result from my role as the data collection instrument, and my personal interpretation of data, I used member checking by the participants to guarantee the reliability of the data. The study results from the grounded theory approach did yield data that may support the development of a new theory of family caregivers' knowledge and understanding of AD for African American family caregivers of those suffering from AD. The results provided attributional barriers or biases that contribute to delayed AD diagnosis in family members. The boundaries of the study only included African American family caregivers ages 18 and older, and excluded any other races or nationalities from participation because of the study's purpose.

Limitations

This study was not designed to be generalizable for all African American caregivers because I only collected data from 8 participants who volunteered to participate in my study. My study thus may not to reflect all African American family caregivers. This study was also limited by my criteria for participation. Participants must have been English speaking, 18 or older, African American family caregivers that resided in the Dallas, Texas metropolitan region. Recruitment only took place in a geriatric and memory center affiliated with a local university, and one local church. Some family caregivers were unable to participate in the study because of their caregiver obligations and responsibilities, and time restrictions. To facilitate participation, I had the participants schedule interviews according to their personal situation, and select the location of the interview.

Significance of the Study

Since diagnosis of AD in African Americans often occurs at later stages, there was the need to assist this population with methods of detecting an early stage. Understanding why African American AD diagnosis happens at later stages and the underlying factors that may contribute to this delay, is imperative to assisting family caregivers. This study contributes to the existing body of literature that examines the delay in AD diagnosis within the African American community using a combined model of health beliefs and causal attributions. In this study, I further examined if the level of knowledge about AD has an effect on the patient’s health outcome and progression of the degenerative illness. Early recognition of AD provides opportunities to initiate treatment that could slow the progression of the disease and connect family caregivers with supportive services. Numerous caregivers have their own careers and personal lives, and the diagnosis of a close relative with AD adds additional stress which may be linked to the progression of AD in the diagnosed individuals (Clark et al., 2005, p. 2012).

African American caregivers of AD patients are normally their children, and are more inclined to have a strong relationship and commitment to helping their family member accept and cope with the disease. This relationship can further lead to many emotions and stress about their parent and the fear that they themselves will develop AD. Caregiver support from family members, physicians, and other healthcare staff are essential to hindering advanced progression of AD within diagnosed patients (Hargrave, 2006). More information about AD is necessary for African American communities to promote awareness and achieve timely diagnosis for African Americans with AD (Hughes et al., 2009; Clark et al., 2005; Mahoney et al., 2005). In Chapter 2, I include comprehensive information about the theoretical and conceptual frameworks and pertinent literature.

Summary

This chapter presented information about the effects that attributional and gender biases have on African Americans receiving a timely diagnosis. AD has become an important public health concern for everyone, but African Americans experience a delay in diagnosis compared to Caucasians. The integrated HBM and attribution theory frameworks served as guides for this research study and provided insight into reasons for further investigation. There are several assumptions associated with this study as well as limitations and delimitations. Chapter 2 provides an in-depth discussion of AD literature, and this study's theoretical foundation and conceptual framework. In Chapter 3, I discuss the methodology, rationale, procedures for recruitment, issues of trustworthiness, and ethical concerns.

Chapter 2: Literature Review

Introduction

The purpose of this study was to examine cognitive barriers that influence delays to early diagnosis of AD in African Americans. I used attribution theory to understand causal attributions and judgments during family caregiver observations. The six constructs of HBM provided the theoretical foundation of this study exploring possible family caregiver perceptions that may serve as barriers which delay diagnosis. In this literature review, I provide pertinent information on major risks factors, prevalence, incidence, and social and ethical issues related to AD in African Americans (Carpentier, Ducharme, Kergoat, & Bergman, 2008; Clark et al., 2005). In this literature review, I describe the clinical manifestation of AD and provide epidemiological information within the African American population (Sinforiani et al., 2010). I discuss the importance of understanding conceptions related to dementia within multiethnic populations, and why diagnosis of African Americans occurs at later stages of the illness (Hinton, Franz, Yeo, & Levkoff, 2005; Hughes et al., 2009). The main objective of this study was to determine whether barriers to AD diagnosis in African Americans differ by gender of the caregiver. I also sought to identify probable barriers in order to develop an effective educational awareness program to improve early AD recognition for caregivers, patients, and healthcare providers.

Literature Search Strategy

The databases I used to gather peer reviewed journal articles for the literature review included: Cumulative Index to Nursing and Allied Health Literature (CINHAL), PUBMED, EBSCO HOST, PSYCInfo, Google Scholar, and Medline. Furthermore, I used the websites from the Centers for Disease Control, National Institute on Aging, and Alzheimer's Association to expand general information on AD. In my searches, I used the following terms: *Alzheimer's disease, dementia, African Americans, Blacks, Caucasians, minority, minorities, barriers, diagnosis, gender differences, family caregiver, healthcare providers, caregivers, health belief model, attribution theory, attributions, fundamental attribution error, attribution bias, early diagnosis, brain anatomy, brain function,* and *neuropsychological*. The majority of articles I used date to the past 5 to 8 years. The theoretical foundations and conceptual framework of the investigation required the inclusion of classic literature dating from 1958. In areas where research on AD in African Americans was limited, I used supportive articles that examined other ethnicities for comparison.

Conceptual Framework

Attribution Theory

Attributions are implicit judgments as to why a given observable behavior or behavioral outcome occurs (Weiner, 2008; Manusov and Harvey, 2001). This form of causal reasoning has been extensively studied, but as yet, no single model of attributional reasoning dominates research in the field (Hall, French, and Marteau, 2003; Forsterling, 2001; Hewstone, 1983). Causal thinking is, instead, marked by a series of constructs and models, each of which has demonstrated the explanatory power relative to specific aspects of, or circumstances under which, attributional judgments are made (Tyran & Allen, 2002; Anderson, 2001; Weary & Reich, 2000; Fiske &Taylor, 1991). In this investigation, attributional concepts were used to identify the causal reasoning of individuals relative to the early signs and symptoms of AD in a family member, and to understand how causal reasoning impacts the decision to seek medical care for the target family member. Consequently, this examination of the literature deals primarily with the constructs and theories associated with attributions that are generated about another individual who has been observed displaying a behavior that is both unexpected and negative from the observer's perspective. A brief history of the relevant attribution theories is presented here.

Dominant Attribution Theories

Heider's model. The study of causal attributions began with Heider's research into the process by which human beings explain how and why events occur (Weiner, 2008; Weary & Reich, 2000; Heider, 1958). Heider's research focused on the way lay people make sense of the surrounding world, a process he termed *common sense psychology* (McLeod, 2010; Weiner, 2008; Paton, Johnston, Katona, & Livingston, 2004; Anderson, 2001). Heider conceived of interpersonal relationships as the foundation of the causal attribution process (Heider, 1958, pp.296-97; Harvey & Weary, 1981, p.11). He envisioned attributions as the product of an internal assessment of cause and effect based on patterns of factors assumed to contribute to the behaviors of others (Heider, 1958). Heider's research resulted in a set of concepts deemed antecedent to causal inferences made about another individual (Heider, 1958). Table 2.1 presents Heider's major antecedent concepts and their corresponding definitions.

Table 2.1

Heider's Major Antecedent Concept and Definitions

Major Antecedent Concept	Definition
Consciousness	A self-awareness of one's behavior, social environment, and outcome(s).
Observation	A cautious evaluation performed by an observer about another person's behavior in a given environment.
Distress	Negative environmental influences, such as anxiety or pain, affecting the observer's behavior and/or personality.
Causes	People or circumstances that impact the individual observed and leads to behavioral outcomes.
Capability	The observer's assessment of an observed individual's ability or power to perform a particular task or not.
Effort	The observer's assessment of an attempt by the observed to make an individualized change or improvement of a situation.
Desire	A self-motivated want by the observed individual to work hard to make positive changes personally and in the environment.
Emotions/Feelings	The observer's sentiments towards the observed individual based on behavioral influences, resulting in positive or negative outcomes.

Note. Adapted from Heider's (1958). *The psychology of interpersonal relation.* New York: Wiley.

Heider (1958) theorized that before people assign causality to an event, they assess the contributions of the factors presented in Table 2.1. The result is an intuitive interpretation as to whether the cause of a given behavior or outcome is due to either a characteristic of the person involved in the event, or by environmental factors that influenced the circumstances under which the event took place. Heider categorized the first type of causal inference as an internal attribution, and the second type as an external attribution (McLeod, 2010; Weary and Reich, 2000; Andrews, 2001; Forsterling, 2001; Anderson, 1991).

Heider further specified that the assignment of either internal or external causality is influenced by the observer's need to respond to the outcome (Fosterling, 2001). An observer responsible for taking action to ensure that a negative event does not happen again is motivated to find a cause that can be controlled in the future (Fosterling, 2001). Heider further noted that assessment of causality is influenced by the extent to which the observer has had prior experience with, and has formed a favorable or unfavorable impression of the individual involved in the incident (Heider, 1958; Weary & Reich, 2000; Forsterling, 2001; McLeod, 2010).

Heider specified how experience influences the development of attributions (Anderson, 1991), and concluded that all the factors operative in personal relationships could not be specified because study subjects are unable to adequately convey the subconscious or intuitive aspects or their thought process. Heider, however, considered all of his concepts to be equally important and deserving of further research (Heider, 1958, p.295). Heider's work stimulated other social psychologists to examine both the form and function of the causal reasoning process.

Jones and Davis model. Jones and Davis extended Heider's research on internal and external attributions by finding evidence that observers are more attentive to human agency than environmental factors (Jones & Davis, 1965). Jones and Davis further determined that observers rely on intuitive decision rules or heuristics to assign causality (McLeod, 2010; Forsterling, 2001; Weary & Reich, 2000). Jones and Davis' correspondence inference theory elaborated these decision rules by stating that the behavior of the observed individual is deemed to be a function of their underlying intent, which is, itself, a reflection of the individual's personality. Accordingly, if the observer's knowledge of the observed individual's personality is consistent with an intentional behavior, this perceived correspondence results in an internal attribution. Conversely, if the observer's perceived knowledge of the observed individual's personality is inconsistent with intent, the behavior is deemed accidental and is assigned an external attribution (Ray, 2011; McLeod, 2010; Forsterling, 2001; Jones & Davis, 1965; Psychology Press, n.d.).

Jones and Davis refined the theory to include five concepts. These concepts, their corresponding definitions, and the corresponding heuristic derived from each concept are presented in Table 2.2.

Table 2.2

Jones and Davis Concepts, Definitions, and Subsequent Heuristic

Concept	Definitions	Heuristic Derivation
Decision	A personal assessment by the observer as to whether the observed behavior occurred in the absence of observable limiting factors.	In the absence of observable limiting factors, the observer is more likely to surmise that the behavior was caused by the person involved.
Behavioral(intentional vs. unintentional)	The observer evaluates the link between the behavior and the known personal characteristics of individual involved in the behavior.	When the behavior is consistent with what is known about the observed individual's character traits, the observer is more likely to consider the behavior an intentional act. When the behavior is not consistent with the individual's known character traits, the observer is more likely to deem the behavior unintentional.
Social Desirability	The observer's assessment of the observed behavior's level of normative appeal.	The lower the level of the social desirability of the behavior, the more likely the observer is to hold the individual solely responsible for the occurrence of the behavior.
Non-common effects	The observer's assessment of the unexpected aspects of the observed behavior compared to the outcomes of all the other possible alternatives.	If the observed behavior is not shared by other possible alternatives, then the observer is more confident of judgment of intentional motivation.
Hedonistic Relevance	The observer performs an assessment to determine whether the observed behavior is beneficial or harmful to others.	When the observer judges the behavior to be harmful the attribution is more likely to be judged a reflection of personal traits.

Note. Adapted from McLeod, S. (2010). Attribution Theory. Retrieved from http://www.simplypsychology.org/attribution-theory.html; Försterling, F. (2001). *Attribution: An introduction to theories, research, and applications*. Hove [u.a.]: Psychology Press.; Harvey, J. H., & Weary, G. (1981). *Perspectives on attributional processes*. Dubuque, IA: Wm. C. Brown.

Jones and Davis' correspondent inference theory extended Heider's research by casting internal causal attributions as negative judgments. The theory highlights a cognitive bias in which people equate harmful, socially undesirable outcomes with comparable unpleasant character traits and personal intent. In essence, correspondent inference theory suggests that a bad outcome is synonymous with a bad person and sets the stage for Kelley's further examination of the heuristic thinking and the biases associated with this cognitive process (Forsterling, 2001; Weary & Reich, 2000; Harvey & Weary, 1981).

Kelley's model. Kelley's (1967) research furthered the precision of the decision rules established by Jones and Davis by examining the co-variation among the major determinants of causal attributions. Kelley conducted multiple empirical studies of observer-observed dyads to detect cause and effect (Weary & Reich, 2000) and in 1973, he developed Kelley's cube, a set of algorithmic decision rules describing the heuristic pattern employed in assigning the locus of causality in a given observed event. These decision rules are presented in Table 2.3.

Table 2.3

Kelley's Significant Dimensions for Developing Causal Attributions

Decision Rule	Definition	Patterns of Related Causes
Consistency	The degree to which an individual repeatedly displays the same behavior(s) in multiple occurrences of the same situation. The key pattern component is constancy over time.	High consistency is aligned with an internal locus of causality. Low consistency is aligned with an external locus of causality.
Distinctiveness	The degree to which an individual repeatedly displays the same behavior(s) across similar situations. The key pattern component is similarity across contexts.	High distinctiveness is aligned with internal locus causality. Low distinctiveness is aligned with an external locus of causality.
Consensus	The degree to which other individuals display the same behavior(s) in the same or similar situations The key pattern component is constancy across individuals related to the person and effect.	High consensus is aligned with internal locus of causality. Low Consensus is aligned with external locus of causality.

Note. Adapted from McLeod, S. (2010). Attribution Theory. Retrieved from http://www.simplypsychology.org/attribution-theory.html; Försterling, F. (2001). *Attribution: An introduction to theories, research, and applications*. Hove [u.a.]: Psychology Press.; Mowday, R.T. (1987). Beliefs about the Causes of Behavior: The Motivational Implications of Attribution Processes. Retrieved from http://dsmgt310.faculty.ku.edu/SuppMaterial/KelleyAttributionTheory.htm

Kelley's cube focused on the pattern of decision rules that led to assigning either an internal (caused by the individual) or an external (caused by outside influences) locus of causality for the observed behavior. According to Kelley, the locus of causality is assigned by a form of cognitive triangulation in which three pieces of data are encoded and considered. The observer is seeking a match to one of two patterns that have a high probability of correctly identifying causal locus. These complete patterns are shown in

Table 2.4

Kelley's Pattern for Assignment of Locus of Causality

	Consistency	Distinctiveness	Consensus
Internal Locus of Causality	High	High	High
External Locus of Causality	Low	Low	Low

Note. Adapted from McLeod, S. (2010). Attribution Theory. Retrieved from http://www.simplypsychology.org/attribution-theory.html; Hewstone, M. (1983). Attribution theory and common-sense explanations: An introductory overview. In M. Hewstone (Ed.), *Attribution theory: Social and functional extensions.* (pp. 1-26). Oxford: Basil Blackwell; Harvey, J. H., & Weary, G. (1981). *Perspectives on attributional processes*. Dubuque, IA: Wm. C. Brown.

Kelley's research, and the research of others using this model (McLeod, 2010; Forsterling, 2001; Weary & Reich, 2000; Harvey & Weary, 1981; Kelley, 1967, 1972), provided compelling evidence of the use of these decision rules in causal attributions, but the evidence also supported the use of cognitive short cuts in which observers bypassed the effortful process of triangulation and made judgments based on a single datum. Kelley explained the capacity of observers to arrive at a causal judgment following a single observation by invoking the representative heuristic from the work of Kahneman, Tversky, and Slovic (1982). Kahneman et al. (1982) demonstrated that people arrive at rapid decisions based on matching the observed features of an object or situation with patterns of features held in memory. If a pattern is well-represented by a single feature, then the presence of that defining feature triggers identification of the larger pattern and limits the cognitive search for a more precise explanation. In the case of Kelley's decision rules, an observation on any one of the defining factors of consistency, distinctiveness, or consensus implies the entire pattern and, hence, triggers the associated causal attribution. Once key criteria are ignored in a decision making process, the resulting lack of precision leaves open the possibility that the decision maker will commit a judgment error and match limited information to an incorrect cognitive pattern (Weary & Reich, 2000; Kahneman et al; 1982; Kelley, 1967, 1972).

Fundamental Attribution Error (FAE). From their research, Jones and Harris' noted a systematic cognitive bias toward assigning internal causality in other-directed attributions. Further to this, the researchers noted that the personal characteristics to which the outcomes or behaviors were attributed most often reflected traits consistent with the outcome itself, rather than a reflective assessment of the person's character. This bias was strongly associated with attributions toward individuals of whom the observers had little personal knowledge, and allowed a causal judgment to be made in the absence of fundamental information. Jones and Harris referred to this phenomenon as correspondence bias (Jones & Harris, 1967). Researchers investigating correspondence bias have linked elements of the bias to Heider's, Jones' and Kelley's conceptualizations (Ross, 1997; Gilbert & Malone, 1995; Jones, 1990, 1979; Gilbert & Jones, 1986). Consistent with Heider's work, researchers have found evidence that the default cognitive mode is to place more significance on the human agent as causal rather than the surrounding environment. This heuristic, like all heuristic thinking, is frequently, but not always, correct and spares the observer the effort of thoroughly investigating and evaluating true causality (Forsterling, 2001; Weary & Reich, 2000; Gilbert & Malone, 1995; Gilbert & Jones, 1986; Hewstone, 1983; Kelley 1967; Jones & Davis, 1965; Heider, 1958). Consistent with Jones' research, an internal causal attribution inclines the observer to link the behavior to corresponding human traits to explain why the behavior occurred. The primary difference between internal causal attributions as originally conceived by Jones, and the internal attributions inherent in correspondence bias is that in Jones' model, the focus of assessment is on the individual. Information about the individual involved in the behavior or outcome is reviewed to determine which known personal characteristics best explain the outcomes observed. In correspondence bias, the focus is on the behavior or outcome. The outcome itself is judged as either good or bad, and reflective of a set of potential human characteristics, which may, or may not, accurately reflect the individual involved in the occurrence. A trait or set of traits is selected as most congruent with the outcome observed and applied to the individual without consideration of objective evidence. This latter characteristic of correspondence bias is consistent with Kelley's observation that attribution judgments are made after considering limited information and assuming the remainder of the evidence will follow a preconceived pattern. The end result is a potentially faulty judgment (Lagdridge & Butt, 2004; Tyran & Allen, 2002; Forsterling, 2000; Gilbert & Malone, 1995; Jones, 1990; 1979; Jones & Davis, 1965). The consistency and strength of this bias inspired Ross (1977) to refer to correspondence bias as the fundamental attribution error (FAE), a term that has remained dominant in the literature (Riggio & Garcia, 2009; Follett & Hess, 2002; Forsterling, 2001; Weary & Reich, 2000; Forgass, 1998; Gilbert & Malone, 1995; Jellison & Green, 1981; Taylor & Fiske, 1975).

The FAE is most noticeable when individuals seek to explain a negative outcome involving another person (Forsterling, 2001; Sabini et al., 2001; Weary & Reich, 2000). In instances of this other-directed FAE the perceiver, seeking to explain why the negative outcome occurred, invokes correspondingly negative personality traits and applies them to the individual involved (Krull, 2001; Sabini et al., 2001). External causes are not considered. The general heuristic results in a biased translation: a harmful outcome is the result of a flawed human being. This bias inclines the observer to attempt to correct the person’s failure through some form of punishment (Weary & Reich, 2000). Not only is this response potentially unjust, it also leaves open the possibility that the negative outcome will recur due to causal but unexamined situational factors (Weary & Reich, 2000; Forgass, 1998; Gilbert & Malone, 1995).

In contrast to the other-directed FAE, a self-directed FAE occurs when an individual takes credit for a positive outcome without considering the potential influence of outside factors. This bias initially enhances self-esteem but may result in subsequent failures when the individual relies on personal traits to recreate the positive results when, in fact, situational factors were causal and unexamined. These subsequent failures may frustrate the individual and ultimately lower self-esteem (Sabini et al., 2001; Gilbert & Malone, 1995; Hewstone, 1983). The FAE is further expanded in the work of Weiner and is discussed in conjunction with his model as presented below.

Weiner’s Three Stage Attribution Model. Weiner extends both the application of heuristic reasoning from the work of Kelley, and the impact of heuristic bias from the research on correspondence bias/FAE, in his three stage model of causal attributions.

Originally termed the theory of motivation and emotion, Weiner's model deviates from the preceding attribution theories, in that it is not designed to account only for the assignment of locus of causality. Instead, it details the heuristically-driven rationales observers generate following the assignment of causality in the context of achievement (Weiner, 1979, 1985, 1986). Consistent with the work of Heider, Davis and Jones, and Kelley, Weiner's first stage in the attribution process consists of three criteria: 1) a behavior is observed, 2) the behavior is deemed intentional, and 3) an internal or external locus of causality is assigned to the behavior (Weiner, 2008, 1986; Weary & Reich, 2000; Forsterling, 2001; Hewstone, 1983). The second stage of Weiner's model focuses on explaining the outcome of the behavior in terms of either achievement or failure, according to one of four causal factors. Two of the factors, personal ability and personal effort, refer to a person's capacity or motivation for achievement in a given situation, while the other two factors, the difficulty of the task, and luck refer to outside influences. In the third stage of the model, the four causal factors are assessed according to three explanatory dimensions. First is locus of control which is consistent with the correspondence theory. This bipolar dimension focuses on personal traits, designating the extent to which the individual involved in the action is deemed to possess the ability or the motivation to succeed or the extent to which the outcome is related to a circumstance outside the individual. Second is stability which is consistent with Kelly's dimension of consensus. It is the extent to which the situation in which the outcome occurs is stable or mutable. Third is controllability which does not have a counterpart in prior theories, but reflects the extent to which the individual exerted control over the outcomes in a given situation. The major components of Weiner's stages 2 and 3 are presented in table 2.5.

Table 2.5

Weiner's Three Stage Model

	Stable	Unstable
Internal Locus and Uncontrollable	Ability	
Internal Locus and Controllable		Effort
External Locus and Uncontrollable	Task Difficulty	Luck

Note. Adapted from Weiner, B. (2008). Reflections on the history of attribution theory and research: People, personalities, publications, problems. *Social Psychology, 39*(3), 151-156. doi:10.1027/1864-9335.39.3.151; Weiner, B. (1986). An attributional theory of motivation and emotion. New York: Springer; Weiner, B. (1985). An attribution theory of achievement motivation and emotion. *Psychological Review,* 92, 548-573.

According to Weiner, the dimensions of the model are combined to yield four causal heuristic patterns that can be triggered to explain a given behavior or outcome. Ability is an internal, stable trait which is also inborn and, therefore, not under the control of the individual. Effort too is an internal trait, but because an individual can choose either to exert or not exert effort in a given situation, effort is both unstable and controllable. Task difficulty is determined outside the individual, and represents an external locus of control. It also is stable relative to any given task and is uncontrollable by the individual. Luck is an external phenomenon that varies by situation and cannot be invoked. Consequently, luck has an external locus of control and is unstable and uncontrollable (Weiner, 1979, 1986, 2008; Forsterling, 2001). Weiner (1979, 1985) classified ability, effort, and task difficulty as dominant causes and luck as a non-dominant cause. Weiner also postulated the sequence through which a given attribution is made, and incorporated the effect of emotion in the attributional process. This sequence is represented in Figure 2.1 below.

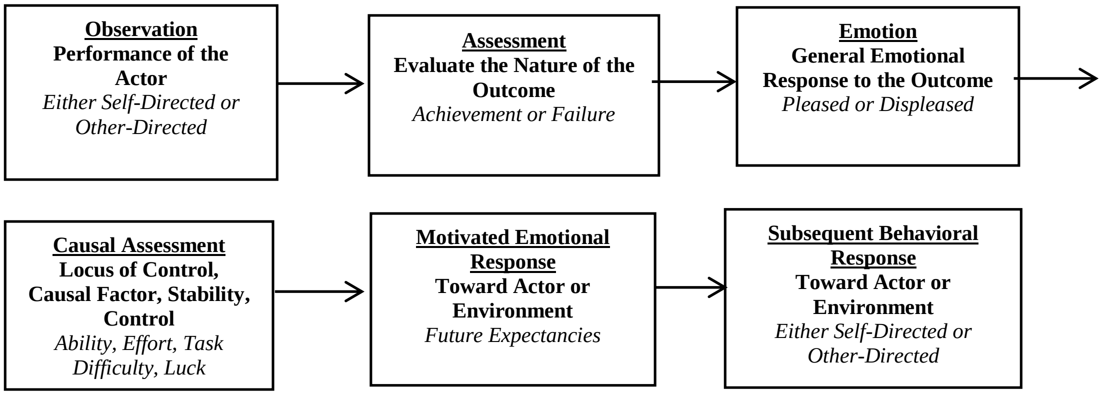

Figure 2.1. Sequence of Attributions and Effect of Emotion. *Note.* Adapted from Weiner, B. (1985). An attribution theory of achievement motivation and emotion. *Psychological Review*, 92, 548-573; Weiner, B. (1979). A theory of motivation for some classroom experiences. *Journal of Educational Psychology*, *71*(1), 3-25. doi:10.1037/0022-0663.71.1.3

To fully understand the Weiner model, both self-directed and other-directed attributions must be taken into consideration (Forsterling, 2001; Weiner, 2000, 1979, 1986; Wong & Weiner, 1981). According to the sequence, the observer notes both the role of the actor in the outcome or behavior as well as the outcome or the behavior itself. From this data, the observer generates an emotional response to the outcome. An outcome of achievement is likely to generate a favorable emotional response, while an outcome of failure is likely to generate an unfavorable response. Next, the observer invokes one of the four heuristic causal assessment patterns which accounts for any prior knowledge the observer may have relative to the actor and the circumstances under which the outcome took place. The causal assessment generates a second emotional response, this time directed toward either the actor or the environment as causal. At the point of the second emotional response, a set of expectations are generated based on the combined influence of the causal attribution and the emotional response to both the outcome and the actor or environment. If the expectations are directed toward an internal locus of control, then the observer determines what to expect from the actor in future scenarios similar to the event witnessed. If the expectations are directed toward an external locus of control, the observer determines if the environment is likely to contribute to repetitions of the witnessed event with the same actor, or with other actors. In the last stage of the process, the observer determines how to respond to either the actor or the environment. The response is to either support or anticipate the recurrence of a positive outcome or to reduce the likelihood of, or anticipate the recurrence of, a negative outcome (Weiner, 1971, 1979, 1985, 1986; Forsterling, 2001; Weary and Reich, 2000).

To better illustrate Weiner’s model, I presented a hypothetical situation. Consider a classroom test situation. A teacher is reviewing the exam scores of two students, one student has always been a high achiever, and one student has been inattentive and consistently scores at the bottom of the class. On the exam, the high achieving student scores in the 95th percentile for all students taking the exam and the low achieving student scores in the 85th percentile. According to Weiner, the teacher would be pleased by both outcomes, but would assign a different other-directed causal attribution to the two students. For the consistently high achiever, the teacher would be influenced by prior knowledge of the student’s capacity and assign a causal attribution of ability and potentially effort, as would be consistent with a stable uncontrollable personal trait and an unstable controllable action respectively. The attribution of ability and effort would influence the teacher's positive affect toward the high achieving student and generate the expectation of that student's continued success. The teacher's response to this attribution would be the willingness to act as an advocate for the student in future academic pursuits. For the consistently low achiever, the teacher would also be influenced by prior knowledge of the student's capacity and initiative and assign a causal attribution of luck to explain the unusually high score. This attribution generates a negative, dismissive affect toward the student with no expectation for future success, and a lack of willingness to advocate for the student in future academic pursuits.

Weiner (2000) also examined the importance of the self-directed attribution in which the individual formulates causes for personal actions. In this causal attribution, the individual focuses intensely on personal causes of success or failure for a particular event. Self-directed reflect a bias toward protecting a positive self-image and, as with other-directed attributions, are initially triggered by whether a given outcome is positive or negative. A positive outcome is attributed to the personal qualities of ability and effort, whereas a negative outcome is attributed to uncontrollable circumstances such as task difficulty or luck.

I presented a hypothetical situation to better explain the self-directed attribution process by again considering a classroom test situation. This time the attribution was generated by a student to explain his or her own test performance outcomes. Weiner's theory predicts a student receiving a high test score would be most likely to attribute that outcome to the personal qualities of ability or effort, regardless of whether the student had been a high or a low performing student in the past. The predicted emotions generated by the attribution process would be both pleasure with the outcome and a motivation to repeat the performance using essentially the same strategy as employed in the original circumstances, with an expectation of repeated success. Conversely, Weiner's theory predicts that a student faced with a failing grade would be most likely to attribute the outcome to the difficulty of the test or bad luck regardless of their prior history with academic success or failure.

Weiner also accounted for attribution bias by noting both self-directed and other-directed attributions are frequently based on limited information (Weiner, 1971, 1979, 1985). According to Frieze and Weiner (as cited in Weiner, 1986) perceivers form judgments about the observed behavior during initial observation, which are open to modification if additional information is later obtained. This superficial judgment often leads to the FAE, as the search for disconfirming evidence is discouraged because an explanation has been generated, however faulty that explanation may be. As noted earlier in this discourse, the other-directed FAE bias focuses causal explanations on internal factors to explain another person's behavior in a given circumstance, and focuses on attention of external factors in the case of self-directed attributions (Forsterling, 2001; Sabini, Siepman, & Stein, 2001; Weary and Reich, 2000). Both of these biases preclude the potential to learn the proper lessons from a given outcome. Weiner further noted that the other-directed FAE included a bias to judge culpability based on internal characteristics and, in the absence of any prior knowledge of the actor's virtues, assign the cause for positive outcomes to external sources. In short, in the absence of disconfirming information, an observer is prone to assume that good outcomes are the result of luck, and bad outcomes resulted from a flaw in the actor's ability or personal character (Weiner, 2000, 1985, 1979). Weiner's complex theoretical model on attributional investigations inspired other studies related to motivational and educational components within the field of social psychology in aspects of behavior, cognitive processes, and bias relevantly to understanding interpersonal and intrapersonal attributions (Weiner, 2008, 2000, 1985; Forsterling, 2001).

Applied Research of Attribution Theory

Researchers have examined laypersons' and caregivers' attributions towards patients with AD, HIV, learning disabilities, challenging behavior, addiction and cancer (Switzer & Boysen, 2009; Weigel, Langon, Collins, & O'Brien, 2006; Polk, 2005; Williamson, Dooley, Martin-Cook, et al., 2005; Cobb & Chabert, 2002; Follet & Hess, 2002; Tarrier, Barrowclough, Ward, Donaldson et. al., 2002). I presented a brief description regarding the attribution theory applications.

Switzer and Boysen (2009) used illness vignettes, and a religiosity measure to determine if stigmatizing attitudes towards individuals with either a physical or mental illness were related to the observer's level of religious commitment. The study sample comprised 120 community members and college students from a Northeastern city in the United States. The researchers found that stigmatizing attitudes were consistent with the FAE in that participant's attitudes were more negative toward individuals suffering from addictions than individuals suffering from cancer. The researchers interpreted their findings to indicate that observers were more likely to view addiction as a controllable outcome and, thereby, equate the negative consequence with undesirable personality traits, regardless of situational information. The researchers also found that reliance on the FAE was not influenced by the degree of religiousness espoused by study participants. This finding led the researchers to conclude that religion did not affect the extent to which individuals stigmatize what are perceived as negative controllable illness states (Switzer et al., 2009).

Williamson, Dooley, Martin-Cook, et al., (2005) conducted a cross-sectional investigation of 103 unpaid caregivers to determine if attributions regarding the problematic behaviors of cognitively impaired or disabled elders were associated with caregiver resentment. Attributional outcomes were measured using an instrument that divided types of problematic behaviors into those typical of cognitive impairment (external attributions) and behaviors typical of controllable, stable personality traits (internal attributions). Caregiver resentment was measured using a composite caregiver resentment and caregiver burden scale. The researchers found that behaviors typical of cognitive impairment were correlated with both internal attributions of controlling and manipulative behavior and caregiver resentment. The researchers concluded that cognitive impairment behaviors generate caregiver resentment when the caregiver attributes those behaviors to manipulative and controllable personal traits and that caregivers fall prey to the FAE in spite of their awareness of external explanatory circumstances.

Polk (2005) used attribution theory to guide his analysis of a grounded theory investigation into the uncertainties experienced by family caregivers attempting to communicate with, and understand the communication cues and responses from, their cognitively impaired family member. Polk (2005) used open-ended interviews to understand the primary research question as to the nature of the family caregiver’s role. Polk found that negative communications from the cognitively impaired generated the greatest uncertainty among caregivers as to both cause of response and how they, as a caregiver should respond to the communication. Polk (2005) concluded that further research is required to examine caregiver’s causal attributes towards afflicted family members to better understand how to lessen caregiver stress related to uncontrollable behaviors exhibited by their afflicted family member.

Wadley and Haley (2001) performed a laboratory-based manipulation on 221 female undergraduate students, to examine whether labeling or attribution theory best explained the reaction of potential caregivers to cognitively impaired family members. The researchers used fictitious case scenarios in which either mothers or fathers were exhibiting negative behaviors. In some scenarios the parent was given a confirmed diagnosis of either Alzheimer’s disease or major depression. In other scenarios no diagnosis was offered as a potential explanation for the undesirable behaviors. Participants were asked to review the scenarios and rate their causal explanations for the negative behaviors, as well as their emotional reaction to those behaviors and their willingness to help the parent in question. Wadley and Haley (2001) analyzed participant data to determine if causal explanations reflected illness stigmatizing and were, therefore, best explained by labeling theory, or if the explanations were more consistent with the use of internal or external attributions. Wadley and Haley (2001) found that participant causal explanations were more consistent with attribution theory than labeling theory as causality was deemed to be internal or external and no illness stigmatizing was detected. In addition, the researchers found that participants expressed more sympathy and potential assistance toward parents diagnosed with AD and major depression than those for whom no medical explanation was provided. In addition, the researchers found that participant's reported more anger and relied more heavily on external attributions, essentially attributing the negative behaviors to personal traits, when the parent in question was the father rather than the mother. The researchers concluded that the gender of the afflicted family member may influence a prospective caregiver's emotional and behavioral response (Wadley & Haley, 2001).

In summary, researchers have employed attributions to better understand how attribution bias contributed to medical stigmatizing, explained caregiver resentment when caring for the cognitively impaired, affected caregiver sense of certainty about the meanings of communications by cognitively impaired loved ones that require caregiver interpretation, and contributed to family members' level of sympathy and willingness to help the cognitively impaired. The findings from each of these investigations included a distinction between internal and external attributions, and demonstrated a consistent propensity for study subjects to commit the FAE when the cognitively impaired behave in negative manner. The one interesting variation on this finding is evident in the Wadley and Haley (2001) investigation, where knowing that the individual exhibiting the negative behavior was cognitively impaired, elicited internal attributions and a positive response toward mothers but not toward fathers. The negative behavior of fathers' still elicited fundamental attribution bias from the study participants, all of whom were female. This study is currently the only investigation in the literature to determine that gender may play a role in attribution bias and the family member response to unexpected negative behavior. Although this study manipulated the gender of the cognitively impaired parent in the scenarios, the lack of male participants leaves open the question of whether gender has a similar impact when males assess parental negative behavior. In addition, it is not clear if the bias is truly gender based, or if it is, in fact, relational, with a potentially stronger bond to, and tolerance for, mothers who tend to function as the family nurturer. Caregivers are primarily female (American Psychological Association (APA), 2014), but that circumstance does not rule out the potential for male family members to offer attribution judgments that may impact the response of female caregivers.

None of the existing studies examine either the form or function of attributions generated toward family members exhibiting negative behaviors consistent with cognitive impairment, prior to a diagnosis of cognitive impairment. Research findings to date provide preliminary information that is suggestive of the potential for attribution bias under these circumstances, but knowing whether or not attribution bias does, indeed, exist is not possible without a specific examination of pre-diagnosis family attributions. Further to that, current research also provides information from which one can infer that attribution bias directed toward a family a member could delay the inclination to seek a medical evaluation, by focusing causality on personal traits rather than the possibility of cognitive impairment. Such attribution bias could well contribute to delayed diagnosis in Alzheimer patients, but attributions have not been examined in this context. In addition, Wadley and Haley's (2001) research raised questions of gender bias and whether laboratory findings extend to genuine family situations. Are females treated more charitably than males when family members are faced with unexpected negative behaviors? Does the gender of the family member observing the negative behaviors influence the form and function of the attribution? Finally, do any gender-related attribution differences play a role in delaying the decision to seek a medical assessment for the afflicted family member? I used the attribution theory to better understand if or how attribution bias contributed to a delay in family members' decision to seek a medical evaluation for cognitive impairment in the target population. I further examined whether gender differentially influenced either the attributions made toward the impaired family member or the decision to seek care. I also determined how attributions fit into a larger pattern of barriers influencing the delay of AD diagnosis among African Americans. To examine that larger pattern of barriers, I used the health belief model (HBM). Information on my use of that framework follows.

Theoretical Foundation

Health Belief Model (HBM)

The HBM originated in the 1950s from the efforts by U.S. public health service social psychologists to understand why individuals failed to participate in available health screening programs and failed to adopt preventative health behaviors in their daily lives

(Carpenter, 2010; Hughes et al., 2009; Turner, Hunt, DiBrezzo, & Jones, 2004; Abraham et al., 1998; Glanz & Rimer, 1997; Hochbaum, 1958). The tuberculosis (TB) outbreaks of the 1950's were fertile grounds for exploring the factors that influenced individuals' decisions to seek or not seek the free mobile TB screening services offered by public health services. Researchers determined that the public's testing rationale was best defined by personal beliefs regarding the individual's risk for contracting the illness, coupled with a personal cost-benefit analysis weighing beliefs regarding the existence of effective measures for reducing the risk against the existence of any barriers to accessing or adopting the risk reduction measures (Abraham et al., 1998; Glanz & Rimer, 1997; Hochbaum, 1958). Figure 2.2 presents the health-related belief sets that constitute the core HBM constructs.

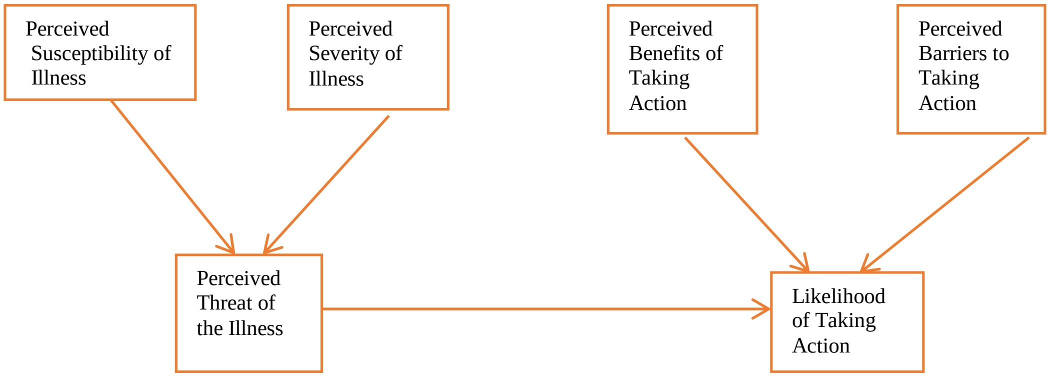

Figure 2.2. Core constructs of the health belief model. *Note.* Adapted from Glanz, K. and Rimer, B. (1997). Theories at a Glance. A Guide for Health Promotion Practice. National Cancer Institute, National Institutes of Health, U.S. Department of Health and Human Services. NIH Pub. No 97-3896. Washington, DC: NIH, Revised September 1997; Abraham et al., (1998): From health beliefs to self-regulation: Theoretical advances in the psychology of action control, Psychology & Health, 13:4,569-591.

The HBM consists of four interrelated belief sets defined as follows:

Perceived susceptibility. Perceived susceptibility is one's subjective assessment of personal risk for contracting a given disease or manifesting a given illness (Hughes et al., 2009; Turner et al., 2004; Glanz & Rimer, 1997; Strecher & Rosenstock, 1997). Hochbaum (1958), suggested that when individuals perceive their risk of exposure or vulnerability to a disease or illness state to be low, they are less inclined to adopt preventive measures than when they assess their risk to high (Hochbaum, 1958). Perceived susceptibility varies among individuals (Rosenstock, 1966).

Perceived severity. Perceived severity is one's belief regarding the danger inherent in acquiring or not treating a given disease (Janz & Becker, 1984). Strecher and Rosenstock (1966) and Hochbaum (1958) proposed that perceived severity is linked to an individual having adequate knowledge of the disease or illness state. Additionally, Hochbaum (1958) observed that individuals desire to know if the disease is life-threatening or disabling before taking proper actions. Perceived severity also varies among individuals.

Interaction of Perceived Susceptibility and Perceived Severity. Once an individual assesses the susceptibility and severity of the disease, the two constructs mesh to form a unified belief termed the perceived threat (Shamar, 2011). When an individual identifies susceptibility and severity as high, the perceived threat is high, and the individual is more likely to become motivated to engage in risk reduction activities. Conversely, when both perceived susceptibility and perceived severity are low, the perceived threat is low, and the individual is less likely to seek preventive measures (Carpenter, 2010; Turner et al., 2004).

Motivation is more complex when conflicts occur between perceived susceptibility and severity. If an individual believes that the susceptibility is low, severity is not acknowledged, and risk behavior remains unchanged (Carpenter, 2010). An individual's perception of an adverse outcome is significant to personal judgment of susceptibility and severity (Carpenter, 2010). Glanz, Rimer, and Lewis (2002) affirmed that an individual will seek assistance when severity is life threatening.

Perceived benefits. Perceived benefits are an individual's assessment of the proposed advantages associated with risk reduction behaviors (Sharmar, 2011; Glanz & Rimer, 1997). Perceived benefits are reliant upon the individual's rational and physical judgments (Burke, n.d.). If the perceived benefit for a given threat is low, a person is less likely to pursue a preventative or proactive approach. If the perceived benefit for a given threat is high, a person is more likely to take a proactive approach to reduce the risk for an unpleasant outcome (Carpenter, 2010; Glanz & Rimer, 1997).

Perceived barriers. Perceived barriers are any factors that influence an individual to change their behavior (Hochbaum, 1958; Rosenstock, 1966; Carpenter, 2010). Barriers include financial outlays, access to the perceived beneficial alternative, time constraints and other opportunity costs (Shamar 2011; Carpenter, 2010). A mutual relationship between perceived benefits and barriers is assessed to determine whether an individual will try a proactive approach for prevention of potential risks (Strecher & Rosenstock, 1997). The cost-benefit trade-off determines whether an individual will take action towards healthy behavior. If an individual perceives the benefits to changing behavior as reasonable and the threat of not taking action severe, the likelihood of taking action increases. The cost-benefit trade-off influences whether barriers to taking a given action outweigh benefits obtained from taking that action. If there is an elimination of barriers that would typically prevent an individual from taking action, the individual is more likely to make positive behavioral changes. Benefits and barriers work together in the determination of an individual's proactive approach for support, yet when benefits are higher than barriers the individual will more likely partake in positive behavior change or engage in a beneficial action (Glanz & Rimer, 1997; Strecher & Rosenstock, 1997; Burke, n.d.).

Subsequent Additions to the Model

Three additional sets of factors are identified to improve the predictive and explanatory power of the HBM. These factors are not core model constructs because they are employed or not employed based on the intent of the research. A discussion of these factors and their specific contributions to the HBM follows.

Cues to action. Cues to action variables were first considered in 1958 when Hochbaum conjectured that the decision to take action to reduce the threat of illness required a trigger to set the decision into motion (Hochbaum, 1958). Cues to action are conceived as those internal or external circumstances that signal an individual to take preventive action relative to a particular illness or hazard. These triggers include perceived physical, psychosocial, or environmental circumstances that heighten an individual's awareness of risk, as well as outside reminders that encourage the individual to follow through on a prior decision to take preventive care. Cues to action are most frequently employed as practitioner designed triggers in health education and health promotion initiatives, however, the effectiveness of these cues has not been well documented (Rosenstock, 1974; Janz & Becker, 1984; Glanz, Lewis, & Rimer, 1997). When cues to action are included in conjunction with the HBM, they serve as modifying variables (Rosenstock 1966; Hochbaum, 1958).

Self-efficacy. Self-efficacy is a construct first conceived by Bandura in his work on social cognitive theory and refers to individuals' confidence in their capacity to engage in a given behavior (Bandura, 1977). This construct has proven to be both predictive and explanatory independent of social cognitive theory and is often used as a variable of interest in psychosocial research (Bandura, 1977). This construct's inclusion in the HBM is, consequently, contextual (Carpenter, 2010; Bandura, 1977).

Other Modifying Variables. There are several modifying variables that influence an individual's health beliefs and practices if used in conjunction with the HBM constructs (Carpenter, 2010; Hughes et al., 2009). Socioeconomic factors that influence a person's health beliefs are related to social status, social support, and human capital (CDC, 2014). These social determinants include capital, power, and resources within a given community (CDC, 2014). Janz and Becker (1984) affirmed that the demographic modifiers of age, gender, ethnicity, and race, in conjunction with the psychosocial influences of culture impact health-related perceptions. Social support refers to an individual's perception of having help from others after an unfavorable situation, which may promote self-care (Nauert, 2010; Schneider, 2006). Social support can have a healthy impact on an individual’s behavior (Nauert, 2010). Human capital refers to an individual’s competency, social and personal skills, cognitive capability and educational attainment to obtain higher earnings (Lee, Kiyu, Milman, & Jimenez, 2007). Human capital has a direct effect on an individual’s healthcare because individuals at the poverty level may lack skills needed to earn a modest living which would result in health inequities (Lee et al., 2007). These modifying variables have an indirect influence on the HBM main constructs when collectively evaluated, due to the alteration of individual health behaviors.

Health Belief Model and Attributions. Hewstone (1983) conceptualized the core attributes of the HBM as attributional beliefs and reframed the HBM using Weiner’s attribution theory. According to Hewstone, the perceived susceptibility and severity of a given illness impacts the extent to which that illness is viewed as controllable and whether the illness is viewed as stemming from external or internal sources. Hewstone (1983) also conceived of ability, effort, task difficulty, and luck as contributory to beliefs regarding causal factors in health and illness. According to this model, a genetic predisposition for a given illness could be considered uncontrollable and a function of luck. Health behaviors would be viewed as controllable and would include judgments regarding personal ability and task difficulty as these factors applied to actually controlling any given behavior. A review of the most recent literature employing an attributional application of the HBM follows.

Literature and Research Based Analysis. Researchers have rarely used an attributional application of the HBM within socio-health studies. The following are the most recent examples of this approach and address the topics of high-blood pressure, heart disease, breathing difficulties, and HIV/AIDS education (Adekeye & Adeusi, 2011; Abrahams, Costa-Pereira, Florey, & Ogston, 1999; King, 1983, 1982). I briefly discussed research related to the utilization of attributional health beliefs.

King (1982) used a prospective design to investigate the connection between health beliefs constructs and causal attributes as they influence an individual to seek screening for high-blood pressure (HBP). The investigator predicted that causal attributes of HBP would affect health beliefs, act in conjunction with health beliefs to influence the patient’s behavior, and possibly show a more direct influence on behavioral intention. A sample of 103 adults responded to the study questionnaire encompassing constructs from both frameworks as they related to the decision to attend a screening for HPB. King used multivariate and correlational analyses to discriminate between attenders and non-attenders. King’s first analysis on all HBM and attribution variables identified eight significant discriminating variables: “intention, control over health, situational causal attributions, costs and barriers to screening, controllability of cause of HBP, benefits to screening, efficacy of screening, and consensus” (King, 1982, p.1085). King (1982) also found that three attributional factors, controllability (working less, doctor visits), behavioral intention (chance of attending screening), and situational (stress, bad luck) were significant predictors of the decision process to seek medical screening of HBP between attenders and non-attenders (p.1083).

King (1983) also conducted a prospective, quantitative investigation of the utility of using an attributional approach to health beliefs in patients with heart disease. King

(1983) collected questionnaires from a population of 83-heart patients to measure beliefs concerning perceived susceptibility (to further serious heart problems), perceived severity (to determine the degree of concern over an illness), perceived benefits (to examine the satisfaction with hospital treatment), and perceived cost (to determine health beliefs that contribute to patient's difficulty in continuing recommended advice from healthcare provider). King conducted a previous pilot study generated by heart patients to determine attributional items used for this study, which revealed 21 possible outcomes for the occurrence of heart disease. King (1983) divided the attributional outcomes for patient's perceived cause into four main categories: 1) Environmental (stress from work, stress from home, stress from family illness, sudden lifestyle change), 2) Personal (general tension and nerves, being tired, being overweight, poor diet, smoking, drinking, lack of physical activity), 3) Uncontrollable physical conditions (hereditary, congenital, weakened immune system, underlying illness, related to childhood disease, and 4) Chance (bad luck, fate, will of God) (p.294). From the list of 21 possible causes, the researcher evaluated patients' responses as to the chosen attributed causes for their own heart condition. King (1983) used a multivariate regression equation to detect the connections between attribution and health belief items to predict health behavior. King's (1983) multivariate regression findings showed significance existed between patient's causal explanations for heart disease and health beliefs of perceived severity and perceived costs. The investigator concluded that patients who were concerned with their heart conditions attributed causes to smoking, tension, overweight, and bad luck;

however, attributions contributed to over 23% of the variation of perceived severity and 35% of perceived costs or treatment difficulty in patients.

Abraham, Costa-Pereira, Florey, and Ogston (1999) conducted a quantitative, two-stage community survey in the United Kingdom. Out of 568 respondents reporting breathing difficulties, the researchers generated two subsamples to discriminate between those individuals who did and did not consult a physician regarding their symptoms. Abraham et al. (1999) explored the cognitions of respondents breathing difficulties using causal attributions, an extended health belief model framework, and self-efficacy to differentiate between the two groups. The researchers found that individuals with lower perceived severity of symptoms, attribution of wheezing to smoking, and lower self-efficacy with respect to explaining breathing difficulties to a physician discriminated between those who did and did not obtain a medical consult (Abraham et al., 1999). Researcher's results suggested that self-efficacy could be a significant factor in participants seeking medical assistance for health behavior. Abraham and colleagues concluded that using both the HBM and causal attributes would facilitate the development of health programs to decrease breathing difficulties in patients with recurrent, frequent, or serious breathing problems and encourage medical help-seeking amongst patients (Abraham et al., 1999).

Adekeye and Adeusi (2011) used a quantitative methodology to examine the impact of attribution patterns, attitudes, and knowledge of HIV/AIDS on sexual behavior change within 603 University students in Nigeria. Researchers used a stratified, proportional, and systematic sampling technique to evaluate the population of the college, sex, age, and current level of study. Researcher’s administered questionnaires to participants at the start of classes. There were four standardized scales used to measure the constructs of attribution patterns, attitude, sexual behavior and knowledge of HIV/AIDS. Adekeye and Adeusi (2011) analyzed data using regression analysis to test attitude, illness attributions, and knowledge on the sexual behavioral change; analysis of variance (ANOVA) to compare mean differences of sex and age, and the correlation coefficient to assess the association between study variables and demographics factors of age, sex, and sexual activity. The investigator’s findings showed that neither attitude patterns nor attitudes towards HIV/AIDS were significantly related to sexual behavior change among subjects. The researchers determined that the best predictor for sexual behavior change was the variable of knowledge of HIV/AIDS. Gender showed a significant effect on sexual behavior change in participants, while age showed no effect. The researcher’s examination of the HBM constructs showed that perceived benefits was strongly correlated with sexual behavior change, attribution patterns, and attitude and knowledge of HIV/AIDS. The researchers concluded that making young adults knowledgeable about HIV/AIDS and aware of the perceived benefits of behavior change could reduce risky sexual behavior.

Frameworks and Summary

The literature combining the HBM framework with attribution theory has taken several forms. Hewstone, (1983), suggested that health beliefs either trigger, or are accompanied by, causal attributions. Hewstone’s conceptualization implied that both cognitions have the potential to influence subsequent behavior. King (1982) suggested that attributions actually determine subsequent health beliefs. Her proposed model for this integration is presented in figure 2.3.

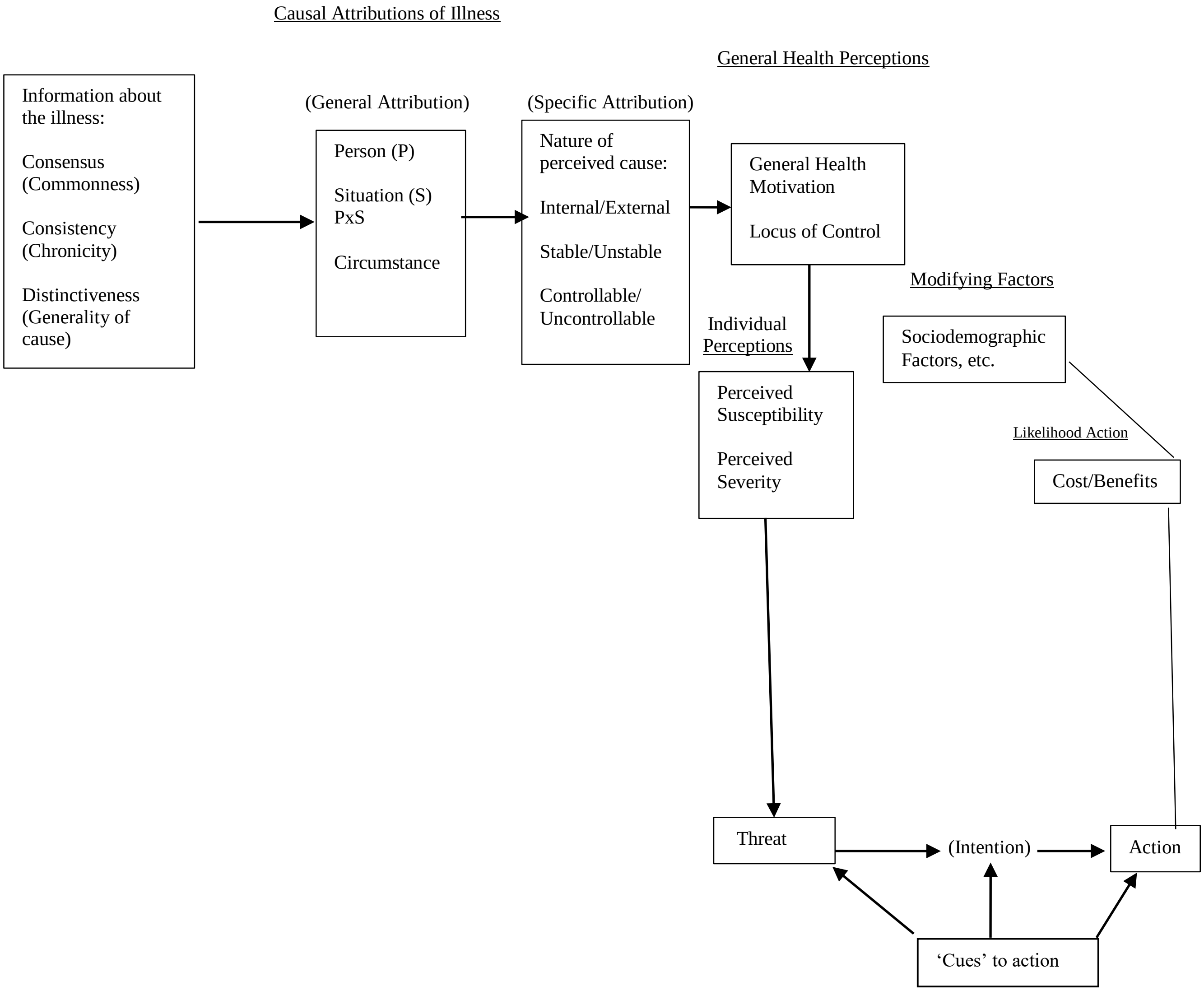

Figure 2.3. Proposed synthesis of Attribution Theory and the Health Belief Model: a model to predict behavior. *Note* Adapted from King, J. B. (1983). Illness attributions and the health belief model. *Health Education & Behavior, 10*(3-4), 287-312; King, J. B. (1982). The impact of patients' perceptions of high blood pressure on attendance at screening: An extension of the health belief model. *Social Science & Medicine, 16*(10), 1079-1091.

King tested the model by examining its ability to discriminate between attendees and non-attendees of a high blood pressure screening program and found that causal attributions acted in conjunction with health beliefs, and also had independent effects on the behavior under investigation, however, King failed to confirm the complex model in its entirety. King next investigation employed a simpler model to investigate the relationships among the attributions and health belief variables in cardiac patients and, again investigated the influence of both HBM and attribution constructs on participation in hypertension screening programs (King 1983). The reduced model was consistent with Hewstone's more general conceptualization and is presented in figure 2.4.

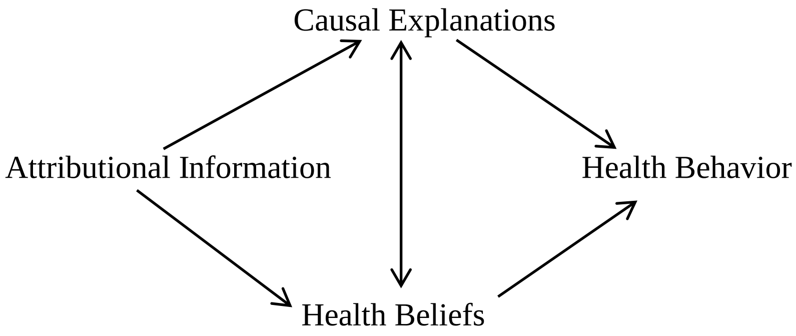

Figure 2.4. Influence of HBM and Attribution Constructs for Hypertension Screening. *Note.* Adapted from Hewstone, M. (1983). Attribution theory and common-sense explanations: An introductory overview. In M. Hewstone (Ed.), *Attribution theory: Social and functional extensions.* (pp. 1-26). Oxford: Basil Blackwell.

King found that cardiac-related causal attributions among cardiac patients were strongly correlated with perceived severity and perceived costs and correlated, but less strongly, with susceptibility and benefits. The findings supported the assertion that attributions and health beliefs are both operative in health cognitions. With respect to the investigation into attendance at a high blood pressure clinic, King found that Kelley's construct of consensus, Weiner’s construct of controllability, and the HBM constructs of costs and benefits strongly discriminated attendees from non-attendees. King concluded from the two investigations that different health related behaviors appear to be tied to different combinations of attribution and belief variables (King, 1983).

Abraham et al., (1999) employed King’s latter framework in their attempt to discriminate between individuals with breathing problems who consulted a physician and those that did not consult. These researchers used an extended version of the HBM as they included the self- efficacy construct. The researchers found that perceived severity and self-efficacy were major discriminating variables that operated in conjunction with external attributions specific to respiratory difficulties. The researchers recommended that health interventions that targeted the combination of attribution and HBM construct measures most predictive for consulting behavior among individuals with breathing difficulties would encourage medical help-seeking.

In contrast to Hewstone, King, and Abraham et al., Adekeye and Adeusi’s (2011) research focused on the determinants of health behavior change and employed a variable often used as a precursor in change interventions involving the HBM; accurate knowledge of the illness or disease state (King, 1982, 1983; Hewstone, 1983; Abraham et al., 1999; Adekeye & Adeusi, 2011). In this study, the researchers found no association between attributions and behavior change relative to reducing the risk for HIV/AIDs. The researchers did find, however, that accurate knowledge of HIV/AIDs, coupled with an appreciation of the benefits of risk reduction techniques were not only the key predictors of behavior change, they were independently correlated with attribution patterns.

Although the researchers themselves reported, but did not interpret this latter finding, King's model stipulates that attributions are based on prior knowledge, whether that knowledge is accurate or not, and, therefore, accounts for the correlation of attributions with knowledge of HIV/AIDs and belief in the benefits of risk reduction behaviors. The exact measurement items used in this investigation were not specified, but given the pattern of correlations, this study again supports the use of an extended version of the HBM, this time one including knowledge, as a companion framework to an attribution framework. The lack of information on measurement items makes it impossible to accurately determine contribution of the paired frameworks as better measures may well have yielded attribution effects, rather than having those effects subsumed by the knowledge component. More generally, however, this study again supports the need to identify disease specific attributions and beliefs to gain a more refined understanding of the determinants of a given health-related behavior.

Rationale for Using the HBM

The findings from each of these studies supported the use of both attribution theory and the HBM as a comprehensive framework for understanding how cognitions drive health behaviors. Adekeye and Adeusi (2011), Abraham et al. (1999), and King (1983, 1982) noted in their research that an integration of attributions and health beliefs raise specific questions to future research when using this approach. King (1982) stated that attributions do not always play a part in health decisions, yet may be important, which raised several questions. "When do people seek or use particular explanations in the decision making process"? "What is the function of these explanations in the decision to comply with the advice and in recovery, as well as take preventative measures”? “When and how do explanations interact with other health beliefs in their effects on behavior”? (p.1090). The overall findings from the literature further suggest that the key salient attribution and HBM constructs may differ from illness state to illness state, and differ according to whether the health behavior under consideration is help-seeking or behavior change oriented. In addition, the findings implicate attribution constructs from both the Kelley and Weiner frameworks and both core and extended constructs from the HBM as potentially operational in health behavior-related decisions and actions.

Rationale for Using HBM in Conjunction with Attribution Theories

My study intention was reflective of both the King, (1983) and Abraham et al. (1999) investigations as I sought to understand the specific cognitions that contributed to the family caregiver’s decision to seek care for a cognitively impaired family member and to better understand the pattern of cognitions that could lead to a delay in the diagnosis and treatment of AD. The literature supported using an extended HBM framework as well as attribution constructs from both Kelley and Weiner. I, consequently employed a comprehensive set of constructs from the attribution theories and the HBM, as well as an examination of the fundamental attribution bias as supported by the attribution literature examined in the section on Attributions. Further to this, the Wadley and Haley (2001) study on attributions related to cognitive impairment and the investigation by Adekeye and Adeusi (2011) suggest that gender may be a significant influence on the occurrence of the fundamental attribution bias and on decision-making and behavior. I then, therefore, included gender as a factor in my investigation. The model for the combined frameworks I used to guide my investigation is presented in Figure 2.5.

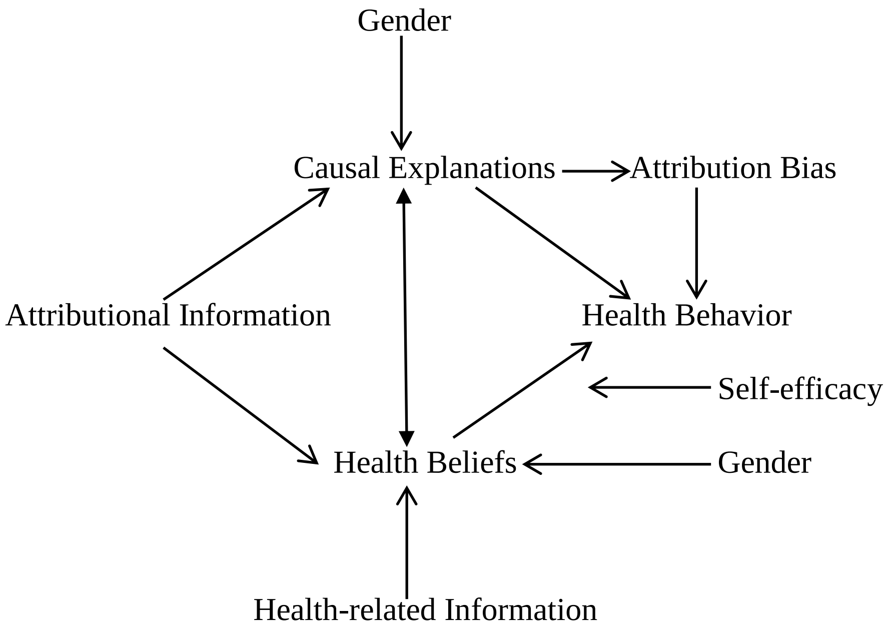

Figure 2.5 Combined Health beliefs and Attributions Model. *Note.* Adapted from King, J. (1983). Illness attributions and the health belief model. *Health Education & Behavior, 10*(3-4), 287-312.

Figure 2.5 represented the potential set of relationships suggested by the combined attribution and HBM-attribution literature. The core model is adopted from King as it is illustrated in figure 2.4, and assumed that causal attributions and health beliefs both influenced the health related behavior in question: the family caregiver's decision to seek a medical evaluation of a loved one displaying symptoms consistent with cognitive impairment (King 1983; Abraham et al., 1999). Both Adekeye and Adeusi (2011), Abraham et al. (1999) determined that an extended version of the health belief model yields more discriminating data than do the core HBM concepts alone when employing a combined Attribution and HBM framework. Consistent with factors included these two studies, self-efficacy has been added as a construct influencing the translation of the belief that a loved one should see a medical professional to actually acting on that belief and accessing the medical care system. Adekeye and Adeusi's (2011) finding that knowledge of an illness can influence or even substitute for beliefs regarding severity and susceptibility leads to the inclusion of this extended component of the HBM to determine if knowledge of AD is an important component of the overall decision to seek care. The final component of the model is a reduced examination of sociodemographic variables. Gender proved significant for both the form and function of causal attributions (Wadley and Haley, 2001) and in results obtained using the HBM (Adekeye and Adeusi, 2011), so this demographic variable is specified in the model. Because my study population is African American, the race demographic was held constant. The literature on attributions and HBM provide no further guidance on sociodemographic variables so further additions to the model with respect to this information was considered after an examination of the key literature on AD.

Key Literature

Clinical Manifestations of Alzheimer's Disease

Definition of Alzheimer's Disease. Alzheimer's disease is the most-common form of dementia in individuals over the age of 65 (AA, 2014a; National Institute of Neurological Disorders and Stroke, (NINDS), 2014). All forms of dementia result in memory loss, impaired judgment and functioning, and subsequent behavioral and personality changes, but the pathologic changes in brain structure vary by the type of dementia, as does the progression of, and prognosis, for the disease (NINDS, 2014). The pathology and symptomology specific to AD follow.

Pathological Changes in Alzheimer's Disease. Research on AD has demonstrated significant anatomical aberrations, as well as characteristic changes at the cellular level (AA, 2013; CDC, 2013; Gong, Chang, Viola, Lacor, et al., 2003). The brain of an individual who suffered from advanced AD is withered and contracted relative to a normal brain. These gross anatomical findings are due to nerve cell death, and a corresponding loss of tissue, and are evident throughout the brain. The wasting is particularly severe in the hippocampus, that region of the brain responsible for memory formation (AA, 2014a). Microscopic examination reveals abnormal formations, termed plaques and tangles, which appear to be tied to nerve cell death; however, no conclusive evidence yet exists to specify the exact mechanisms responsible for brain cell death and the progression of AD. Plaques are abnormal clusters of beta-amyloid protein fragments that are theorized to block the synapses that permit the chemical transfer of information from one neuron to the next. Plaques are also thought to trigger the immune system to attack, destroy, and consume the afflicted cells. Tangles occur when tau proteins, which normally lie in parallel lines to act as a conveyor system for cell nutrients, collapse and twist. This collapse interrupts nutrient transport and, therefore, the resulting tangles are also implicated in brain cell death (AA, 2014a; Callone et al., 2006; Gong et al., 2003).

Pathologic Changes by Race. Miles, Froehlich, Bogardus, and Inouye (2001) used previous population studies to examine differences between African Americans and Caucasians relative to vascular dementia, Parkinson's- related dementia, and Alzheimer's dementia. The researchers' also examined the effect of race on cognitive test results (Miles et al., 2001). The study researchers' findings revealed clinical, molecular, and epidemiological differences between African Americans and Caucasians with African Americans demonstrating a higher prevalence of vascular dementia due to risk factors of hypertension, diabetes mellitus, and stroke and a lower prevalence of Parkinson's dementia than Caucasians. A significant genetic etiology revealed on a molecular level showed that Caucasians had a potent risk factor of apolipoprotein, APOE-4 allele compared to African Americans (Miles et al., 2001). The Comprehensive Assessment and Referral Evaluation (CARE) diagnostic, Mental Status Questionnaire, Short Portable Mental Status Questionnaire, and Blessed Memory-Information-Concentration test showed poorer scores within African Americans than Caucasians that suggested cognitive deficits differences among races. The differences in dementia among African Americans and Caucasians suggest an urgent need for the development of preventative and treatment methods according to each race (Miles et al., 2001).

Pathological Changes by Gender. According to a five-year study by the Spampinato, Rumboldt, Weininger, Vavro, Patrick, and Parker (2012) from the Radiological Society of North America (RSNA) gender differences exist in the brain structure of cognitively impaired individuals with AD. Dr. Spampinato and colleagues evaluating the magnetic resonance images (MRIs) of 60 males and 49 females' found that gray matter loss in cognitively impaired individuals was greater in women than men. The MRIs were performed 12 months before AD diagnosis and at the time of their diagnosis that may have implications for the onset of AD and mild cognitive impairment (MCI) therapies. Men and women experienced gray matter atrophy within different regions of the brain during disease progression of MCI to AD with men exhibiting more aggressive behavior, and women experienced more gray matter loss. The investigators further suggested that clinical trials for new drugs, researchers should consider differences in brain atrophy patterns by gender (RSNA, 2012).

O'Hagan, Wharton, and Kehoe (2012) used mice to examine the possible association of life cycle fluctuations in estrogen levels related to the risk of developing AD. The researchers found that estrogen-renin angiotensin system (RAS) maintains blood pressure, interconnections could explain recent conflicting findings that reduced estrogen levels and hormone therapy in females during menopause transition may increase their risk of high-blood pressure and RAS changes to cerebrovascular and increase AD risk. Although researchers used mice, O'Hagan and colleagues suggested that the relevance to humans is that if estrogen levels are constant during menopause, then females will have a less likely chance of developing hypertension and AD. The researchers concluded that there should be further examination of clinical trials targeting RAS or estrogen systems for prevention of AD and treatment should pay be attentive to gender-specific biochemical factors as possible confounders.

Pathological Changes by Race and Gender. Zamrini, Parrish, Parsons, and Harrell (2004) explored co-morbidity in black and white male and female patients with possible AD. The researchers used a computerized database from their Memory Disorders Clinic data file from the last 10 years to obtain the AD diagnosed patient information. The researchers divided subject data into two groups. The first group included black and white patients matched on age at presentation to the clinic, age of AD onset, duration of illness, Mini-Mental State Examination scores, and variation of co-medical illnesses (Zamrini et al., 2004). The second group included all white individuals that were randomly matched to black individuals with the same variables as Group 1. Zamrini et al. (2004) found that in Group 1, black individuals exhibited a higher rate of hypertension than whites, yet whites had a higher incidence of atrial fibrillation and cancer in comparison to blacks. In the second group, men were younger at the presentation to the clinic than women, the duration of illness was shorter for black men than white men, white women, and black women, and the MMSE scores were lower in blacks than whites. In accordance to Group 1, blacks had a higher rate of hypertension, yet whites had higher rates of atrial fibrillation, cancer, coronary artery disease, high cholesterol, and gastrointestinal disease (Zamrini et al., 2004). The investigators concluded that within group 1 and 2, blacks with possible AD had a higher rate of hypertension than whites with possible AD. The researchers suggested that the comorbid illness in black and white individuals with possible AD is due to differences in the groups rather than a statistical Type II error (Zamrini et al., 2004). The researchers did not find any significant findings specific to gender.

Cognitive Symptoms and Progression in Alzheimer's Disease. Alzheimer's disease results in cognitive and functional changes which differ from those changes associated with normal aging (AA, 2014a; Mayo Clinic, 2014; AA, 2011). According to the Alzheimer's Association (2014a) top 10 warning signs and Leifer (2009), possible early signs and symptoms of Alzheimer's disease include short-term memory loss, wandering, inability to cook, bathe, read, or write, loss of appetite, speech impairment, depression, mood swings, uncertainty of normal occurrences, inability to recognize friends and family, aggressive behavior, uncontrollable bladder and urinary tract infections (UTIs), and constant repetition of statements and questions. The Mayo Clinic (2014) noted that skills such as reading, dancing, singing, music enjoyment, storytelling, and engagement in creative activities may not be affected until later stages of AD.

The timing of Alzheimer’s disease progression varies from person to person, but stages of progression have common characteristics (AA, 2014b). The general stages of AD are classified as early, middle, and late with seven steps of illness progression over the three stages. The first stage includes no memory problems: a person functions normally. The second stage includes slight forgetfulness: a person may forget common words or placement of daily objects. The third stage is a mild cognitive impairment (MCI): a person has difficulty pronouncing words or names and performing tasks, problems are noticed by family and friends, and the doctor may detect concentration or memory problems. The first three steps are considered the early stage of AD with the third stage of MCI possibly being identifiable by a physician or caregiver. The fourth stage is a moderate cognitive decline with symptoms confirmed: a person forgets recent events, incapable of performing challenging mental mathematics, irritable behavior, and unable to recall personal information. The fifth stage is a moderately severe cognitive decline with gaps in memory: a person is confused about location and time, unable to remember their address or telephone number, requires assistance choosing clothing daily, and still remembers important details about identity and family as well as how to eat and use the bathroom. The fourth and fifth steps are considered the middle stage of AD. The sixth stage is a severe cognitive decline: a person's memory worsens and is unable to remember recent experiences, yet can remember certain long-term memories. A person may experience difficulty with family and friend's names, sleep pattern changes due to uncertainty of time and day, need assistance with toileting, may experience delusions, compulsive, or repetitive behavior, and may wander or become lost. The seventh stage is a very severe decline: a person is unable to respond to their environment, unable to hold a conversation, exhibits involuntary movement, and requires ongoing assistance with daily activities (AA, 2014b, p.1). During this stage, both short and long-term memories are affected. The sixth and seventh steps of progression are the late stage of AD. The identification of stages of a degenerative illness occurs during the patient's time of diagnosis. After the last stage of Dementia, it then leads to memory loss (initially short-term) which eventually affects the person's normal behavior and everyday lifestyle activities like cooking, reading or driving (AA, 2011a, p.1). According to the Mayo Clinic (2014) and AA (2014a, 2014b), most sufferers live an average of eight years after noticeable symptoms, although some sufferers may survive up to 20 years.

Cognitive Decline and Progression of Alzheimer's Disease by Race. Although the literature does not present evidence of differences of cognitive decline and progression by gender, evidence does exist suggestive of a difference by race. Barnes, Wilson, Li, Aggarwal, Neelum, et al. (2005) recruited 452 persons with a clinical diagnosis of AD from Rush Alzheimer's Disease Center and adult daycare centers in Chicago, to determine if there was an association between race and rate of cognitive decline. The researchers administered nine cognitive tests to each participant, including tests for episodic memory, working memory, language and verbal comprehension, and visual spatial acuity (Barnes et al., 2006). African Americans showed a lower level of global cognition at the baseline compared to non-African Americans; however, their decline was, on average, 25% slower than the decline exhibited by Caucasians (Barnes et al., 2005). The researchers concluded that that the rate of cognitive decline of AD is slower African Americans compared to Caucasians, specifically for episodic memory. Barnes and colleagues suggested that one possibility concerning the association of race to cognitive decline is that African Americans may be misdiagnosed with AD more frequently than Caucasians.

Treatment for Alzheimer’s Disease. There is currently no cure for Alzheimer’s disease (Alzheimer’s Association, 2014c), but there are drug and non-drug treatments that assist with cognitive and behavioral symptoms and slow the rate of decline (Alzheimer’s Association, 2014c). Aricept, Exelon, and Razadyne are cholinesterase inhibitors that slow the progression of AD in individuals with early and moderate stage AD (AA, 2014c). Vitamin E is sometimes prescribed because it has been shown to postpone decline in the ability to perform activities of daily living in AD sufferers (AA, 2014c; Isaac, 2008). The Alzheimer’s Association (2014c) stated that non-drug therapies include practitioner’s examination of patient’s behavioral changes, in addition to, training to implement coping strategies to manage behavioral changes of individuals with AD. The non-drug approach helps practitioners manage behavior symptoms to promote emotional and physical comfort for suffers with a primary goal of identifying and addressing the needs of the affected individuals in expressing themselves as AD progresses (AA, 2014c).

Treatment Difference for Alzheimer's Disease by Race and Gender. Studies have shown slight variations in drug treatments for AD patients based on race and gender (Hernandez, McClendon, Zhou, Sachs, & Lerner, 2010; Perryman, Lewis, & Rivers, 2009). Hernandez and colleagues explored differences in acetylcholinerase inhibitor (AChEI) and memantine medications based on race, ethnicity, and geographic locale for 3,000 subjects. Additional variables included gender, age, marital status, level of education, dementia severity, AChEI use, memantine use, and source of referral. The researchers evaluated whites, blacks, and Hispanics on an individual and community level using a multivariate analysis to determine the importance of race, geographic location, and ethnicity on medication use (Hernandez, McClendon, Zhou, & Lerner, 2010). The researchers found that blacks were less likely to use AChEI and memantine compared to non-Hispanic whites. There were no significant findings associated with medication use among blacks in comparison with whites. Findings showed disparities of younger age to be weakly related to the increased likelihood of anti-dementia drug use, and higher education increased the likelihood of memantine use. The researchers concluded that blacks were less likely to take AChEI and memantine than whites and Hispanics were less likely to take memantine than whites. Participants who were referred by clinics were more likely to take AChEI and memantine than those not referred (Hernandez et al., 2010).

Perryman, Lewis, and Rivers (2009) explored prescribing patterns for AD medication by race and ethnic group. The researchers used a time series to analyze three years of secondary data from AD Medicare beneficiaries. The study examined the use of medication by age, gender, race and ethnicity, level of memory loss and the presence of comorbid states. Perryman and colleagues identified Aricept and Exelon as the primary medication prescribed for the study population. The researchers' found that blacks and Hispanics were more likely to receive Aricept than whites. Blacks in comparison to Hispanics with diabetes, memory loss, and psychological disorders were less likely to receive Aricept treatment (Perryman et al., 2009). Diabetes patients were also taking Aricept, Exelon, and mood altering medications. In this study, all variable associations lacked identification. The use of Aricept for AD treatment in both blacks and whites decreased from 76 in 2001 to 37 in 2002 for blacks and 382 in 2001 to 183 in 2002 for whites. The researchers concluded that patients for AD treatment were not taking mood enhancers, although hormones were present in medications which may indicate hormone therapy as a treatment option for the post-menopausal sample population (Perryman et al., 2009).

Differences by race and gender are important to understanding the cognitive, functional, and genetic changes that occur when a person is suffering from AD (Spampinato et al., 2012; Zamrini et al., 2004; Miles et al., 2001). As the researchers suggested, these differences support the need for preventative methods adjusted by race and gender (Spampinato et al., 2012; Miles et al., 2001). Hormonal changes within females during pre and post menopause also indicates a need to take hormonal influences into account in developing treatment and preventative measures to possibly delay AD onset. The literature on racial and gender differences in the progression and treatment of AD supported my study focus on cognitive barriers that possibly delay the early diagnosis of AD specifically in African Americans and argues for an additional examination of gender differences within the African American subpopulation. I provided the epidemiology of AD in the next section.

Epidemiologic Information on Alzheimer's Disease

Prevalence and Incidence of Alzheimer's Disease

Alzheimer's disease (AD) accounts for 70% of all dementia cases in the United States and is the sixth leading cause of death among the elderly (AA, 2014a; CDC, 2013). In 2014, there were 5.2 million individuals with AD, about 200,000 of whom were under the age of 65 (Alzheimer's Association, 2014a). This degenerative chronic disease affects all races and nationalities, but the prevalence of AD is increasing among African Americans. The prevalence of AD affects 88% of elderly African Americans and 44% elderly Caucasians within all age groups (AA, 2014a). Figure 2.7 shows the general proportion of AD cases by age groups. Individual's ages 75-84 years have a higher proportion of AD with those 85 plus years following with the next highest proportion as seen in figure 2.6.

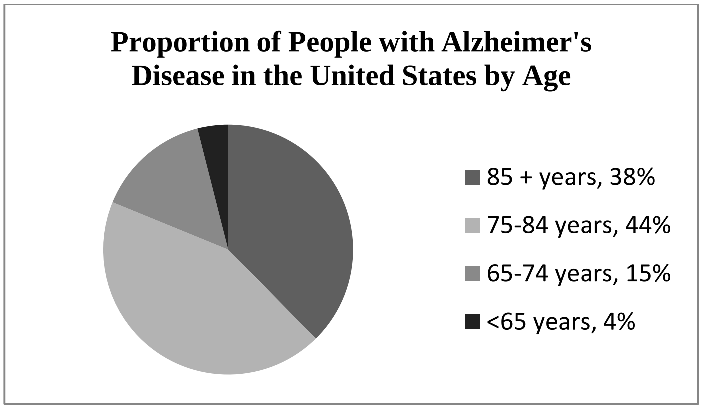

Figure 2.6. Proportion of People with AD in the United States by Age. *Note.* Adapted from the Alzheimer's Association. (2014a). Alzheimer's disease Facts and Figures. Retrieved from http://www.alz.org/downloads/Facts_Figures_2014.pdf *and* Hebert, L., Scherr, P., McCann, J., Beckett, L., & Evans, D. (2001). Is the risk of developing Alzheimer's disease greater for women than for men? *American Journal of Epidemiology, 153*(2), 132-136. *Percentages are not equal to 100% because of rounding.*

The number of new AD cases is increasing (AA, 2014a). The AA (2014a) projects that by 2050, the number of persons over 65 years of age with AD will triple from the current five million to approximately 16 million. Every 67 seconds, someone in the United States develops AD and by mid-century the number of cases will double and occur every 33 seconds (AA, 2014a). There are approximately 470,000 persons over 65 years old in the United States that will develop AD in 2014 (AA, 2014a, p.1). In 2014, there will be an estimated 59,000 new cases among persons 65 to 74 years old. There will be 172,000 new cases among persons 75 to 84 years old and 238,000 new cases among persons 85 and older (See Table 2.6) (AA, 2014a, p.19).

Table 2.6.

Number of New Cases of Alzheimer's disease in 2014 by Age Group.

Number of New Cases	59,000	172,000	238,000
Age Group	65-74 years old	75-84 years old	85 years and older

Note. Adapted from Alzheimer's Association. (2014a). Alzheimer's disease Facts and Figures. Retrieved from http://www.alz.org/downloads/Facts_Figures_2014.pdf

Prevalence of Alzheimer's Disease by Race

African Americans and Hispanics are more likely to develop AD compared to Caucasians (AA, 2014a). The number of African Americans is increasing from an estimated 44.5 million in the 2012 census, and the CDC projects that the number will reach 77 million by 2060. There will also be an increase in the number of cases in this group (CDC, 2013; Hughes et al., 2009; Tang et al., 2001). According to the Alzheimer's Association (2014a) the prevalence of AD in individuals 65 to 74 years old is 9.1% for African Americans compared to 2.9% for Caucasians and 7.5% for Hispanics (See Figure 2.7). The prevalence among individuals 75 to 84 years of age is 10.9% for Caucasians, 19.9% for Hispanics, and 27.9% for African Americans (AA, 2014a, p.1).

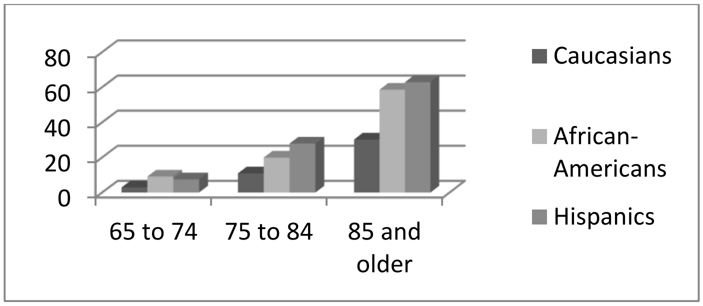

Figure 2.7. Proportion of People Age 65 and Older with Alzheimer's disease and Other Dementias. *Note.* Adapted from the Alzheimer's Association. (2014a). Alzheimer's disease Facts and Figures. Retrieved from http://www.alz.org/downloads/Facts_Figures_2014.pdf and Gurland, B., Wilder, D., Lantingua, R., Stern, Y., Chen, J., Killeffer, E. & Mayeux, R. (1999). Rates of dementia in three ethnoracial groups. *International Journal of Geriatric Psychiatry, 14(6),* 481-493.

Prevalence of Alzheimer's Disease by Gender

According to the AA (2014a), two-thirds of those diagnosed with AD are women. There are 3.2 million women and 1.8 million men out of 5 million individuals diagnosed with AD over the age of 65 (AA, 2014a, p.1). Women in their 60s are more likely to develop AD than breast cancer (AA, 2014a). Among all races, more women develop AD than men (AA, 2014a).

Risks factors of Alzheimer's Disease

AD is the primary cause of morbidity and mortality in the United States (AA, 2014a; AA, 2011). The currently accepted risk factors for AD are advancing age, genetic predisposition, brain-related cardiovascular disease, traumatic brain injury, social isolation, and a lack of activity or cognitive reserve (AA, 2014a; CDC, 2014; Flicker, 2010). Female's longevity puts the group at greater risk due to advance aging. Modifiable risk factors of poor diet, lack of exercise, and smoking increases risks for cardiovascular disease which ultimately increases a person’s risk for developing AD (Flicker, 2010). Age is considered the main risk factor, in addition to, gender and heredity influencing the risk for the development of AD (AA, 2014a; Flicker, 2010; Vina et al., 2010).

Risks factors by Race

There are risk factors for AD that vary by race and ethnic groups (AA, 2014a, 2014b; CDC, 2013). African Americans are at a higher risk for strokes and heart attacks, and other cardiovascular ailments consistent with potential cardiovascular brain disease (AA, 2013; Leung et al., 2011; Hughes et al., 2009; Weiner et al., 2007; Barnes et al., 2006). African Americans and Latinos have higher rates of vascular disease that may put these groups at a higher risk for AD than Caucasians (AA, 2014a).

Mortality and Morbidity of Alzheimer’s Disease

AD is the fifth leading cause of death of individuals over 65 years of age (AA, 2014a; CDC, 2014). In 2010, it is estimated that 600,000 people 65 years and older that died from AD. There were 400,000 individuals 85 years and older and 200,000 65 to 84 years of age (AA, 2014a; CDC, 2014). Data from Medicare suggests that 1/3 of all seniors who die within one year die from AD or another dementia (AA, 2014a). AD increased 68% between 2000 and 2010, while the top five causes of death percentages decreased (See Table 2.7).

Table 2.7.

Percentage Changes in Selected Causes of Death in the U.S. of all Age Groups from 2000 to 2010.

Cause of Death	Breast Cancer	Prostate Cancer	Heart Disease	Stroke	Human Immunodeficiency Virus (HIV)	Alzheimer's disease
Percentage Change	-2%	-8%	-16%	-23%	-42%	+68%

Note. Adapted from Alzheimer's Association. (2014a). Alzheimer's disease Facts and Figures. Retrieved from http://www.alz.org/downloads/Facts_Figures_2014.pdf

AD is the primary cause of disability and poor health (AA, 2014a). Severe dementia typically leads to immobility, difficulty swallowing, and malnutrition which may increase the risk of death (AA, 2014a). Most AD sufferers become dependent on caregivers to assist with AD symptoms to sustain daily living (CDC, 2014).

Healthcare Burden of Alzheimer's Disease

In 2013, family and unpaid caregivers provided 17.7 billion hours of unpaid care for AD patients equating to 1,139 hours of care per year (AA, 2014a). In 2013, the economic value of care provided by family and unpaid caregivers was 220.2 billion (AA, 2014a). In 2012, an estimated 9.3 billion resulted in healthcare costs caring for AD patients. In 2014, Medicare and Medicaid expected to pay 150 billion in overall healthcare costs for individuals with AD and a total of 214 billion from all financial sources (See Figure 2.8) (AA, 2014a).

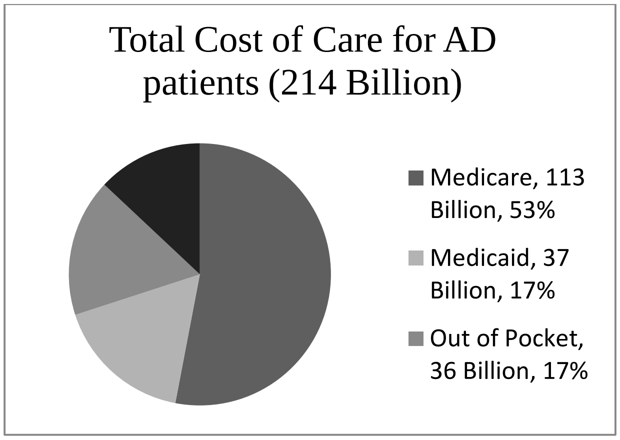

Figure 2.8. Total Costs of Care for AD patients 65 years and older. *Note.* Adapted from Alzheimer's Association. (2014a). Alzheimer's disease Facts and Figures. Retrieved from http://www.alz.org/downloads/Facts_Figures_2014.pdf

In summary, as the prevalence and incidence of AD increases, further research is required to educate lay individuals and health care providers on techniques to diagnose at-risk individuals early on (AA, 2014a, 2013; CDC, 2013; Vina & Lloret, 2010; Musicco, 2009 and Tang et al., 2001). In addition, increased risk factors in African Americans supported my reasoning to further investigate why this group is diagnosed at later stages than other races and determine barriers that contribute to this delay (Leung et al., 2011; Sinforiani et al., 2010; Hughes et al., 2009; Beinhoff et al., 2008; Weiner et al., 2007; Barnes et al., 2006). The next section presents literature on the delay of AD diagnosis.

Delayed Diagnosis of Alzheimer's Disease

General Information on Delayed Diagnosis

The early recognition of AD is essential in sustaining a normal quality of life for the sufferers and caregivers afflicted by the illness (Leung et al., 2011; Hughes et al., 2009; Clark et al., 2005). The caregiver's daily life activities could result in many burdens. Sometimes early signs and symptoms in family members may go unrecognized unintentionally (Leung et al., 2011; Hughes et al., 2009; Clark et al., 2005). According to Harvard Health (2005), mild cognitive impairment (MCI) is considered the earliest stage of identifying a possible onset of AD. There is a lack of efficient methods to detect dementia early on, therefore, the individuals that are at risk often experience a delay or misdiagnosis until symptom progression occurs (Harvard Health, 2005).

Delayed Diagnosis by Race

AD is becoming more prevalent in individuals over the age of 65 (CDC, 2013; AA, 2012). Older African Americans are one of the largest minority groups in America (CDC, 2013). African Americans are prone to having a higher risk of early onset of AD due to underlying chronic illnesses. African Americans experience a late diagnosis of the disease compared to Caucasians (Hughes et al., 2009; Clark et al., 2005).

Hughes et al., (2009) examined barriers to early diagnosis of AD in 17 African American family caregiver's retrospective experiences. The investigators utilized the HBM constructs to determine barriers that family caregivers of the AD patients experience during the stages of diagnosis for loved ones. The researchers administered face-to-face semi-structured interviews to obtain participant's experiences with family members. The researchers found that most participants lacked knowledge about AD prior to the family member's diagnosis. Participants did acknowledge that there is no cure for AD and expect to see a decline in their loved one's health. There was some uneasiness when participants responded to if they would develop AD in the future. Hughes and colleagues mentioned that the diagnosis of AD occurs at later stages compared to other chronic illnesses such as cancer and cardiovascular disease (CVD) due to treatment advancements and expenses. The researchers concluded that future studies should explore barriers to an early diagnosis in African Americans from the primary care physician and community service provider's perspectives. There is a requirement for AD educational awareness programs for African American families (Hughes et al., 2009).

Ayalon and Arean (2004) evaluated the knowledge of AD in 97 Anglos, 37 Latinos, 30 Asians, and 30 African Americans, and 10 unidentified individuals. Each group completed a survey about AD in which the researchers measured knowledge of AD using 17 true-false questions. The questions included acculturations (if live in the United States and the number of years speaking English), highest educational attainment, ethnicity, and other demographic information such as marital status, birthplace, and age. The findings from this study suggested that Anglos with a mean total score of 10.41 were more knowledgeable about AD than African Americans (8.36), Asians (4.96) and Latinos (3.94). The level of education accounted for partial differences recognized within Latino and Anglo participants concerning the knowledge of AD. The researchers controlled age within the sample and found an association with the number of years speaking English with the awareness of AD in Asians. The researchers concluded that ethnic groups lack adequate information about AD that may explain the absence of AD service use by these groups. The researchers stated that there is a requirement for an evaluation to identify barriers to knowledge of AD to educate minority groups better about the significance of early intervention (Ayalon & Arean, 2004).

Delayed Diagnosis by Race and Gender

The influence of parent gender in early diagnosis of AD may be a potential factor to consider when reducing barriers (Griffith & Lopez, 2009; Wadley & Haley, 2001). In the African American community, males exemplify masculine characteristics and are considered the head of household. Males often lack the initiative to seek medical assistance (Grant, Davis, Rivers, Rivera-Colón, Ramos, et al., 2012; Wade, 2008).

Griffith and Lopez (2009) investigated patient gender of males on barriers to AD diagnosis and treatment. The researchers examined primary care physicians (PCPs) of an African American and Hispanic male to determine if PCPs lack the ability to diagnose the men with AD or any cognitive decline. The researchers found that the diagnosis of men occurs at later stages than women due to healthcare provider's lack of recognition of cognitive decline. If barriers become defined and recognizable among healthcare providers and caregivers, diagnosis may be performed at earlier stages of the illness (Griffith et al., 2009).

Contribution of the Family Caregiver to Delayed Diagnosis

Leung et al. (2011) explored barriers to early recognition and AD diagnosis among Anglo-Canadian populations of early stage diagnosed patients and primary caregivers. From 2006-2009, the researchers recruited six Anglo-Canadians with AD and seven caregivers from the Alzheimer's Society of Calgary. The researchers utilized five major themes: awareness of cognitive trouble, regarding meaning of problems to symptoms, seeking medical assistance, acknowledgment of the severity of cognitive changes, and to obtain a definite diagnosis. Patients stated recognizing memory problems before their caregivers. From semi-structured interviews, most patients and caregivers took at least three years to seek medical help from either the primary care physician or a local healthcare provider, which caused a delay in AD diagnosis. However, some patients and caregivers did recognize early signs and symptoms of dementia two to four years prior to the medical diagnosis. The researchers concluded that primary caregivers and healthcare providers must be able to recognize dementia-related signs and symptoms to reduce delay in AD diagnosis (Leung et al., 2011).

Clark, et al., (2005) examined factors that delay a timely diagnosis in African American AD patients. The researchers examined socioeconomic status (SES), educational levels, time and location of diagnosis (inner city or suburban clinic), and MMSE scores for patients and caregivers. Findings showed that caregivers and patients exhibited lower educational attainment and patients experienced higher rates of diagnosis at inner city clinics than suburban clinics. There was no difference in MMSE scores among participants. There was a similarity in caregiver recognition of cognitive problems and consultation with a physician. The researchers disclosed that the majority of African American patients and caregivers experienced a difficult time accepting the initial diagnosis of AD in comparison to Caucasians due to lack of physician consultation at primary care facilities. Caregivers and patients at suburban clinics first consulted a primary care physician for diagnosis before coming to the clinic and were more likely to be diagnosed at earlier stages than the inner city patients. Family caregivers experienced denial about loved one’s diagnosis of AD that contributed to the diagnosis delay. The investigators concluded that a timely diagnosis is crucial for African Americans at risk for AD. It will require assistance from healthcare providers and caregivers in being able to recognize barriers in the beginning stages (Clark et al., 2005).

Connell, Roberts, McLaughlin, & Carpenter (2009a) examined the attitudes of dementia diagnosis in black and white family members of patients diagnosed with AD. The researchers used convenience sampling from two major cities by conducting a telephone survey with 178 family members of individuals with AD. Participants rated the importance of eight benefits and 16 barriers to obtaining an AD diagnosis. The researchers found that the family members deemed several obstacles in the delay to seek help for loved ones. It included no cure for AD, therefore, no diagnosis is necessary, expensive healthcare costs, and that memory loss is a part of normal aging (Connell et al., 2009a). The researchers concluded that African American caregivers delayed the process of seeking help for family members with AD, in addition to, expressing a lack of knowledge about AD. African American participants responded to only hearing about AD without acquiring further research information concerning the illness (Connell et al., 2009a). After caregivers finally realized that their family members were exhibiting abnormal behavior, caregivers made inquiries to seek professional assistance to obtain an understanding of why family member’s cognitive ability declined.

Knopman, Donohue, and Gutterman (2000) explored factors associated with the delay in AD diagnosis. The researchers mailed self-administered questionnaires to 1480 caregivers of AD patients. The researchers used two measures to examine the delay of AD diagnosis with caregiver information: 1) The period of time from first AD signs until the recognition of an exact problem and 2) The period of time from the recognition of a problem to the first doctor consultation. The researchers categorized caregivers at the date of patient’s diagnosis and the relationship of caregivers to patients. The investigators determined that there was a mean delay in time from the first observation of symptoms to problem recognition for diagnosed individuals. The delay in the past 12 months was 1.20, the past 13 to 48 months at 1.56 and the past 49 months at 2.25 (Knopman et al., 2000, p.302). The diagnosis time frame influenced delay from problem recognition to the initial doctor consultation. The researchers found that caregiver’s relationships did not affect the delays. Only 38% of caregivers had reported the correct diagnosis at initial physician consultation. Caregivers provided multiple causes for the delay in seeking medical assistance. These included uncertainty of severity (47%); assumed changes in patient’s normal aging (37%); difficulty to discuss cognitive changes with the patient (27%); anger from patients (27%); patient refusal to visit a doctor (24%); and caregiver denial of patient confirmed AD diagnosis (9%). Caregivers were allowed to submit multiple reasons for the delay in seeking medical help; therefore, the percentages exceed 100%. The researchers concluded that there is a lack of understanding the difference between cognitive changes in healthy aging in comparison to AD. Knopman and colleagues mentioned that there is an ongoing need for public and professional education to communicate the fundamentals of AD diagnosis as well as routine dementia screening to overcome barriers. There is additional research required further to distinguish stages in AD delay, especially in both genders and culture backgrounds (Knopman et al., 2000). Knopman (2000) was the most recent published study using my variables of interest.

Contribution of Primary Health Care Provider to Delayed Diagnosis

AD is a fatal, incurable chronic disease that typically requires extensive health care provider attention (Leifer, 2009). This results in a lifetime discomfort, frequent and expensive doctor's visits, medical tests, medications, and therapies for the sufferer. In occurrences, most of the time individuals experiencing early signs and symptoms of AD may obtain a consultation from their primary care providers (PCPs). The PCPs should take the initiative to examine patients further for memory problems during routine visits (Leifer, 2009). The examinations for determining AD can be expensive (Ernst & Hay, 1994). The expenditure of caring for an Alzheimer’s patient may become costly and demanding for the caregiver, resulting in potential barriers (Husaini, 2003). Caregivers make difficult decisions when deciding what facilities to place loved ones for adequate medical assistance for AD care. The CDC (2013) stated that the cost for patients with Alzheimer’s disease is very expensive at $24,500 per patient averaging over 84 billion a year. In 1991, the total costs for patients were 67.3 billion (Ernest & Hay, 1994).

Physicians and healthcare providers may not notice changes in patients, especially if the patients maintain healthy behavior during semi-annual and annual visits. It is imperative for healthcare providers to be proactive in recognizing early signs and symptoms of AD. The recognition could prevent the delay of diagnosis and implement treatment for patients (AA, 2013, 2012; CDC, 2013; Hughes et al., 2009).

African Americans are more widespread than Caucasians in acquiring AD (AA, 2013; CDC, 2013; Hughes et al., 2009; Clark et al., 2005). AD is being associated with other chronic conditions, such as cardiovascular disease (CVD), high blood pressure

(HBP), and diabetes (CDC, 2013). AD suffers experience more adverse health occurrences including falls and infections. Sufferers receive more psychotropic medications and are more likely to be hospitalized than those with the same variables without AD (Malone, McLaughlin, Wahl, Leiban, et al., 2009).

Bradford, Kunik, Schulz, Williams, and Singh (2009) conducted a literature review to determine the prevalence and contributing issues influencing neglected and delayed AD diagnosis in health care settings. The researchers estimated the prevalence of neglected and delayed diagnosis from quantitative data related to analytical sensitivity among health care providers. The researchers determined potential predictors and contributing issues from quantitative and qualitative literature of caregiver, patient, provider, and resource barriers. The investigators found that major contributing factors were problems with attitudes and patient-provider communication, educational deficits, and limited resources (Bradford et al., 2009). The researchers stated that the actual occurrence of neglected and delayed diagnoses of dementia is unidentified although appears to be high. Bradford and colleagues concluded that screening for dementia needs to become more convincing to promote a timely detection of AD and focus to eliminate barriers to a delay in diagnosis.

There is a lack of literature on patient gender differences in African American females and males including variables of barriers, personal attributes, and biases that may impact the delay of early diagnosis of AD. Family members’ attitudes and acceptance towards the diagnosis of AD for patients can serve as potential barriers (Hughes et al., 2009; Carpentier, Ducharme, Kergoat, & Bergman, 2008). The majority of literature concluded that barriers to dementia diagnosis have existed because there is a not a cure for the disease. The research revealed in both black and white family members the belief that there is a treatment and that AD is a normal aging process (Connell et al., 2009; Hughes et al., 2009; Hinton et al., 2005). The possibility of detecting an early diagnosis in patients may slow progression of symptoms and would possibly better assist caregivers with supportive resources (Hughes et al., 2009; Clark et al., 2005). Even though, there is not a cure for AD, patients, caregivers, and healthcare providers must continue to focus on the best care available for the patient. If gender differences reveal barriers and attributes in the process of early diagnosis of AD for African Americans; therefore, this study contributes to decrease the delay of diagnosis and progression of AD in African Americans.

Summary

The literature review indicated that African American men and women are at higher risks of a delayed diagnosis of AD compared to other racial groups (AA, 2013; CDC, 2013; Hughes et al., 2009; Leifer, 2009; Kawas & Corrada, 2006; Clark et al., 2005). The current research study examined whether there are significant gender differences in barriers to accurate and early diagnosis of AD in African Americans. The perspectives of family caregivers are important to the AD delay and how family caregiver’s decisions may impact the healthcare provider’s initial evaluation. Connell et al. (2009a), Connell et al. (2009b), and Hughes et al. (2009) all ascertained that African American caregivers’ major issue and barrier for a timely dementia diagnosis is the lack the knowledge about when to seek help for loved ones. Culturally, African Americans have strong beliefs that the children are to take care of the parents when diagnosed with a chronic illness such as AD, therefore; there is a lower rate of seeking assistance from primary care physicians or health care providers (Connell et al., 2009b; Hughes et al., 2009; Clark et al., 2005). A precise and timely diagnosis of AD offers an opportunity to implement a treatment plan for patients in hope of slowing disease development while providing family members with helpful resources (Mosconi et al., 2007; Clark et al., 2005). Chapter 3 presents information on how the use of the grounded theory explained the process of cognitive barriers to the delay of AD diagnosis.

Chapter 3: Research Method

Introduction

The intent of this study was to explore whether African American family caregivers embrace similar gender biases and causal attributions regarding family members which contribute to a delay in early diagnosis of AD. Consequently, the goal of this investigation was to develop a better understanding of how family caregivers' cognitive barriers contributed to the delay of AD diagnosis. My findings from this study may support the development of a new theory of family caregivers' knowledge and understanding of AD to create more awareness and techniques for the early detection of AD in family members. This information help explains the meaning and consequences of the early signs of mental impairment in elderly African Americans. In this study I was able to determine how attributions, gender biases, and perceived barriers contribute to the increased risk of postponement of AD diagnosis in African Americans, and to establish the extent to which a pattern exists in this population (Griffith & Lopez, 2009; Hughes et al., 2009; Clark et al., 2005; Paton, Johnston, Katona, & Livingston, 2004; and Wadley & Haley, 2001). My examination of gender differences helped to explain cognitive patterns within the African American community, but did not indicate whether African American males or females are at a greater risk for a delayed diagnosis of AD. In this chapter I present the major components of the research methodology, design, rationale, my role, participants, setting, procedures, data analysis, ethical considerations, and informed consent required by the Institutional Review Board (IRB).

Research Design and Rationale

The research questions that guided this study are:

RQ1: To what extent do caregiver perceptions of the value of obtaining a diagnosis of Alzheimer’s vary by gender of the affected family member?

RQ2: To what extent do caregiver perceptions of the accessibility of medical care vary by gender of the affected family member?

RQ3: To what extent do attributions directed toward the affected family member vary by gender?

RQ4: To what extent does the caregiver lay interpretation of the need to seek medical care differ by attributions?

Qualitative research depends on understanding an individual’s behaviors, perspectives, personal experiences, and feelings through thorough description (Creswell, 2009; Hughes et al., 2009; Charmaz, 1990). Creswell (2009) stated that qualitative research use theory as a “general explanation for behavior and attitudes as well as to study questions about gender, class and race” (pp.61-62). Hughes et al. (2009) declared that qualitative research provides underrepresented populations with a voice and the exploration of social experiences, unlike quantitative research that identifies relationships between variables (p.100). The qualitative researcher can connect with the participant through the use of interviews, observations, case studies, and life stories while giving meaning to the phenomenon (Hughes et al., 2009). In this study, I used a broad qualitative approach with a grounded theory design, including in-depth interviews with semi-structured questions, to explore family caregivers’ experiences in order to offer a new theory of lay perceptions. A qualitative methodology is reliable in understanding barriers to early diagnosis and treatment of AD in African Americans and how this unexplored area in the literature may assist family caregivers with better techniques to help at-risk individuals (Hughes et al., 2009; Clark et al., 2005; Mahoney, Cloutterbuck, Neary, & Zhan, 2005). I examined the role that gender plays in family caregivers' decisions to seek medical assistance and an early diagnosis of AD for afflicted family members.

As I previously discussed in Chapter 2, other researchers have quantitatively examined relationships between health beliefs and attributions in illnesses such as breathing problems, heart disease, HIV, and high blood pressure (Adekeye & Adeusi, 2011; Abraham et al., 1999; Hewstone, 1983; King, 1983, 1982); however, there is a scarcity of investigations concerning the combination of health beliefs and attributions among African Americans affected by AD. I considered using quantitative research, but doing so could have reduced the effectiveness of providing an in-depth understanding of family caregivers' barriers, biases, and attributes that contribute to a delay in AD diagnosis. Creswell (2009) stated that quantitative analysis determines relationships between variables while qualitative research focuses on individual experiences, behaviors, and attitudes. For this study, because there was a lack of investigation within the African American population, it was difficult to identify variables. Researchers have explored health beliefs and attributions separately in either African Americans or all ethnicities; however, there has not been an exploration of both concepts to develop a unified theory (Adekeye & Adeusi, 2011; Hughes et al., 2009; Clark et al., 2005;

Abraham et al., 1999; Hewstone, 1983; King, 1982, 1983). I considered other qualitative research approaches including phenomenology, case study, and narrative study. Phenomenology is a qualitative approach where the researcher inquires about lived experiences when little, or nothing is known about the topic of interest. Phenomenology focuses on understanding a concept or phenomenon, whereas the purpose of using a grounded theory approach is to focus on individuals' social situations and the meanings they assign to events (Creswell, 2009; Trochim, 2006). Phenomenological research involves a "small number of participants through extensive and prolonged engagement to create patterns and relationships of meaning" (Moustakas, 1994 as cited in Creswell, 2009, p.13). A phenomenological approach would not have been as useful as a grounded theory approach for this study because I sought to identify and explain participant's beliefs, feelings, barriers, cognitive and unknown biases, and attributions that contribute to their loved one's AD delayed diagnosis. Using a grounded theory approach could generate the development of a new theory of family caregiver's interpretations concerning barriers and biases for an early diagnosis of AD. A case study was not suitable because it provides an in-depth exploration of an event, program, activity, or process of one or more individuals. Likewise, a narrative approach was not suited to my study because it focuses on the lives of one or more persons who tell stories of some sort (Creswell, 2009, p.13).

The grounded theory was developed in 1986 by researchers Glaser and Strauss. A grounded theory approach differs from other qualitative methods because it shapes the data collection in the field while providing structure to data analysis processes of coding, note-taking, and overall writing (Charmaz, 1990). Creswell (2009) declared that a grounded theory approach requires constant comparison of data with emerging categories and theoretical sampling of different groups to maximize the similarities and the differences of information. I compared and contrasted data and identified emerging categories from interviews with the intention of developing a defined theory of family caregiver interpretation. This new theory could allow a better understanding of family caregivers' recognition of early signs of cognitive impairment and possibly prevent a delay in AD diagnosis. Glaser and Strauss (2009) declared that the use of a grounded theory approach allows the researcher to develop a new theory of the entire course of data collection and research. The researcher's focus is on processes of individual's social interactions and the meanings they assign to events. During the process of using grounded theory, the researcher must perform ongoing comparative analysis after data collection. Researchers have noted that qualitative research using a grounded theory approach provides emerging categories and hypotheses for quantitative research needed to explore the concepts further, test the theory, and ascertain facts (Glaser & Strauss, 2009; Charmaz, 1990). My use of a grounded theory in this study provided new information and categories for the reasons family caregivers delay an early diagnosis for their loved ones.

Role of the Researcher

As a researcher, I served as the primary observer and collector of information from participants. I collected data on participant's experiences with their family members affected with AD and made observations during the interview process. I asked semi-structured interview questions (see Appendix G) and recorded answers on each sheet while audio recording participants during each private interview session. After each session, I secured interview sheets, notes, and other confidential participant information in a locked safe in my home. I interpreted participants' experiences during interviews based on my personal knowledge of AD. However, after each interview I emailed or mailed each participant a complete transcript of the interview to ensure that I interpreted and transcribed the information accurately. I had no prior relationships with participants in this study.

Methodology

Participant Selection Logic

The population of interest for this study consisted of African American family caregivers caring for AD-diagnosed individuals at all stages. I used a purposeful sampling strategy to collect pertinent data from participants. Creswell (2009) confirmed that purposeful sampling strategy assists the researcher in selecting the best participants or sites to understand the problem and research questions. Purposive sampling is designed to serve a particular need or purpose by allowing the researcher to recruit a specific group of individuals based on the objective of the study (Rudestam & Newton, 2007; Tongco, 2007). Participants for this study were African American family caregivers for loved ones that have a confirmed AD diagnosis.

The criteria for participant selection consisted of African American ethnicity, English language speaking, family caregivers of suffers with a confirmed diagnosis, male and female family caregivers 18 years and older. The sample population included eight individuals. This number of participants was sufficient to obtain significant information on personal experiences and to avoid saturation of data. Participants were able to determine if they fit criteria to participate in the study from flyer postings at the local geriatric clinic affiliated with a local university. On March 11, 2015, the geriatrician sent confirmation of approval from her division chief to recruit from this location. She sent her division chief a letter of support and he approved recruitment. If participants met all requirements for the study, the contact information was listed on the flyer for further participation.

Sample

I initially recruited study participants from a local university's geriatric clinic in Dallas, Texas. Nationally recognized in the U.S. News and World Report of 2014, this top ranked geriatrics program offers expert diagnosis by specialists who care about the needs of patients and families. This local university has many geriatric specialists to assist individuals with issues they may be experiencing due to the onset of Alzheimer's disease and early dementia. The university's research center is one of the largest in the United States treating patients with AD and other neurological disorders (Local College, 2014). The geriatric clinic, in addition to the memory clinic and local church were appropriate locations to recruit family caregivers for my study because the physicians specialize in assisting AD patients and the church's caregiver's ministry.

Instrumentation

Semi-Structured Interview

For this study, instrumentation included an Olympus (VN-722PC) digital recorder in each private interview session in addition to, observational note taking by the researcher. A grounded theory study primarily uses interview techniques and journal notes (Rudestam & Newton, 2007, p.110). I used an interview protocol (see Appendix C) with primary research questions and semi-structured interview questions (see Appendix E). I did not ask participants primary research questions; only the semi-structured interview questions constructed from the fundamental questions.

Procedures for Recruitment

The methods below served as a chronological guide to recruiting and inform participants, collect and analyze data, and validate findings are below.

1. On January 14, 2015, I contacted, via email, the geriatrician to ask permission to recruit from the geriatric clinic at a local university medical center in Dallas, Texas (see Appendix D). I informed her that I would need to bring her flyers to pass out once IRB approval is granted (see Appendix F) to recruit from her geriatric clinic, in addition to, providing information about the study. On February 24, 2015, the geriatrician submitted a letter of support to her Division Chief for permission to recruit from the geriatric clinic.
    a. I met a Geriatric doctor at an African American Alzheimer’s Family Caregiver’s conference in 2013 and discussed my research project with her, and she informed me to contact her when I was ready to collect my

data. The following week, I emailed the geriatric physician, and she instructed me to keep in touch with her when I am ready for my data collection so that I can recruit from her geriatric clinic. On March 11, 2015 she approved recruitment from the clinic.

2. I provided flyers to the geriatrician on June 10, 2016 to place in her geriatric office for family caregivers to see for self-identification in participation in the proposed study (Appendix F).
3. Once participant’s self-identified for participation in the study, they contacted me via phone to schedule a date, time, and location of the face-to-face interviews.
4. If recruitment flyers do not supply an adequate amount of participants for this study, the geriatrician at the geriatric clinic referred me the neurologist at the memory clinic at the same university for additional recruitment of participants. On April 27, 2015, the neurologist approved for possible recruitment from the memory clinic if required.
5. During the face-to-face interview, I first reiterated the reason for conducting the proposed study and why their participation is important.
6. After the description of the study, I gave each study participant a consent form to sign (see Appendix B). In the initial interview I also asked preliminary questions as listed Appendix C.
7. Following the signing of the consent form, the interview began, and I asked participants semi-structured questions as listed in Appendix E.

8. Subsequent to each interview, I transcribed the digital audiotapes verbatim and analyzed them according to the steps summarized in the data analysis section of this chapter.
9. I then developed and validated themes extracted from transcripts.
10. A week after each interview, a follow-up transcript was either mailed or emailed to study participants to validate data for accuracy during interview sessions.
11. Once participants validated data for accuracy, I began to code data into categories and themes as described in this chapter.

Data Collection and Analysis

Data Collection

The data collection was from a sample population of a local university's geriatric unit in Dallas, Texas. This selection population is relevant due to it being one of the largest organizations that handles Alzheimer's patients in North Texas. Frankfort-Nachmias & Nachmias (2008) stated that a significant necessity for any sample is that if it represents the study population it is drawn. I conducted one-on-one, face-to-face and in-depth interview using semi-structured questions to collect the data during interview sessions. I conducted interviews in natural setting where participants were comfortable such as a home or a public location (Creswell, 2009). Data collection occurred over a period of three months from June to August of 2015. Each interview session took at least one hour to an hour and a half. Data was recorded using an Olympus (VN-722PC) digital recorder as the primary recording device, in addition to, observational note taking by the researcher. Rudestam and Newton (2007) recommends the use of tape recorders to record interviews to reduce the dependence on field notes (p.111). After the initial interview was completed, participants were free to depart and a week after interviews, I sent an email or mailed participants a detailed transcript of the interviews to review for accuracy and preciseness.

Data Analysis

Data collection occurred from each interview, in addition to, a follow-up detailed transcript for participant's to review for accuracy. The data gathered from each interview supplied pertinent information on African American family caregiver's attributes, beliefs, experiences, and biases before and after an AD diagnosis of their afflicted family member. This data determined if family caregiver's attitudes and beliefs about AD, healthcare system, and gender of afflicted family member influence the delay of an early diagnosis. Family caregivers may notice signs and symptoms of AD before healthcare professional (AA, 2014a; Hughes et al., 2009; Clark et al., 2005). After data collection, I used Nvivo 10 computer software for Windows to transcribe data from family caregivers. According to QSR International (2008), NVivo is qualitative data analysis computer software that can be used to handle small and large volumes of qualitative data. Rudestam and Newton (2007) suggest the use of axial coding that relates categories to subcategories consistent with their properties and dimensions. Axial coding allows the evaluation of data to form major categories and create a connection with subcategories (p.185). Once the transcription of data occurred, I color coded data into major themes and patterns based upon similar and dissimilar information. According to Creswell (2009) and Glauser and Strauss (2009), inductive data analysis builds patterns, categories and themes from the bottom up by organizing data into increasingly more abstract units of information. Charmaz (1990) mentioned that coding is significant for the processes, actions, assumptions, and consequences for the researcher to establish preciseness of data analysis, connection, and structure of findings (p. 1168). After transcription, I emailed or mailed participant's the transcribed data to review for confirmation of accuracy.

Issues of Trustworthiness

Trustworthiness is essential for data collection and reviews to ensure that participant's information is kept confidential. The interpretation of results is crucial to determine if the information was accurate or inaccurate and if the research questions were answered correctly (Creswell, 2009). I explained to the participant's the importance of the results and how it may assist with future educational programs. I followed a few of Creswell (2009) recommendations and criteria for validity during data collection. The criteria I used included:

1. Credibility using member checking to determine the consistency and accuracy of the qualitative findings using the follow-up transcripts reviewed by participants. Credibility ensured that the participants approve information to be accurate and allow for them to comment on findings.
    a. I conducted in-depth interview sessions lasting from one hour to an hour and a half with participants to ensure all responses to questions are in detail without any haste.

   b. The researcher used member-checking by participant’s to review transcribed data to ensure that the information recorded is concise and accurate.

2. Dependability and Confirmability- I included details of the process of selecting participants and use similar procedures for all participants during the data collection process. This study included detailed documentation of any changes that needed to occur within in the method, data collection, and analysis. The documentation was checked and re-checked throughout the process. As the researcher, I was responsible for describing changes that may have occurred in the setting and how it may have affected the study’s approach (Trochim, 2006, p.1). Participants chose the location of the interviews so that they could remain in a natural setting and not an intimidating or controlled environment (Creswell, 2009, p.175). The participants reviewed transcribed information for consistency and accuracy. The detailed documentation allowed other investigators to replicate this study as well as explore further research concerning reasons for a delay in AD diagnosis in African Americans.
3. Reliability- I checked transcripts to ensure there are no mistakes made during transcription of data. I formed a codebook to make sure that there were not any errors in the meaning of codes during the coding process. To maintain consistency and reliability throughout the study, I performed the following:

a. Documented as many steps of the procedure as possible during the study as well as changes that needed to occur (Creswell, 2009, p.190; Trochim, 2006).
b. The interview protocol was the same for all participants. Each participant was asked the same questions in chronological order.
c. All interview sessions lasted the same amount of time for all participants.
d. Once data was transcribed, I emailed or mailed participants their transcripts for review of accuracy.
e. I also had participants check their transcripts for reliability as a form of member checking (Creswell, 2009).
f. I performed triangulation using various data sources of information to justify themes. Once themes were established from several sources of data from participants, it supplied consistency and reliability to the study (Creswell, 2009, p.191).

Ethical Procedures

The participants in this study were adult males and females who were free to choose whether to participate or not at any given time during the research study. There were no known risks to participating in this study. Participants may experience emotional issues such as sadness, regret, denial, or guilt, but no physical harm should result from taking part in this study. These possible experiences were taken seriously because they could indicate reasons for a delayed diagnosis in affected family members. Participation in this study may create significant psychological stress for family caregivers who are likely to be already under a great deal of stress. On the consent form, I referred participants to Alzheimer's Association of Greater Dallas 24-7 helpline for free to low cost caregiver counseling to assist with possible risks. The Alzheimer's Association of Greater Dallas offers a family caregiver's class that covers meeting daily challenges, communication, safety, managing difficult behavior and caring for the caregiver. They also offer caregiver brochures, access to 24-7 hotline (1-800-272-3900), and support groups for free (Alzheimer's Association of Greater Dallas, 2014). Each participant completed a consent form (See Appendix B) for protection before interviews. In the researcher's home, the field notes, audiotapes, and transcripts were locked in a safe. The researcher validated results and was the only person to have access to the transcripts. The interview protocol (see Appendix C), as well as a state identification card or driver's license will serve as initial identification of participants then I used unique identifiers (e.g. 0001-A, 0001-B) during transcription to protect participant's identity for data validation. After data analysis was complete, audiotapes will be destroyed, and field notes and interview transcriptions will be put in a paper shredder after five years.

Summary

African American family caregivers may exhibit personal biases, attitudes and health beliefs that delay diagnosis of AD in their loved ones. The purpose of Chapter 3 was to describe the research design and methodology along with explaining participant recruitment criteria and selection. I provided rationales for the chosen research design, data collection, data analysis, and sample population. There was a discussion on credibility, dependability, reliability, and ethical concerns for participation in this study. Chapter 4 presents transcribed findings of data collected.

Chapter 4: Results

Introduction

The purpose of this qualitative, grounded theory study was to explore if African American family caregivers have similar underlying attributional and gender biases about family members that may contribute to the delay in early AD diagnosis. My goal was to determine family caregivers' perspectives to better understand why diagnosis delays occur in African American populations. The findings of this study may support the development of a new theory of family caregivers' knowledge and understanding of AD.

I examined whether and the extent to which gender differences existed in family caregivers' decisions to seek medical diagnosis for their loved ones. The findings revealed gender differences indicative of cognitive patterns within the African American community. However, the results did not show whether African American males or females are at a greater risk for a delayed diagnosis of AD. In this chapter I will present detailed information on the study's setting, participant demographics, and my data collection and analysis procedures. I will also present evidence of trustworthiness, the results from the one-on-one interviews, theme identification, and a summary of the findings.

Research Questions

In this study the following research questions guided the investigation. However, the original research questions included variations by gender that could not be answered effectively with the data. Therefore, I did not remove the gender variable from the questions and I used the data as effectively as possible without always including the variable. The research questions are as followed:

RQ1: To what extent do caregiver perceptions of the value of obtaining a diagnosis of Alzheimer's vary by gender of the affected family member?

RQ2: To what extent do caregiver perceptions of the accessibility of medical care vary by gender of the affected family member?

RQ3: To what extent do attributions directed toward the affected family member vary by gender?

RQ4: To what extent does the caregiver lay interpretation of the need to seek medical care differ by attributions?

Data Collection

This study used face-to-face, one-on-one interviews to collect data. I collected data from eight participants; however, ten individuals contacted me. Two did not meet participation criteria and were thus not chosen to participate. Data collection followed the exact protocol presented in Chapter 3. Initially, I called or texted (dependent on participant preference) each participant 24 hours before the scheduled interview as a reminder. Most participants confirmed their scheduled date and time, but one participant had to reschedule due to personal issues. I used the following protocol during each interview.

First, I greeted participants and introduced myself as the primary research for this study. I began the interview process by giving each participant a copy of the consent form as I read it in its entirety (see Appendix B). I then asked each participant if they had any questions about the consent form or study and if they were still willing to participate. We then both signed two copies of the consent form: one for my records and one for the participant. I used the interview protocol (see Appendix C) to get participants' demographic information. I interviewed each participant using 17 semi-structured interview questions (Appendix E), which I designed to guide the discussion. At the end of each interview, I allowed participants to share additional information that they would like me to know about their experience as a primary family caregiver.

Data collection locations varied including five participant's homes, two workplaces, and one public library within the Dallas, Texas metropolitan region. My choice of locations was dependent on participants' choices to ensure a natural and comfortable setting (Creswell, 2009). Recruitment for the study began on June 10, 2015; however I did not conduct my first interview until August 4, 2015, and concluded the interviews on October 16, 2015.

The interviews ranged from 16 minutes and 29 seconds to 1 hour, 42 minutes and 56 seconds of recorded data. I recorded the data using an Olympus recorder model VN-722PC in addition to taking notes on semi-structured interview sheets. I focused on participants during interviews, took notes, and observed participant's behaviors (facial expressions, emotions, and body language) to help me better answer the primary research questions. I transcribed after the interviews after each was completed. Although the 17 semi-structured questions (Appendix E) were intended to elicit detailed and specific responses from participants, some chose to give very succinct information and others were more open to sharing information. Within one week of each interview, I transcribed the interview and emailed or mailed the complete transcript to the participant for review to ensure that all data was accurate and credible. All of the eight participants approved transcripts within a week or two after I emailed or mailed the transcript. There were two unusual circumstances encountered during data collection. Participant 0001-A lost her husband to death three weeks after our interview and the interview with 0005-E went beyond the allotted time (one hour and a half) stated in Chapter 3.

Setting

After I received Walden’s Institution Review Board approval on June 5, 2015, # 06-05-15-0158986 (see Appendix B), I invited African American primary family caregivers 18 years and older caring for loved ones with AD to participate in the study. A local university medical center for geriatric care served as the primary recruitment site.

Initial recruitment efforts failed to yield the required sample size. Therefore, I took additional steps. On July 15, 2015, I went to my second approved recruitment site (a memory clinic) and provided the research coordinator 30 flyers to pass out to possible participants. The second recruitment site also failed to yield the required sample size, and so on August 6, 2015, I submitted a change of procedures to the IRB to add yet another recruitment site. On August 18, 2015, I received approval to recruit from a local church and subsequently distributed flyers to interested individuals in the church’s caregivers’ ministry.

Participants contacted me via phone to express their interest in the research study, and I asked further questions to ensure that they fit the criteria (see Appendix A). The one-on-one, face-to-face interviews took place at various locations such as participants’ home, workplaces, and a public library study room. Participants were free to choose a comfortable location for the interviews. I conducted five interviews at participant’s homes, two at participants’ workplaces, and one at a public library. All of the locations were quiet, except for at two participant’s home due to random interruptions from others however, there were no issues with recording the data. At each interview, I provided participants with informed consent forms (see Appendix B) and thoroughly reviewed the form before beginning the in-depth, semi-structured interviews. There were no personal or organizational conditions that influenced participants or their experience at any time during the study which may influence analysis of the study findings.

Data Management

Interview data (protocol, interview questions, and recorder) were transferred to a storage clipboard to ensure consistent protection of data during transport from my home to the interviewee’s location. After completing each interview, I transferred all participant’s data to a locked safe in my home. I created unique identifiers on the interview protocol (Appendix C), semi-structured interview sheet (Appendix E), and transcript to identify study participants and keep personal information confidential at all times.

Data Analysis

During data analysis stages, I used a USB port to transfer data from the Olympus recorder to my computer, and copied them into NVivo for Windows 10 for the first six, and Windows 11 for the final two. I then used NVivo to listen to each interview at a slower pace and transcribe each interview verbatim, within one week of each interview.

After transcription, I listened to and reviewed each interview to make sure transcripts were precise, accurate, and free of errors. I then emailed or mailed the transcribed interviews to participants to for member-checking to ensure the accuracy and precision of the data. For one participant, I initially sent the transcript via email, but there were technological issues with his computer so he requested that I mail the transcript. After receiving approval of member-checking from all eight participants, I printed all interviews and performed a preliminary analysis of the transcripts to obtain a general understanding of what the data were showing.

I followed Strauss and Corbin's (1998) steps for this inductive process. I first performed line-by-line coding, an open-coding technique in which I used a pencil to underline key words in the transcripts to break the data in smaller portions. Subsequently, utilizing an inductive data analysis, I used color highlighters to distinguish each broad concept to identify and organize distinct categories and patterns in the data. The second level of data analysis involved axial coding in which I re-read the text to confirm patterns and categories, and to determine relationships between patterns and categories (Rudestam and Newton, 2007). In the third level of analysis, selective coding, I transferred final concepts and categories into a data table to show major themes (Creswell, 2009; Glauser and Strauss, 2009). In summary, I coded data into specific codes and themes using first the preliminary open-coding method, second, axial color coding to relate codes/categories to primary research questions, and finally selective coding.

Demographics

I completed a total of eight in-depth interviews for this study. During the initial interview protocol, I asked each participant preliminary demographic questions (Appendix C). Participants were assigned a unique identifier and were asked their name, address, age, gender, caregiver status, marital status, and the highest level of educational attainment. This information was important to obtain accurate background information and to determine participant's relationship with AD patients.

Table 4.1 shows the demographic information collected from the eight African American family caregivers. The age of participants ranged from 41 years to 84 years. The sample of African American family caregivers included six females (75%) and two males (25%). Five (62.5%) individuals were married, two (25%) single, and one (12.5%) divorced. The majority of caregivers were caring for a parent (n=6), with some caregivers caring for a spouse (n=2) as shown in Table 4.1. There were variations in the marital status as well as the level of educational completion among family caregivers. All participant's resided in the Dallas metropolitan area.

Table 4.1.

Demographic Information of African American Primary Family Caregivers (N=8).

Caregiver Unique Identifier	Age	Gender	Marital Status	Loved one Caring for	Level of Education Completion
0001-A	65	Female	Married	Husband	Graduate school
0002-B	58	Female	Married	Mother	4-year college
0003-C	67	Female	Single	Mother	Some college
0004-D	41	Female	Married	Father	Some college
0005-E	46	Female	Single	Mother	4-year college
0006-F	84	Male	Married	Husband	4-year college
0007-G	62	Female	Married	Mother	4-year college
0008-H	54	Male	Divorced	Mother	Some college

Family caregivers were asked about the year of their family member's diagnosis, stage of AD at diagnosis, current stage of AD and number of years their loved one had been living with AD. Table 4.2 summarizes participant responses to those questions. Some family caregivers were unable to provide information due to lack of knowledge about loved one's medical records or being unable to remember specific the time frame.

Table 4.2.

Report of Patient's year of diagnosis, diagnosed Alzheimer's disease stage, current Alzheimer's disease stage, and years living with AD.

Caregiver Unique Identifier	Year of confirmed AD diagnosis	Diagnosed stage of AD	Current AD stage	Years living with AD
0001-A	2011	Early-to-mild (moderate)	Moderate-to-severe	4 years
0002-B	2010	Early-to-moderate	Moderate-to-severe	5 years
0003-C	Unknown	Early-moderate	Early-to-moderate	Unknown
0004-D	2010	Early-vascular Dementia after TIA stroke	Mid-stage, moderate	5 years
0005-E	2011	Early-stage Dementia	Early-to-moderate	4 years
0006-F	2013	Early-Dementia (next appointment called it Alzheimer's	Unknown	2 years
0007-G	2000-2001 (uncertain of exact year)	Very early stage	Severe	14-15 years

0008-H	Unknown	Unknown (possibly moderate)	Middle-moderate (possibly; uncertain)	Unknown

Evidence of Trustworthiness

As described in chapter three, the evidence of trustworthiness for this investigation first included an explanation to the participants about the importance of the results and how the data may assist with future educational and awareness programs. I adhered to Creswell (2009) recommendations and criteria for validity during data collection. The criteria I used included the following:

1. Credibility using member checking to determine the consistency and accuracy of the qualitative findings using the follow-up transcripts reviewed by participants a week after interviews were conducted. Most participants approved the transcripts within a week with 2-3 participant’s approving after a few weeks due to personal circumstances. Credibility ensured that the participants approve information to be accurate and allow for them to comment on findings. Participant 1 only had comments on the findings regarding two minor spellings errors and I immediately corrected those.

    c. I conducted in-depth interview sessions lasting from 16 minutes to an hour and forty-five minutes with participants to ensure all responses to questions are in detail without any haste.

   d. I used member-checking by participants to review transcribed data to ensure that the information recorded is concise and accurate which insured triangulation of data.

2. Dependability and Confirmability- I included detailed documentation of the process of selecting participants and used similar procedures for all participants during the data collection process using the interview protocol and questions. I included detailed documentation of any changes that needed to occur within in the method, data collection, and analysis. The documentation was checked and re-checked throughout the process. As the researcher, I was responsible for describing changes that may have occurred in the setting and how it may have affected the study's approach (Trochim, 2006, p.1). Participants chose the location of the interviews so that they could remain in a natural setting and not an intimidating or controlled environment (Creswell, 2009, p.175). The participants reviewed transcribed information for consistency and accuracy. The detailed documentation allowed other investigators to replicate this study as well as explore further research concerning reasons for a delay in AD diagnosis in African Americans.
3. Reliability- I checked transcripts three times to ensure there are no mistakes made during transcription of data. I reviewed the data to make sure that there were not any errors in the meaning of codes during the coding process. To maintain consistency and reliability throughout the study, I performed the following:

a. Documented as many steps of the procedure as possible during the study as well as changes that needed to occur (Creswell, 2009, p.190; Trochim, 2006).
b. The interview protocol was the same for all participants. Each participant was asked the same questions in chronological order.
c. All interview sessions were anticipated to last the same amount of time for all participants; however some participant's chose to have short or lengthen responses to interview questions. There were variations among participants.
d. Once I transcribed data within a week after the interview was conducted, I emailed or mailed participants their transcripts for review of accuracy.
e. I also had participants check their transcripts for reliability as a form of member checking (Creswell, 2009).
f. I performed triangulation using various data sources of information to justify themes and to ensure credibility and transferability of data. Once I established themes from several sources of data from participants, it supplied consistency and reliability to the study (Creswell, 2009, p.191). As suggested by Creswell (2009), thick, rich description helps disclose findings and add validity to more realistic results (pp.191-192).

Results

The purpose of this study was to determine whether African American family caregivers embrace similar gender biases and causal attributions about family members that contribute to a delay in early AD diagnosis. The ultimate goal of this investigation was to develop a better understanding of the influence that family caregiver's cognitive barriers contribute to the delay of AD diagnosis with the hope of supporting a new theory of family caregivers' knowledge and understanding of AD. There were 10 common themes that emerged from the interviews: early Alzheimer's disease detection, knowledge level of Alzheimer's disease, gender differences play a role in seeking medical assistance, communication with loved one about Alzheimer's disease, physician support critically important, seeking medical assistance for loved one, early signs of behavioral changes, family caregiver emotions to cognitive changes in loved one, family member influence to seek medical assistance, and delayed diagnosis. Each research question was addressed below according to concepts, patterns, and themes presented. There are excerpts included from participants within each theme for this study to support findings.

Theme 1: Early Alzheimer's Disease Detection

The first theme answered research question two: "To what extent do caregiver perceptions of value of obtaining a diagnosis of Alzheimer's vary by gender of the affected family member? Participants were asked if a confirmed medical diagnosis early-on for your loved one would have helped with better treatment for AD. Most participants expressed the unimportance of early detection due to various reasons. A daughter mentioned that early detection probably is important but at the time of her mother's diagnosis there was only one drug for treatment. Participant 0002-B responded, Ummm, probably not, cause early-on it may have I mean, you know, umm. At that time they didn't have as many drugs, you know. At that time it was mostly Aricept, but now they have like three or four different ones.

Participant 0004-D stated that her father received treatment at the time of diagnosis. Therefore, early detection would not automatically assist with better treatment for AD. She stated,

> I wouldn't necessarily say better treatment, because when he did get the diagnosis, umm he started getting the right treatment right away, which, which would include medicine, mm, neurological testing just to see where the deficit was, or how severe it was and try to see exactly what stage at that point which came of course after the diagnosis.

Some participant's expressed that early detection for AD was unimportant because technology and drug treatment have not been deemed effective, in addition to there not being a cure for the degenerative illness. They stated,

> 0005-E: No, because where they are with umm, technology and all that they have to offer, it was no different, you know. If it could've been done a year before, you know. It, where they are is at a [still] (unclear) point, you have to know that it was even, it was even more negative a year ago, two years ago, three years ago, whatever. They offer the same kinds of treatment, i.e., you know the drugs that

> they give and those drugs even don't give, umm any guarantees for anything, umm. So besides riding it out the way that we are, managing it, she, her tolerance level in her head is pretty low for certain medicines or whatever.

> 0007-G: I don't. I don't. No, cause I, I, it hasn't been excuse me, it hasn't been proven or researched how effective Aricept is. We know, they said it, the purpose of it is to slow the progression up, but how do you know. Because there is no defined uh length of time each stage is, so how do I know if it slowed it down, I don't know that.

Four out of eight participants thought that obtaining an earlier diagnosis would not have assisted with better treatment for their loved ones. Family caregiver's attributed that early AD detection was unimportant for several reasons: no cure, lack of advance technology, drugs not certain to work due to lack of African American participation in clinical trials, and that nothing would change. All four participants were females with three family caregiver's caring for their mother, one family caregiver caring for her father. However, three participants believed that obtaining an early Alzheimer's disease diagnosis for loved one's would have helped with better treatment (therapy, medications, and resources).

Theme 2: Knowledge Level of Alzheimer's Disease

The second theme answered research question 2: "To what extent do caregiver perceptions of the accessibility of medical care vary by gender of the affected family member?" Participants were asked about their knowledge level of AD before their loved ones confirmed diagnosis. Some participants were knowledgeable about Alzheimer’s disease before diagnosis of their loved one. Participants shared that they were knowledgeable because of a prior personal experience with AD in their family having either a parent or grandparent with the disease. They stated,

> 0003-C: Yes. I was knowledgeable about it because of the family history actually. Talking to cousins, umm, umm, finding out some things myself, umm, we have a caregiver's ministry here at the church and although we would talk about other things, caring for our loved ones, that would happen and then the Alzheimer's piece came, came up and at that time, you know, I guess I was in a state of denial. I tried to get as much information as I could and then, probably trying to think well does that apply to my mother or not, ah, nah, that doesn't apply to her, she's not doing that (laughs), you know. You know, something like that. Umm, her dad, yeah, her brother yeah, her sister yeah, but nah not my, not my mother. My mother is the baby girl, everybody else is gone, just about, she only has two brothers left out of 12.
>
> 0004-D: I was because my stepfather, so my mom is remarried (laughs), so umm, my stepfather also had a diagnosis of Alzheimer's disease and umm he was diagnosed probably in the mid 1990's so my mom was his caregiver for many years until he passed away recently in March. So I was familiar with it and got to see it first hand, his was totally different type of Dementia.

Some participants stated that they were not knowledgeable about Alzheimer’s disease because they did not hear about AD because it was not as prevalent as it is now in the community, in addition to, unawareness because it had no effect on them or family. They stated,

> 0006-F: Not really, not really knowledgeable, but I had uh, uh I think, I think her mother had had uh, uh Alzheimer's but her mother did not live with us. Her mother lived in California with one of the, with the older daughter and, and uh, and so. I had seen that and then we had, then we had been around my grandmother for a period of time umm, but, but uh during the time that we lived uh around my grandmother, she did not show signs of Alzheimer's. knew it, I didn't know, I didn't know it was Alzheimer's but I knew something had caused grand momma not to be able to communicate the way that uh she had prior to the time that she went to California.
>
> 0007-G: I don't think I really heard that much about Alzheimer's then, because we're looking at about 15-20 years ago. I didn't really hear about Alzheimer's umm, and I don't know if that's just because that wasn't a term in the black community that was used. You very seldom, before my mom, I've never heard of anybody uh, being diagnosed with Alzheimer’s. When she was first diagnosed, I never heard anybody say that in the black community, again it was always uh old age, they just, that was just a natural progression when you got older you forgot stuff and you became senile. So, you know, I didn't know about Alzheimer's.”
>
> 0008-H: Uh. Not as knowledgeable as I should have been and definitely not as knowledgeable as I am now. Beforehand, I really didn't think about it (pause). Before I took over her affairs, I really didn't think about it.

Some family caregiver's expressed that they were somewhat knowledgeable about Alzheimer's disease because a close family member was diagnosed with it, but they still lacked knowledge about the disease due to lack of personal involvement with AD. A wife stated,

> 0001-A: I was somewhat cause my dad had it, but my, we didn't know that's what it was probably, my daddy probably had it 15 years before we knew it. So at that time when he was diagnosed with Dementia I still didn't know as much about the disease uh, to really my husband was diagnosed but I knew with my dad, and he died of Vascular uh, Dementia, yeah so it was probably about 10 years. You know when you're not the caregiver, I didn't have a clue what my mom was going through cause she doesn't live here and most caregivers, you just trying to get through each day so it's just the small thing.

One respondent stated that being a nurse; she still was not as knowledgeable about AD until she became a primary caregiver. She stated,

> 0002-B: Umm, somewhat knowledgeable, just from the fact that I'm a nurse, you know, but no personal, you know, knowledge. I mean I knew umm, in general about it but not specifically when you're living with it that's a whole different thing.

In some responses, these finding led to misconceptions about normal aging which delayed family caregiver's from seeking medical assistance for their loved ones. Some participant's mentioned family history as an important factor in becoming knowledgeable about AD. Three participants were knowledgeable about Alzheimer's disease before their loved one’s diagnosis, three were not knowledgeable before diagnosis, and two were somewhat knowledgeable. The three family caregiver’s that were knowledgeable about AD were caring for two females and one male. The three family caregiver’s that were not knowledgeable about AD were caring for all females. The family caregiver’s that were somewhat knowledgeable about AD were caring for a male and a female. There were variations of caregiver’s AD knowledge level about the gender of the affected family member.

Theme 3: Gender Differences Play a Role in Seeking Medical Assistance

The third theme answered research question two, “To what extent do caregiver perceptions of the accessibility of medical care vary by gender of the affected family member? Participants were asked the gender of their loved ones and if the gender played a role in delaying medical assistance. There were variations in responses and participant’s excerpts that expressed that gender was significant in seeking medical assistance. One female participant stated that she was in denial about her mother experiencing cognitive changes even though she was aware of the family history of AD. She admitted to being in denial about changes that affected seeking a timely diagnosis for her mother. She stated,

> 0003-C: Umm, it's female, my mother. Umm mmm (pause). I guess my denial, umm and seeking, because I would've been the one to kind of push the issue but just in denial and ah nah not this not my mother (laughs), you know. Umm, her dad, yeah, her brother yeah, her sister yeah, but nah not my, not my mother. My mother is the baby girl, everybody else is gone, just about, she only has two brothers left out of 12. There was 12 of them, but they all lived, they all but two

> umm, died in their 70's plus and so umm, very blessed family, very blessed with longevity, umm. And so, I just said nah, no, un-un.

A female participant communicated that her dad was very honoree man being from a military background and she felt that he was a typical male that did not visit the doctor regularly. She thought gender was a major contributing factor that affected seeking medical assistance. She stated,

> 0004-D: Oh. Oh, yeah. I mean for him, yeah, you know, honoring you know. Sometimes men, typically don't wanna go to the doctor and they're like oh I'm okay I can handle this and so I think definitely being a male, umm, is a big role cause even my stepdad, you know, big role in delaying. But he had like a stern wife to be like no (laughs), we're gonna go, you know. But I definitely think so and I think that was a contributing factor, but also the factor that being a Veteran and always being taught to suck it up, go on, survive, and that's what he did, and that's what he, I mean. Military 30 years, that's all he's known.

Most participants expressed that gender of their loved one was not a factor in delaying to seek medical assistance. Some participants identified that there’s medicine for the disease, and their mothers can beat it until the realization of no cure for AD. A wife stated that she was obligated to care for her husband because she honored her marriage vows. She expressed her concern for her husband’s health as he was suffering from another chronic illness. She stated,

> 0001-A: His gender is a man, a male (laughs). Yeah. Not at all. It's my husband. I had no other choice, there's what marriage vows are about. I think one thing with

> his kidney, being so protective of his kidney when any little thing went wrong he would go to the doctor. So he's not the atypical, stereotypical man, people portray that won't go get medical help. Uh, yeah he, he was not reluctant to do that.

A son stated that when he became aware of his mother’s cognitive changes he sought medical assistance for adequate treatment. He took the responsibility to become the primary caregiver for his beloved mother, therefore gender was not significant to him in seeking medical assistance. He stated,

> 0008-H: No, because I, the way I saw it was get her the medicine she needs so she can beat it, you know. It won't be an issue, she can beat it. But like I said, uh, when I got her out here that's when I moved to get her the, try to get her into some program around here that could truly fix what was wrong with her, but before I realized there is no cure right now.

Six out of eight participants believed that gender was not a major contributing factor to a delayed medical diagnosis of AD in their loved one. However, only two out of eight participant’s thought gender of their afflicted family member played a role in delaying medical assistance. The six family caregiver’s that believed that gender was not a factor that contributed to a delayed medical diagnosis were caring for five females and one male. The two family caregiver’s that believed that gender was a major contributing factor to a delayed medical diagnosis were caring for one female and one male. Some family caregiver’s that stated gender was not a factor for diagnosis delay expressed that loved ones were faithful in going to the doctor for routine check-ups. Family caregiver’s that stated gender was a factor for diagnosis delay expressed that denial on their part and being the only child contributed to not seeking medical assistance. One family caregiver stated that her father being the honoree person and sometimes males do not want to go to the doctor, also being a Veteran with a distinct mannerism.

Theme 4: Communication with Loved One about Alzheimer's Disease

The fourth theme answered research question one and four, "To what extent do caregiver perceptions of value of obtaining a diagnosis of Alzheimer's disease vary by gender of affected family member?" "To what extent does the caregiver lay interpretations of the need to seek medical care differ by attributions?" Participant's expressed various communication techniques used with loved ones to discuss possible onset of Alzheimer's disease. One participant mentioned the renewal of health insurance to her husband as a way to encourage an annual check-up and to obtain an AD diagnosis as she had noticed cognitive changes. She stated,

> 0001-A: I think, I mentioned it about the insurance. I used the insurance, the Cobra, it was getting ready and I was telling him. I noticed that uh, you know you're forgetting where you misplacing things, uh, maybe you should see a neurologist for us to just see what's going on you know, uh. It won't hurt just to see while we are on Cobra. So I approached it that way. And at first he was a little reluctant, but then he said well if you think I need to, you know, then I will and so that's how I, we approached it. And then I talked to umm, he, I mean he thinks his kidney doctor walks on water, that's his kidney doctor and when the kidney doctor said couldn't confirmed because I told the kidney doctor somethings I had observed and the kidney doctor say yeah won't I refer you to a neurologist, so he

> was more amiable, you know, once the kidney doctor said it. Yea, I'm going to probably say, probably it was like in January, I mean uh December. Cause, we actually made, probably it was November-December, cause we made the appointment in January. We wanted to do it after we, you know. After we came back from visiting our family and friends in Phoenix.

A female participant explained to her mother the cognitive changes that occurred after hospitalization and the transition to move with her immediately for care. She stated,

> 0002-B: Ummm, hmmm. Prior to her being discharged from the hospital, cause umm she wasn't going to be able to go; we didn't feel safe with her being at home by herself, so. Ummm, just informed her that she was going to have to come to live with me.

An only daughter expressed that she did not communicate with her mother because she did not want her mother to become upset as she was aware of the family history of AD. She stated,

> 0003-C: Un-un (No). I guess I just felt that I didn't want to put that in her head. Umm, because she knows her history. Umm, that's real strange we've never been asked about Alzheimer's like in a, umm, medical history, not there, I don't recall ever seeing anything about family members or you being diagnosed with Alzheimer's, so that that could be, if there are warning signs, you'll ask, you know. You would know that, what to expect down the line, but. Right, right. Yeah, I didn't want to put those thoughts into her head. Un-un (No). I want to

> protect her as much as I can, and just say okay we all get upset and we all, you know, lose things, and you know, just probably in denial, but.

A female participant disclosed that when she visited her father in another state, she would ask him questions about changes noticed and informed him of living changes that were required. She decided to move her father to live with her so that she could constantly monitor his cognitive changes and determine to seek medical assistance for him. She stated,

> 0004-D: Umm, well during a visit, I would continuously ask questions as far as, you know, why are your living arrangements like this? Why are they not kept clean and neat, cause that's very opposite of who you are, umm, and then there would always be a reason or an excuse as to why he wasn't doing what he was doing, whether it was oh I'mma get it, I'mma get to it, you know, just drawing excuses. Also let him know we need to start umm, making preparations for you to come out of this house, umm and actually to see if we could move you into umm better living conditions within the community to try to keep him there where he was familiar. So that, we played with that for a little while, a little bit over a year we played with that to see how that would work. So all those questions came up, so that's why we never made umm the decision to do any of those umm, and decided to rather instead move him to Texas where I could monitor him and take care of him, make sure everything was gonna be okay. Umm, I sat down and talked with him, let him know that hey this is what we see is going on, umm and it was just very upfront and honest. We see these behavior changes, we see the, this

> environment how it is and we see that this is, again not like you, something totally different. Umm, so we just communicated. I spoke with him gently about that, didn't, you know, nothing embarrassing, it was between he and I and probably one or two other family members.

A very concerned daughter used examples to communicate cognitive changes with her mom to avoid the argumentative behavior. She stated,

> 0005-E: Umm, with my mom it had to be by way of examples, umm. If the bill wasn't paid, you know, and it was still sitting up there awhile or in, in this case it had to be the day that the lights, that the electricity went off. I was at work and it went off and she called me because she was scared and I always, I always had her a cell phone from day one; I've always paid her cell phone bill, added her phone to my account so she's always had a cell phone, you know. I sat down and she received it. She was real receptive, because it was early and she had already noticed signs.

A loving husband mentioned cognitive changes to his wife prior to her doctor's appointment. He expressed that she did not completely understand or believe what he was telling her. He stated,

> 0006-F: I, I would, I would believe that I mentioned to her umm maybe a month or two before, about a month or two before we made our umm appointment with the neurologist. I think we talked about it a little bit then, of course umm we had already talked with the uh, her doctor and he had told me that there, that there were certain things that he could do and certain things he could not do and

> recommended umm the, the uh neurologists and then I made the appointment with him and then after I made the appointment with him then I began to kind of talk to my wife about things. Yeah. I simply talked to her. Yeah, I simply talked to her. And I, even though umm, even though she didn't, didn't umm understand and/or believe what I was, I was saying.

A female participant would always talk to her mom about cognitive changes noticed, but she thought that her mom was stubborn. Her mom would commit to doing something and then forget and get upset as if she was never aware. She stated,

> 0007-G: Oh we would always have discussions, because I, at that point I thought she was just uh, being honoree. How could you, you know. I would call and say would you stop and pick up the kids and she'd say okay and then they'd call and say what time ya'll gonna pick us up. And I said I told your granny and when I call her, she would say you never called me. So we would have exchanges but never anything to indicate that was wrong, because again she, you know, personality and you just forgot, you don't wanna admit it. Well, those things we brought to her I guess, I, because there wasn't a discussion about it prior to diagnosis because I had no reason to think that there was a medical condition; it's just you. And so we would just have the uh, interactions on why you didn't do something you said you were gonna do, so you know. We both just get mad and be done with it til the next time.

A son that was unaware of cognitive changes with his mother as she lived in another state and kept her diagnosis a secret. He began to examine her medications and became aware that his mother was diagnosed with AD. He stated,

> 0008-H: She was already diagnosed so I. I never even discussed the changes I saw in her with her umm, because once I figured out that she had been, I never even knew she was diagnosed until I start looking at the medications she was taking then I asked my, my ex-wife, who is a registered nurse what were these for and that's how I found out that she was taking uh Dementia medication, Alzheimer's medication.

Six out of eight family caregiver’s wanted to be certain that their loved ones were experiencing cognitive changes before mentioning it to them. Two out of eight family caregiver’s did not even discuss changes that they were seeing with their loved one due to personal denial and avoiding arguments. Family caregivers expressed how they initiated discussions with loved ones, but waited some time to obtain a diagnosis. In one case, the loved one was already diagnosed before the family caregiver was aware. There were differences in communication techniques based on the gender of the affected family member.

Theme 5: Physician Support is Critically Important

The fifth theme answered research questions one and two, “To what extent do caregiver perceptions of obtaining a diagnosis of Alzheimer’s vary by gender of the affected family member? To what extent do caregiver perceptions of the accessibility of medical care vary by gender of the affected family member?” Participants were asked about the reactions of the physicians to their observations concerning their loved ones. Most participants stated that physician support is very important whether they encountered a supportive physician early on or later in the process of diagnosis. Participants' detailed responses are below about their experience with the physician and its significance. Most participants expressed how the physician did his job and performed cognitive test to diagnose her husband. In contrast, one participant mentioned that the physician showed a basic concern and performed routine cognitive tests on her mother. All participants expressed how significant the physician is in the diagnosis process for their loved ones whether they physician was initially supportive or not.

One female participant shared that the physician showed a basic concern and performed job duties for cognitive analysis for her husband. She stated,

> 0001-A: Did his job, wasn't surprised. Gave standard tests. Diagnosed him with Dementia. Didn't give drugs at that time, said they wouldn't be good at this time. I asked him about cognitive therapy, did he think that would benefit since he was early diagnosed and he said it's really left up to the individual if they're motivated to do it, uh but if they don't want to do it it's not going to help them, uh. I mean he was very informative. He just told it like it was, you know. Based on his diagnosis.

Another female participant expressed that the physician was not interested in the patient's overall health and taking the next step to observe and examine the patient for health changes, but he was more concerned with minimal check-ups and prescription refills. She stated,

> 0004-D: Umm, just like a, a general, basic concern, umm I guess that most physicians have when a family member comes for the first time with concerns of possible Alzheimer's disease. Umm, asked a lot of questions, what my observations were, how long I had noticed these signs and symptoms, umm. Asked my dad some questions, and of course they just noticed, you know, his just mannerisms, his behaviors. They did, of course a full work up, umm, and said it sounded like based off of what I was saying, what other family members were reporting, umm. It sounded like it could be, you know some type of Dementia like Alzheimer's. Umm, that's one thing we did notice about this particular physician, he just really wasn't the type of physician that seems really interested, just hey come see me every couple of months, you need refills on your prescriptions, how you doing, okay send you on your way. So I think a lot of times, umm, the physician plays a great role in that because if they're not interested, if their just there to see the patient on a yearly or quarterly basis umm, and not really seem interested then that makes a big difference. Even if I was to be there, cause I've had that experience were you take them to a physician and they're all about writing prescriptions and not even listening.

Participant 0005-E whose mother was diagnosed with AD expressed the compassion shown by the physicians and case worker when seeking medical assistance for her mother. She felt like the health staff perform their job well and relieved her to have assistance for her mother. She stated,

> 0005-E: The one thing that I remember seeing on their faces was this look of compassion and it was because, you know, they, they understand how hard it is to break that news to a loved one, you know. Yeah compassion, concern, yeah. They had a look of compassion, you know that agreed with what I was feeling. And umm, I appreciated that, umm, you know, that meeting at that table that day I was met with that, that feeling. I got that energy from all of them, you know, because they knew they had to break some bad news, you know. They knew they had to tell us something that was gonna ultimately alter the rest of our lives, you know that day. And so, umm, yeah, yeah. It was yeah, it was compassion.

A male participant stated that the physician was supportive, and he did his job when obtaining a diagnosis for his wife. The husband could tell that there were cognitive changes in his wife as the physician was examining her. He stated,

> 0006-F: Umm, when I umm, when, when he examined her umm, I could tell from the way he was questioning her that there was something wrong. I didn't know exactly what it was, but I knew that there was something wrong. Another thing that he did was, he gave her three uh numbers and then he said to her, I'm gonna, I’m gonna uh ask you for these back in, in the way that I gave them to you, umm in a few minutes and he kept talking then all of a sudden he came back to the numbers, she couldn't do it, she couldn't give him the numbers the way he asked her for. Yeah (supportive), he said she will probably uh. I said I'm going to, I'll give her medications and uh the medication that I give her, if she takes it, it will

> probably not get any worse than she is now, but it's not gonna get any better for the most part.

One participant stated that the physician did was not detailed about Alzheimer’s disease and only gave her mother a diagnosis without prescribing medication. She felt that they physician suggestion of her mother playing brain games was irrational as her mother already engaged in such activities. The family caregiver felt that the physician lacked the support that was required for an AD diagnosis for her mother. She stated,

> 0007-G: I mean he talked, he didn't really go into depth about Alzheimer's umm, and we didn't think enough of it in the beginning to really research it. I think he did a diagnosis and that was done and he felt that it's not a whole lot to talk about, it is what it is and she wasn't at a point. Because he didn't even give her umm the Aricept at the beginning, he just said, you know, it's very early stages, watch her do this and this. Have her do puzzles, have her do a lot of things that would make her engage her brain. Which was amazing because my mother has always been an avid reader and has done puzzles. She would do 2500 piece puzzles, you know, two or three times a week and so she read and did crosswords and so those kinds of things kind of umm. To me I think that maybe taboo about engaging the mind because she always did that stuff, prior to diagnosis, so. (She thought physician was not very supportive).

There were various family caregiver’s perceptions concerning the accessibility to medical care as well as the reaction to the physicians to changes noticed in loved ones. The majority of family caregiver’s expressed the importance of physician support when seeking a confirmed AD diagnosis for their loved ones. However, two out of eight family caregiver’s stated that they physician was not very supportive and may be the reason for a delayed diagnosis. Family caregiver’s expressed that the physicians either did their job by performing the standard cognitive tests and others stated that the physician was not supportive and lacked compassion for the patient and family. In one case, the family caregiver was unaware of the physician experience because his mother received a diagnosis of AD before anyone’s involvement and did not disclose medical information to the family. The findings included affected family members consisting of two males and six females that examined differences among cases and family caregiver experiences with physicians. There were no apparent distinctions in relations to the gender of the family caregiver’s loved ones.

Theme 6: Seeking Medical Assistance for Loved Ones

The sixth theme answered research question three, “To what extent does the caregiver lay interpretations of the need to seek medical care differ by attributions?” Participants were asked if they experienced any denial about the signs and symptoms their loved one was showing and if they have any regrets about not seeking medical assistance when they first noticed cognitive changes. This theme examined family caregiver’s feelings and reactions to changes noticed in their loved ones before and after a diagnosis. Family caregiver’s either expressed having denial and regrets, only regrets, only denials, or neither about seeking medical assistance for their loved ones.

A wife affirmed that she did not experience any regrets or denial for seeking medical assistance for her husband because she sought help as soon as she deemed appropriate. The only regret she had involved not allowing her husband to take medicine for AD as he was already on multiple medications for other underlying health conditions. She stated,

> 0001-A: No, I think I did it as soon as I could. No, I don't have any regrets. I guess if I was going to have any regrets, it might be when uh, his neurologist, when I told him about the patch you know and he said, maybe we could try the pill. It was another FDA approved pill and we talked about it but he never uh wrote the prescription for it and I never brought it up cause I'm like you know, he's taking enough drugs. Because he was taking like 17 pills a day, so I'm like you know what there is no cure so why am I gonna give him one more pill for his kidney to try to process, you know.

Several participants shared that they did not experience any regrets or denial in seeking medical assistance for their loved ones. Their reasons were that early signs of the disease can go unnoticed for a while and when they realized there were serious cognitive issues with their loved one they immediately sought medical assistance. They stated,

> 0002-B: Ummm, no not really in the early stages, you know cause it was so subtle so you gotta, ummm, but as it progresses like now it's very obvious, you know. No, cause that's basically when we noticed it, you know it was very obvious after, you know. Like I said, when a lot of times with the elderly people, umm have any kind of hospitalization then it's like okay I can tell she is a little bit more forgetful than she normally has been. Okay now, so that's when we really noticed it.

0005-F: No, no denials because I seriously believe that I, when I noticed it I seriously believe that I got involved right away. Umm, so no I don't regret. I really and honestly, truly believe that when I, when I realized what was happening I got involved right away and changed it up and you know. And included other people in our world, i.e. Dr. (undisclosed name) and, case worker (undisclosed name), and all of that so.

0007-G: No, but my sister did. I don't, not based on the research and stuff that I have done on it. There was nothing more and even though she takes uh the Aricept, umm. Because it's still so much gray area with research on Alzheimer's that I can't tell if it's slowing the, because I know there's no cure, but I can't tell if it's slowing it down or if this is the natural progression of it. So I'm not sure (pause). No, ah. (pause). I just, no I just think it, it's not enough information. It is, even though they are researching and doing stuff, it's still a long way to go to even come to a good conclusion about Alzheimer's so.

0008-H: No, I know she had, there's no doubt in my mind she has the. I'm not, I never denied she's had it. The only uh, I guess the only thing I would see as, I viewed. I always viewed my mother as such a strong woman that she can control this, she can beat this, she you know. It can't take her, because I've always viewed her as that type of a lady. No, that's the first I did was get her to uh, a medical facility and getting her in with (undisclosed hospital) here because I knew that if there was any place that could help her, it would be that place.

Two female family caregiver’s, caring for a mother and father, deeply expressed that they did experience regret because they did not immediately seek help for their loved ones. The family caregiver’s knew that their loved one’s behavior were abnormal, but there was some hesitation in seeking medical assistance. They stated,

> 0003-C: Yeah, I, uh. I regret that I didn't jump right on it. Umm, that although there's really nothing you can do about it, umm. There is medication I found out that could slow the process, but it's inevitable, it's gonna happen, it's gonna go full blown. Umm, but I think if I could kind of kept her at bay, umm and then my whole family, my dad, umm, cause he's become the enemy and stuff like that then he wouldn't have had to go through the different things that he had to go through cause she, she really put a whack, whack him with it, with stuff. I don't mean physically, I just mean mentally, you know, mental abuse uh. Talking real nasty to him and umm, denying everything that he said or he's hiding her purse and she's the one that's hiding it, umm.
>
> 0004-D: I did. Umm, early-on when. I knew something wasn't right but didn't know what it was and when my mom thought it's just oh it's just PTSD, it’s why he's doing this. I kind of denied that. I said nah, I don't really think its PTSD, that's the only part I denied. Yes. Umm, I feel that even though there was a distance as far as me living in Texas, he was living in Florida. Umm, which is contributing factor to me not really being able to, you know, stay on top of things with his physician. Not having, I guess the proper legal documentation to even ask questions over the phone, like who's this person calling to find out medical

> information. I think that was one factor, the other one is umm, yeah I think its regrets because well then maybe if I would have on a trip, vacation to go see him, you know. Say hey let's make an appointment to go see a doctor because this is not right, so let me, let me go in with you and let me tell them what I see.

A devoted husband shared that he knew his wife had AD, but he felt that she was not as ill as she was until he sought medical advice. He stated,

> 0006-F: There were umm, probably a couple of occasions that I, that I felt like uh, she was not uh actually as sick as she might have been, if that's what you're talking about? No, no, no no. I, I, I, I, uh sought uh, umm, medical advice as soon as I noticed that there was something that wasn't right, you know, with her. No, no, no.

Three out of eight participants stated that they did experience denial about the signs and symptoms that their loved one was showing early-on but did not seek medical assistance. Four out of eight participant’s stated that they did not experience denial, and one caregiver stated not really. In regards to regret, six out of eight caregivers stated they experienced no regret while two out of eight caregivers stated that they did experience regret about not seeking medical assistance. Family caregiver’s that stated that they did not experience denial or regret supported reasons to there not being a cure for AD or information on successful treatment. Participants also expressed their fear of developing AD because of their experience as a primary family caregiver and family history.

Theme 7: Early Signs of Behavioral Changes

The seventh theme answered research questions one and two, “To what extent do caregiver’s perceptions of value of obtaining a diagnosis of Alzheimer’s vary by gender of the affected family member?” “To what extent does the caregiver lay interpretations of the need to seek medical care differ by attributions?” Participants were asked about what negative characteristics, signs, and symptoms they noticed in their loved ones before a diagnosis. Participants were also asked if they thought that their loved one’s behavior was due to his or her personality. Participant’s detailed responses concerning possible early signs noticed in loved one before diagnosis are below. Some participant’s expressed that they did not know what was happening with their loved ones before a confirmed diagnosis, although they noticed abnormal behavior. A wife stated,

> 0001-A: Uhhh, confusion. And I uh, (coughs). I am trying to think back. I knew it was something. I didn't know what it was, but I could see you know, change. And early on there were accusations of me stealing things cause he would forget where he put it you know and uh. So during those times you know, we would have little spouts about you know, I didn't have to steal and I didn't take your stuff, you know, daadadaa. That kind of stuff. It was like ugh, why is he accusing me and that kind of thing, so there was some resentment as well confusion. Uhhh, confusion. And I uh, (coughs). I am trying to think back. I knew it was something. I didn't know what it was, but I could see you know, change. And early on there were accusations of me stealing things cause he would forget where he put it you know and uh. So during those times you know, we would have little spouts about

> you know, I didn't have to steal and I didn't take your stuff, you know, daadadaa. That kind of stuff. It was like ugh, why is he accusing me and that kind of thing, so there was some resentment as well confusion.

A female participant stated that her mother was diagnosed with AD after she was hospitalized for dehydration. The family caregiver had noticed some forgetfulness in her mother but was not sure that severe cognitive changes were occurring until she was hospitalized. She stated,

> 0002-B: How she initially got diagnosed, she umm became dehydrated, so she end up going to the hospital, she had to be hospitalized. And umm, you know any time an elderly person is hospitalized sometimes they will regress. And then she was just showing some forgetfulness. She was umm becoming a little forgetful but it wasn't that very obvious and you know so, some of that we kind of contributed to just being hospitalized.

One female participant stated that she was the only child and did not know what was happening to her mother. She noticed some memory loss, but she did not want to admit that this was happening to her mother until changes escalated. She stated,

> 0003-C: I really didn't understand what was going on umm. I'm an only child and she's my very best friend. So, when things started happening like, loss of memory umm, not remembering where she put stuff and all that. That was real disturbing, because, she didn't, you want your mother to be perfect all your life. Umm, accusing my dad of umm, hiding her purse or stealing her money, umm, til it would just blow up into a crisis.

A female participant caring for her father mentioned that he was experiencing sudden anger, confusion, unclean living conditions, and hygiene issues which were abnormal. She expressed by her father also being a Veteran; she thought that the symptoms were due to Post-traumatic stress disorder (PTSD) and alcoholism instead of cognitive decline. She stated,

> 0004-D: Confusion, umm, outbursts of anger. I saw umm, unkept household, stock piling of clothing, food, unsanitary living conditions and unkept hygiene. Is it something dealing with the PTSD that's showing up now that hasn't shown up before, you know, is it depression. So thought it may be related more to a hoarding disorder, you know, and obsession of always having things, because he grew up very poor and just wanted to hang on to everything.

A daughter stated that her mother began neglecting daily activities and responsibilities in such instances of not paying bills, missing doctors’ appointments, and improperly dressing. The family caregiver noticed significant changes in her mother after the passing of her loved one’s mother and brother. She stated,

> 0005-E: But I started seeing her missing doing things that she would normally stay on top of. I'd go over and see a bill or something on the table that she had prepped and if I go back over, you know, five days later or three days later the bill was still there. And a few days later that bill is still there, now I may mention it to her and she'd snap, you know, about it. And so, umm, I'm like, and then I'd come over and she wasn't dressed. Her weight had started to drop too prior to her

> mother passing because she just spent all her time on her. She, she would keep up with doctor’s appointments and then she just wouldn't mention the doctors anymore, you know, over the course of time. I'm like that's not like her, cause she at the doctor every other week, you know just making sure she was okay, and so umm be but all that had long gone so yeah. I could tell she was depressed and I knew rightly so, you know, I don't like I said, she so good at hiding stuff that you actually had to see those actual symptoms and things that you noticed about her, you know.

A husband noted that his wife appeared very different than her usual self as she started to become repetitive in her words and actions. He also stated that she was very emotional than before in their marriage, which was abnormal. He stated,

> 0006-F: I could tell, I could tell that there was something different, umm, umm about umm her umm. One thing in particular was, she began to umm repeat herself time and time again which was umm not the way that she umm, that we had lived and operated for some 58 years or 57 years so. Umm, I could tell that, I could tell that there was a problem because of the, of the umm, the way that uh she asked the same questions over and over. I could tell that there was something different because of the way uh of her emotions umm began to uh umm. I need a word here. Umm, she had very emotional, she would get very emotional at times, which was not the the type of woman that she was.

A female participant indicated that her mother would forget to pick up her grandchildren from school or go to the store and stay away for hours until someone had to locate her. She knew something was wrong with her mother repetitive actions, but wasn't certain at the time that it was AD. She stated,

> 0007-G: I guess prior to diagnosis I was upset with my mom because I thought she was being honoree when she would commit to doing something and wouldn't do it because she's actually forgot. But of course, me not knowing what her condition was, it didn't seem feasible that she could forget something. So I thought she was doing it intentionally. (Pause). So, I guess it would be her forgetfulness. The first uh stage for her was the memory loss and so we saw it when she would go to common places that she went all the time and she would get lost going, coming from the store and umm, but I think for a while she didn't share that she had gotten lost. We just said what, it's taking her a long time to get back, you know. Umm, and until she came to my house once and left and 2 hours later she still wasn't home is when we started thinking something is really wrong. And she, you know, she would just repeat stuff over and so they would ask her something and she didn't know and she. I would go see her and when I'd leave and they'd call and say have you talked to (says her name) and she'd say nawl I haven't seen her in over two months, and then you know, they'd call back and say you need to go check on your momma. I just left my momma, that ain't what she said, you know, that kind of stuff and so, yeah.

A male participant stated that he was unaware that his mother was suffering from AD because she lived out of state with his father. After his father's passing, he then found out that his mother was already diagnosed with AD. She was able to maintain a sense of normalcy without any family members noticing cognitive changes. He stated,

> 0008-H: Basically, my mother was diagnosed, she just didn't tell anybody that she had been diagnosed. Early-on uh prior to my father passing away, yes and the only thing that I thought about then was just stuff my dad would say that we really didn't pay any attention to what he was saying, you know. We just thought it was just him and my mom arguing, you know, having disagreements because they were married for, Good Lord, ever (laughs).

Six out of eight family caregivers stated that they noticed signs before an Alzheimer’s disease diagnosis, whereas two family caregivers did not notice signs before diagnosis. Four out of eight family caregiver’s attributed behavior changes to the personality such as issues with writing and spelling, forgetfulness, confusion, anger, loss of direction, daily habits, and repetitive behavior. Four out of eight family caregiver’s did not attribute behavior changes to personality and stated that it was unusual for their loved one to be acting in such a way. Therefore, the findings show that some family caregiver’s believed that changes were due to personality, and some family caregiver’s did not believe that changes were due to personality. Four out of eight family caregiver’s expressed that personality changes that were noticed appeared as a masking of AD under their loved one’s personality. Some family caregivers believed changes were due to underlying conditions such as alcoholism, PTSD, and just masking underneath their loved one’s personality. Family caregivers also noted that behavioral changes included mental changes, such as an onset of depression. Family caregiver’s noticed depression in some AD patients after the death of a close family member. Some family caregiver’s also noted physical changes in loved ones such as diet, weight loss, and hygiene. Behavioral changes differed from each gender of the affected family member, although some changes were similar.

Theme 8: Family Caregiver Emotions to Cognitive Changes in Loved One

The eight theme answered research question three, “To what extent do attributions directed toward the affected family member vary by gender?” Participants were asked about negative feelings they had for their loved ones before and after a confirmed diagnosis. Family caregivers expressed different emotions and reactions to cognitive changes in their loved ones.

There were variations of feelings before and after the diagnosis with most family caregiver’s expressing feelings of frustration, denial, overwhelming, sadness, empathy, sadness, resentment, confusion, bitterness, upset, depression, and lack of understanding of changes that occurred. One male family caregiver expressed that he believed that his mother could control the disease and not let the disease control her. He believed that she was strong enough to be cured naturally of AD. There were differences in family caregiver’s reactions and emotions to changes related to AD in their loved ones according to their loved one’s gender. A devoted wife stated,

> 0001-A: Uhh, I don't know. That's a hard one, umm. Once I knew what it was, I was able to deal with it more, but as the disease got aggressively worse, you know it was harder. Ummm. You know once he started refusing to take his meds and I had to coerce him and he's a kidney transplant and you know I definitely don't

> want him to have kidney failure after twenty-something years and so there was a lot of frustration, you know. I'm like, you know, you're going to end up on dialysis. Well, I'll just go on dialysis, you know or just die. I'll die. You know that kind of... so it was the frustration and constantly trying to remember that it was the disease and not the man. So that was the hardest thing, cause I work still, you know, for a long time, he was here by himself, he could still you know when he was in the mild to moderate, he could still stay home by himself and umm.

A female family caregiver shared that she just loved her mother even harder than before because she knew the end was coming one day soon. She wanted her mother to be as comfortable and peaceful as possible during this transition. She stated,

> 0003-C: Umm, no just loving her more and more than ever. Umm, because you kind of feel like, yeah it's, could be toward the end and you want to keep her as comfortable and umm, not riding in those crisis that she was riding in, just kind of agreeing with her to kind of ease it down and not combat or change the subject or go another way when, umm, you know. When you felt like she was going in a crisis mode, so yeah.

A daughter caring for her father expressed that she felt devastated and upset at the situation that her dad had to face. She shared her that her emotions ranged because she did not realize the responsibility of becoming a primary caregiver. The family caregiver felt that her dad could have made lifestyle changes to prevent health decline. She stated,

> 0004-D: Umm, as far as negative, sometimes feeling overwhelmed, umm, not really mad with him as far as a negative feeling, but feeling umm. I guess the

> biggest word is just overwhelmed, cause it's just so much responsibility and it's like now, now what do we do. Umm, how long is this gonna, you know, you hear the scary stories, you know and how long it lasts and umm, what you have to go through. Umm, I think I also felt probably some resentment a little bit, umm in that, in that's just being honest. Umm, probably felt, somedays felt maybe some sadness, umm and just maybe anger for the situation, that this wasn't gonna be something easy. Just gon come in and take care of dad, it's gonna be good. Build him a room and it's just gonna be good. We'll just keep going on with life. Just taking care of our parent, but its more to it than that. So I think those feeling were just mainly being overwhelmed and never anger with him, but just umm, empathy. I felt a little sorry for his situation. Umm, disappointed because there are somethings I think that umm probably early-on he could've done differently, umm health wise to probably prevent some of those things that was going on, couldn't prevent the stroke.

Two family caregiver’s expressed that they miss their loved ones, because the cognitive decline has taken part of them away and they are not able to perform activities that they once could. A daughter shared that she knows she is losing a part of her mother each day. She stated,

> 0005-E: Yeah, you it, you miss them, you, you, once you realize what you're dealing with you, you actually even though you're looking at them, you miss them almost immediately, because you know you're losing a little bit of them every day, you know what I mean. Umm, and if I'm sad about anything to date is that

> she just, we no longer have a, a co-understanding about what's really going on. I've been left to be the responsible one for what's really happening today, because she's back to denying and anything specific to let on that there's anything wrong, but when you work that hard to hide something, it's, that's exactly how you show it to people, you know.

A husband noted that he will not leave his wife alone anymore and it has change the dynamics of their life. He stated,

> 0006-F: I do. I still feel bad, but I know that there are things that happen to us being a preacher. I know that things happen to us that most times we can do nothing about. Umm, so umm, I do, I do, you know. I hate this happened. We’ve had umm, right now we've had 59 wonderful years together and uh we cannot do those things that we used to do as young folks, you know. (elevator noise). Umm, we cannot travel like we once did, I can, she can't and because she can't I don't, okay. So, I don't leave her alone uh too much, uh. I uh, I care her to church when we can, we she feels like going. Sometimes she doesn't feel like going, but I go to church and then I come straight home, you know. So it's a, it's a kind of thing that uh, that I know I need to uh, that I need to uh look after or care for and uh I do what I think God will have me to do, the right thing, that God will have me to do. Yeah, yeah.

After a confirmed AD diagnosis, most family caregiver’s were able to accept their loved one’s behavior knowing that it was the disease and not the person. However, there were still feelings of sadness, bitterness, resentment, and anger because of the loss of normalcy in their loved ones due to cognitive changes and new circumstances. Family caregiver’s expressed that even though their family member is still physically alive, mentally they are absent.

Theme 9: Family Member Influence to Seek Medical Assistance

The ninth theme answered research question four, “To what extent does the caregiver lay interpretations of the need to seek medical care differ by attributions?” Participants were asked did any other family members influence or delay their decision to seek a medical diagnosis for their loved one. Most family caregiver’s stated that there was a lack of family support in the decision to seek a medical diagnosis for loved ones. Some participant’s shared that family members mentioned changes in loved one after diagnosis.

Several participants confirmed that they were the only person to seek medical assistance for their loved ones. There were no other family members that influence or delayed seeking medical assistance.

A dedicated wife expressed that she was the primary decision maker for her husband as other relatives live elsewhere. Participant 0001-A shared, “Mm mmmm (No). Oh yeah. I mean, we live. It's just us so we don't have any relatives here in Dallas.”

Several participants stated that they were proactive in seeking a medical diagnosis for their loved ones because other family members were not as concerned. Participant 0002-B stated, No. Cause it's just my brother and myself. Participant 0003-C stated, No. No, no. Yes, I would be the proactive one. Participant 0005-E stated, Nobody was as attentive as I was.

A daughter boldly expressed that she was very concerned about her mother, and no one influenced her to seek a medical diagnosis although family members had opinions. She also discussed the lack of awareness of AD in the African American community. She stated,

> 0007-G: They never, they didn't delay me because it was my mother, but they did have uh opinions about it, uh. Again because Alzheimer's isn't a topic, a major topic or something that the African American community had been exposed to, so my mother's sisters who are a lot older than her, umm, had never heard of that. So, they felt that wasn't her issues, you know, that people just forget, she's just getting old and that uh we were just neglecting her. Not necessarily she was sick and it wasn't until probably about 10 years ago that they even accepted it, since they could physically start seeing that there is something different did they even believe she had it.

Five out of eight family caregiver's mentioned that there was a lack of family support to influence the decision to seek a medical diagnosis. Consequently, three out of eight family caregiver's stated that one or more close family members influenced their decision to seek a medical diagnosis for their loved one. One husband shared that his children played a significant role in assisting with seeking medical assistance for his wife's diagnosis. Most family caregiver's expressed that they were the primary caregiver that was proactive in seeking medical attention for their loved ones.

Theme 10: Delayed Diagnosis

The tenth theme answered research questions one and four, “To what extent do caregiver perceptions of value of obtaining a diagnosis of Alzheimer’s vary by gender of the affected family member?” “To what extent does the caregiver lay interpretations of the need to seek medical care differ by attributions?” Statements from participants that expressed that a diagnosis delay occurred for their loved are below. Participants were asked if they thought there was a delay in AD diagnosis for their loved one and if there was a delay, who or what factors contributed to the delay. Participants expressed that they believed there was a delay in diagnosis and contributing factors. One participant caring for her mother stated that the early signs are not easily detected and after her mother’s hospitalization cognitive changes became noticeable. She stated, 0002-B: Ummm, probably somewhat of a delay, especially when the early signs are so subtle, you know really? Yeah, so ummm. When she first got out of the hospital she didn't have the neuropsych eval.

A female participant, who’s the only child, mentioned that denial was the delay because her mother was her best friend and she didn’t want to acknowledge the cognitive decline. She stated,

> 0003-C: Umm, denial was the delay. Not wanting to accept it. Umm, and not really uh, asking, asking the umm, the doctor for a diagnosis, umm, you know to run tests and see just what's going on. I'm concerned, I just, I just didn't do that.

A daughter caring for her father voiced that there was a delayed diagnosis because she lacked adequate knowledge and awareness about AD with her dad living out of state.

She began noticing more evident cognitive changes once her father moved to live with her. She stated,

> 0004-D: I think there was a delay, because now that I am more aware and a little bit more educated on the disease, the various Dementias, now when I think about it, because he moved here in 2010, and we started really noticing, I guess it got really bad about a year or two prior as far as, okay what are we gonna do, what kind of accommodations are we gonna start making, umm, even though family members were there or lived next door in the community would come by and make sure dad's okay this and that.

A daughter expressed that her mother did experience a delay in diagnosis because the physician was not proactive in assisting with monitoring cognitive changes. She stated that possible cognitive changes were overlooked by the physician because her mother was still functioning normally. She stated,

> 0007-G: I do think it was a delay because when we initially took her umm, the physician that she saw did not, because, momma wasn't where she. She couldn't, she never knew what it was, so when she would go to the doctor, she was still cognitive of what was. So she would just way, well I don't know what they're talking about, I'm fine. And the doctor is like, well she seems fine to me. But forgetting to go to the store is not something that, because she forgot. So, I think it was the doctor.

A female participant caring for her mother believed there may have been a delayed diagnosis because she was not sure if anyone would have noticed the changes in her mother because she was still maintaining her daily activities. She stated, 0005-E: I'm not sure, I don't if anybody would've caught it like that because she was still on the go all the time, you know. So maybe, maybe.

Four out of eight family caregiver’s believed that there was a delayed diagnosis for their loved ones due to personal denial, hidden early signs, and normalcy in loved ones. One family caregiver believed that there maybe was a delay in diagnosis, but was not sure because her loved one was still functioning normally in her daily life activities. The contributing factors for the delay varied among each family caregiver and gender of the affected family member. One family caregiver stated that the early signs are so subtle, and it was brushed off to just being elderly. A different family caregiver mentioned that denial was the delay for her loved one as she did not want to accept that her mother would have AD, in addition to, not asking the physician to perform cognitive tests to determine loved one’s condition. Another family caregiver also stated that denial played a factor in delay along with alcoholism, PTSD, and not having the family to accompany father to the doctor. Another family caregiver expressed that her mother was going to the doctor on her own, and the physician didn’t further investigate for cognitive problems and just took the patient’s word because her mom was still cognitive. Lastly, one family caregiver that stated maybe to a delayed diagnosis expressed that there were long periods of time that her mother hadn’t gone to the doctor as she was still independent and functioning normally.

Summary

The purpose of this qualitative, grounded theory research was to understand if family caregivers' perceptions influence the delay in an early AD diagnosis for their loved. I interviewed eight African American primary family caregivers. Five family caregivers were interviewed in their home, two at work office, and one at a public library. Seven family caregiver's were women who either cared for a mother or father, and one male caring for his mother. The findings of this investigation showed that African American caregivers do hold integrated belief sets that contribute to the delay of an early AD diagnosis for their loved ones. The combined evidence from the ten themes may support the development of a new theory of family caregivers' knowledge and understanding of AD to create more awareness and techniques so that family caregivers can detect AD early on in their loved ones. Although family caregiver's stated that their loved ones were diagnosed at even an early stage, there were still delays in seeking medical assistance in which a diagnosis could have happened even earlier than it occurred. There was a slight variation regarding gender differences playing a role in seeking medical assistance for loved ones. However, six out of eight family caregiver's stated that gender did not delay their decision to seek a timely medical diagnosis. Family caregiver knowledge level was very significant in their determination of seeking medical assistance for their loved ones. Family caregiver's indicated that it was challenging to determine that the early signs seen in their loved ones were primarily due to the early onset of AD because of their loved one's personality and behavior changes. Family caregivers were alert and aware of early signs and symptoms in some instances; however, the decision on when to seek medical help was difficult to determine.

Family caregiver’s also stated some significant recommendations (Appendix H) that are required. First, caregiver support, especially from family and friends, although a couple of family caregiver’s did receive support from family members or friends. Second, knowing how to navigate resources for AD care and assistance (financial, legal, and medical). Some caregiver’s stated that taking care of a loved one with AD is a financial burden, and it’s difficult to avoid not sending their loved one to a nursing home. Third, an increase of awareness and educational programs in the African American community to decrease the secrecy among families with loved ones suffering from cognitive decline and poor judgment among individuals in the community. Lastly, family caregivers expressed the need to become more knowledgeable about the disease to educate the next family generation in the hope of early recognition if they were to experience an early onset of AD.

In Chapter 5, I further examined the 10 themes with an interpretation of findings, limitations to the study, and future recommendations for research on Alzheimer’s disease. I discussed the positive social change implications that are necessary, and provided a summary of the entire research project.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative grounded theory study was to investigate if African American family caregivers have similar thoughts, beliefs, and gender associated biases toward their family members that may contribute to a delay in early AD diagnosis. This study was investigative in nature, and I used one-on-one semi-structured interviews to explore phenomena about family caregivers' perceptions of early diagnosis of AD. In the previous chapter I presented the findings from data collection and analysis of eight in-depth interviews of African American primary family caregivers who were recruited using a purposive sampling approach (Creswell, 2009). I gathered data on family caregivers, and after data analysis, identified 10 themes that support the development of a new grounded theory. These 10 themes are: early AD detection, knowledge level of AD, gender differences play a role in seeking medical assistance, communication with loved one about AD, physician support is critically important, seeking medical assistance for loved ones, early signs of behavioral changes, family caregiver emotions to cognitive changes in loved ones, family member influence to seek medical assistance, and delayed diagnosis.

The ultimate goal of this research was to develop an enhanced comprehension of the how family caregivers' hidden and cognitive barriers may contribute to a delayed diagnosis of AD. The findings may be used to support the development of a new theory of family caregivers' knowledge and understanding of AD that will create more awareness and techniques to detect AD early onset in their loved ones. The development of a new theory of family caregivers’ knowledge and understanding of AD may explain the meaning and consequences of the early signs of cognitive impairment in elderly African Americans. Chapter 5 includes a brief summary of the findings of each theme related to the research questions. This chapter also includes a discussion of the results and their meaning as it correlates to social change. I discuss limitations that arose in the study, offer recommendations for future research to increase the scope of this study, and provide a conclusion that marks the impact of the study.

Summary of Key Findings

The intent of this study was to explore if family caregivers’ thoughts, beliefs, and judgments have an influence on the delay of AD diagnosis in their loved ones. The majority of family caregivers cared for a parent, and others cared for a spouse. I developed semi-structured interview questions to explore how family caregivers’ thoughts, beliefs, and judgments relate to an early diagnosis of AD in their loved ones. A total of ten themes emerged from family caregiver’s responses during in-depth interviews. The themes that I constructed showed that family caregivers’ knowledge level about AD varies, and family caregivers were more knowledgeable about the disease only if a family member had the disease before the participant became a primary family caregiver. Family caregiver’s also expressed that there was a delayed diagnosis of AD in their loved ones, although all family caregivers stated that their loved ones were diagnosed at an early stage of AD. Family caregiver’s mentioned that when they noticed early behavioral changes in their loved one, they were not sure if it was due to cognitive changes and did not seek medical assistance. The need to seek medical assistance among family caregivers varied; three out of eight family caregivers expressed that they did notice changes in their loved one but hesitated to seek medical assistance. The remainder of family caregivers conveyed that they did see changes in loved ones but did not seek medical assistance because there is not a cure or treatment for AD. These factors play a fundamental role in delaying an early AD diagnosis. Family caregivers also expressed their personal fear of developing AD while caring for their loved one and a willingness to become more proactive in learning about early signs and symptoms of AD and educating their children and other family members about the chronic illness. This data showed a range of experiences of family caregivers and their ultimate decisions to seek a medical diagnosis for their loved ones. I will discuss each of the ten themes and interpret the findings below.

Interpretation of Findings

In this study, I addressed four research questions:

RQ1: To what extent do caregiver perceptions of the value of obtaining a diagnosis of Alzheimer's vary by gender of the affected family member?

RQ2: To what extent do caregiver perceptions of the accessibility of medical care vary by gender of the affected family member?

RQ3: To what extent do attributions directed toward the affected family member vary by gender?

RQ4: To what extent does the caregiver lay interpretation of the need to seek medical care differ by attributions?

In order to answer each research question, I used a qualitative, grounded theory approach including semi-structured, in-depth interview questions. To interpret findings and understand caregivers' perception of an early AD diagnosis, I used the combined HBM and attribution theory as my conceptual model to support the development of a new theory of family caregivers' knowledge and understanding of AD. The study included a sample of eight African American family caregivers who provide care for their loved ones in the Dallas, Texas area. The age of participants, family caregiver experience, educational level, and marital status served as significant factors when interpreting the findings of this study. My findings support information that I found in the literature about the importance of AD knowledge and awareness in the African American community in reducing delayed diagnosis. The knowledge level of AD varied among family caregiver's, and a majority were not adequately knowledgeable about AD until after a confirmed diagnosis of AD in their loved ones. Some family caregiver's had experienced AD in their family, but were not the primary caregiver and therefore lacked sufficient knowledge about the illness. Family caregiver's noticed behavioral changes in their loved ones, but attributed changes to their loved one's personality. Several factors influenced the delayed diagnosis in those at risk of developing AD.

Findings Related to Literature

In this study I developed ten themes related to knowledge about AD, seeking medical assistance, early signs of AD, family caregiver feelings about cognitive changes, family member influence, and delayed diagnosis. In this section, I will discuss each theme and how these findings enhance the current literature on African American family caregivers' beliefs about an early AD diagnosis. The information presented indicates the importance of AD awareness and knowledge among this group as well as a need for more educational programs.

For the first theme, half of the participants thought that early detection of AD was insignificant and would not have assisted with better treatment for their loved ones. My interpretation of these findings suggests that the majority of family caregivers lack an understanding and awareness of AD in regard to how the disease progresses and effective treatments that are available to improve their loved one's quality of life (Cahil, Pierce, Werner, Darley, & Bobersky, 2015). If family caregiver's were more aware of the benefits of early AD detection, it could allow for more engagement in learning more about the disease. Clare, Marková, Roth, & Morris (2011) and Hughes et al., (2009) expressed the need for and importance of more educational awareness of AD among family members and the requirement for support from healthcare providers and community stakeholders. Although many family caregivers believed that early detection was insignificant because there is no cure for AD, Hughes et al. (2009) confirmed that early AD detection is significant, and that family caregivers must be able to detect early signs of the disease in their loved ones and seek medical assistance promptly. The AA (2016) declared that early detection is critical for three reasons: it increases access to health and support facilities, provides the affected individual the chance to make legal and financial decision before disease progression occurs, and could delay the affected person placement in a nursing home which could reduce healthcare expenses (p.1). In my study, three participants believed that obtaining an early diagnosis for their loved one would have helped with better treatment and resources, which suggest that these individuals possessed sufficient understanding of AD. The findings support Hughes et al.’s (2009) findings that individuals in the African American community must become more knowledgeable about AD to increase awareness as the numbers are projected to increase.

The second theme developed in my findings revealed family caregivers’ knowledge level of AD and how it may influence their decision to seek medical care for their loved ones. There were variations in responses from family caregivers about their AD knowledge level related to the gender of affected family member. Some participants shared that they were only knowledgeable about AD before their loved one’s diagnosis because of prior personal experience with either a parent or grandparent, but were not the primary caregiver and did not pursue further knowledge on the disease. Some participants indicated that they were not as knowledgeable about AD because they did not hear about it in their community and were not personally affected by the illness on a daily basis. This confirms and extends Connell et al.’s (2009a) research which found that African American participants gave the same rationale for lack of knowledge about AD. Also, Connell et al. (2009a) and Hughes et al. (2009) determined that African American caregivers’ primary barrier for a timely diagnosis is a lack of knowledge about AD and of the appropriate time to seek medical help. Correspondingly, Avalon and Arean (2004) evaluated the knowledge level of AD within various ethnic groups and concluded that all groups lacked adequate knowledge about AD which may delay their seeking of medical assistance. It is essential to identify barriers preventing individuals from obtaining sufficient AD knowledge in order to assist with early intervention and detection of the disease (Avalon & Arean, 2004). The findings from this study extend and confirm previous findings from Cahill et al. (2015), Kada (2015), and Avalon and Arean (2004) which showed that the lack of knowledge among individuals can lead to misconceptions about normal aging among caregivers and increase the delay early AD diagnosis in at-risk groups.

The third theme in my findings identified if gender differences played a role in family caregiver's seeking medical assistance for their loved ones. The majority of family caregivers stated that the gender of their loved one did not influence their decision on whether to seek medical help. However, they noted their relationship was significant. Only two family caregiver's out of eight stated that gender did play a role in delaying seeking medical assistance due to their personal denial about cognitive changes in their loved one. Griffith and Lopez (2009) and Wadley and Haley (2001) investigated the influence of parent gender when deciding to seek medical assistance for a given illness that supports both family caregivers' decisions not to seek medical help. Both daughters did not seek medical assistance for either a mother or father for different reasons. One family caregiver shared because she was the only child and in denial about her mother's cognitive changes. This information extends and disconfirms previous study results that did not take both genders into account and only examined male parents. Griffith and Lopez (2009) results showed that men that experience cognitive decline are diagnosed at later stages due to healthcare provider's lack of recognition of cognitive changes and did not take into consideration the family caregiver role and disconfirms this study results.

The other family caregiver that stated that gender played a factor in her father's diagnosis delay because of her father's Veteran background and that males do not attend the doctor regularly. Additionally, in support of the third theme, Wadley and Haley (2001) investigation discovered that those caring for a parent with AD or major depression expressed more empathy and were more willing to offer assistance than those with no medical explanation of behavior changes. In agreement with Wadley and Haley (2001) results, in this study, family caregiver's did express that they were more empathetic towards their loved ones once they received a confirmed medical diagnosis of AD because they then understood the cause of abnormal behavior in their loved ones. Wadley and Haley (2001) also noted that participants showed more anger and negative traits towards fathers than mothers that experienced negative personality traits, in which data for this study disconfirms this information because there were not distinct gender differences noted. As it relates to this study, Wadley and Haley (2001) concluded that parent gender may influence a caregiver's behavioral and emotional response in a loved one and this research study findings showed that only two caregivers expressed that gender influenced the delayed seeking medical assistance. There may be the need to further explore aspects of gender and the caregiver behavior when seeking a medical diagnosis for AD and other cognitive illnesses.

In the fourth theme family caregivers discussed communication with loved ones about AD, in which family caregiver's techniques to mention cognitive changes varied by gender of their loved ones. Most family caregiver's did not discuss cognitive changes with their loved one until they perceived that cognitive changes were severe regardless of the affected family member's gender. Family caregiver's are used to communicating with their loved ones before cognitive changes and may experience difficulties with effective communication strategies when cognitive decline progresses. My findings indicate that family caregiver's are uncertain on when and how to communicate cognitive changes to their loved ones, which may increase delayed diagnosis (Small and Perry, 2012). Some family caregivers did not mention cognitive decline to their loved ones due to personal denial and avoidance of confrontational behavior. There is the need for educational training on how to effectively communicate with loved ones about cognitive decline (Small and Perry, 2012). Most family caregivers chose not seek medical assistance until cognitive changes were uncontrollable at home and began affecting daily routines. The findings from this data confirm and extends several researchers previous data. If family caregiver's are not knowledgeable about AD and think memory loss is a part of normal aging, there becomes a hesitation on when to communicate with loved ones about cognitive changes (Connell et al., 2009a; Avalon & Arean, 2004; Knopman et al., 2000).

In the fifth theme, my findings showed that physician support is crucial to family caregivers when seeking a medical diagnosis and treatment for a loved one with AD. Most family caregivers mentioned that during medical evaluations of loved ones, the majority of physicians did their job and diagnosed their loved one with AD. Regardless of the family caregiver experience with the doctor during their loved one's initial diagnosis, family caregiver's specified the importance of support from the physician and medical staff. Watkins et al. (2012) confirmed the importance of African American caregivers having trust in the physicians for their loved ones as they undergo the stages of

AD. Along with my findings, Leifer (2009) expressed how primary care physicians must be proactive and examine patients for cognitive issues during routine visits instead of waiting for progressive memory loss to occur. Some family caregiver's did state the importance of their family member having a spokesperson to accompany them to doctor visits to possibly improve their loved one's quality of care by alerting the physician of any noticed cognitive changes that the patient may not disclose on their own. In one study, doctors expressed that a close family member attending doctor visits with the patient does enhance the quality of care they provide to the patient. Therefore, patients obtain a better understanding of the physician's recommendations and explanations (Wolff et al., 2014). Family caregiver's shared how their loved ones were able to maintain normalcy and attend their doctor visits alone in which the physician did not notice any cognitive issues at that given time. Husaini (2003) discussed how many doctors do not suggest patients test for cognitive decline in addition to, many patients cannot afford tests because the cost of prescreening and testing is expensive and not covered by insurance. In confirmation of the findings, several investigators assured that regular screening for memory loss, such as Dementia could reduce barriers to a delayed diagnosis in loved ones (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Knopman et al., 2000). According to the National Public Radio (NPR) (2016), under the affordable healthcare act, cognitive screening is covered by Medicare. However, individuals lack participation due to personal reasons.

In the sixth theme, I examined information about family caregiver's denial of signs and symptoms loved ones were displaying and regrets about not seeking medical assistance when they first noticed cognitive changes. Family caregiver’s interpretation of the need to seek medical care did differ by their personal beliefs, in which most family caregiver’s explanations were that the early signs of AD can go unobserved for some time, but when they recognized and determined that cognitive decline was severe, they then sought medical help. Some family caregiver’s attributed their loved ones cognitive changes to personality and did not feel a need to seek medical help as they thought their loved one was stubborn or honoree. Clark et al. (2005) ascertained that caregiver denial can play a factor in delaying to seek a medical diagnosis in which results in this study confirms previous findings. In conjunction, Connell et al. (2009b), Hughes et al. (2009), and Clark et al. (2005) agreed that African Americans firmly believe that adult children should take the responsibility of caring for their elderly parents who are diagnosed with a chronic illness. Therefore lowering the rate of seeking medical assistance. This data confirms that family caregiver’s take on the responsibility of caring and for their loved ones, either elderly parents or spouses wholeheartedly before seeking medical assistance. In the African American culture and other minority cultures, there is a firm belief to take on the obligation of caring for an elderly loved one to delay putting them in a nursing home until the caregiver deems the burden unbearable (Dai et al., 2015; Brodaty & Donkin, 2009).

In the seventh theme, I examined early signs of behavioral changes family caregiver’s noticed in loved ones. The majority of family caregiver’s expressed that they noticed early signs of cognitive decline, however, did not know what to attribute the abnormal changes. Most changes noticed that family caregivers described are supportive of the AA (2016) "Know the 10 Signs," such as writing and spelling issues, forgetfulness, confusion, anger, loss of direction, repetitive behavior, changes in mood or personality, and abnormal changes that affect daily life. Half of the family caregiver's attributed their loved ones behavioral changes to personality issues that they believed were masked by early signs and symptoms of AD as described by Pocnet, Rossier, Antonietti, and Gunten (2013). Some family caregivers also thought changes were due to other underlying conditions such as depression, PTSD, alcoholism, agitation, and the disease masking under their loved one's personality, in which they were unable to distinguish between normal or abnormal behavior. Depression is related to an increase of cognitive decline during later stages in life ("Depressive symptoms", 2016). Furthermore, the findings of this study confirm and extends Leung et al. (2011) research in which patients and caregivers noticed signs of AD two to four years before a confirmed diagnosis but did not seek medical assistance. It is significant that primary caregivers and healthcare providers recognize early signs of AD in patients to reduce diagnosis delay (Leung et al., 2011). Knopman et al., (2000) found that caregivers are unaware of the early signs of AD and other related memory loss conditions in relation to normal aging and, therefore, do not seek a proper medical diagnosis. Findings from this study also support and extend research from Carelesimo, Cherubini, Caltagirone, and Spalletta (2010) and Knopman et al. (2000) findings and confirm that there is a requirement for public and professional education about AD and routine screening for memory loss in aging individuals.

In the eight theme, I examined family caregiver's emotions to cognitive changes in loved ones. Most family caregiver's experienced an array of emotions before a confirmed diagnosis ranging from denial, confusion, sadness, empathy, resentment, bitterness, depression, denial, and a lack of understanding changes that occurred in their loved ones. However, after diagnosis, many family caregivers were able to accept the changes in their loved one’s cognition and attribute strange behavior to the disease rather than the individual. There were no distinct variations based on the gender of the affected family members as those caring for both females and males experienced similar emotions. Family caregiver’s emotions can be an important factor in delaying a medical diagnosis for their loved ones. In agreement with this study’s findings, Hughes et al. (2009) and Carpentier et al. (2008) reported that family members’ attitudes and acceptance concerning the AD diagnosis for patients can serve as potential barriers, with most family caregivers attributing there not being a cure for the degenerative illness.

In the ninth theme, family caregiver’s were asked if a family member influenced their decision to seek medical assistance. Most participants stated that they were the primary person to seek medical assistance for their loved one without any other family members input. Family caregivers stated that they were the closest family member to their loved one and noticed changes before anyone else in the family. Individuals with a family history of AD should be aware and knowledgeable about early signs of the disease, in addition to, having family members support in assisting with early detection (Rapp, 2014). Family caregivers did mention the lack of support from family members on seeking medical help for their loved one, although some family members did mention changes they noticed after a confirmed diagnosis. Only one participant shared the importance of family support and how he had his children to assist in seeking a medical diagnosis for his wife. Overall, family member influence did not play a significant factor in the determination of family caregiver's to seek medical assistance for their loved ones that indicate that more awareness about AD is required in African American families. Hughes et al. (2009) and Connell et al. (2009b) agreed that AD educational awareness and becoming more knowledgeable about normal aging as opposed to early AD signs is necessary for AA families. These authors' findings support results from this study.

The last theme was related to family caregiver's thoughts about delayed diagnosis in their loved ones. Half of the participants thought that there was a diagnosis delay in their loved one because of personal denial, unrecognized early signs, and normality in loved ones. There were no distinctive findings concerning gender of the affected family member. Some family caregivers stated that it was difficult to notice early signs of AD and determine there was a problem because their loved ones were able to maintain healthy daily habits without alerting concern. The results from this study confirm Connell et al. (2009a) in which African American patients attributed delayed diagnosis to there being no cure for AD; therefore, there is no need for a diagnosis, costly health care, and memory loss is a part of normal aging. Misconceptions about AD early signs can have a detrimental impact on the affected family member, delaying treatment for the affected family member and modifying best practices for caregiving, which all stem from a lack of knowledge about the illness (Lowe, Balsis, Hughes, Shine, & Carpenter, 2015). Consequently, Connell et al. (2009a) and Knopman et al. (2000) also found that caregiver's reasons to delay seeking medical diagnosis were attributed to difficulty mentioning cognitive changes to loved ones, patient angry behavior, patient refusal to visit doctor, and caregiver denial of patient AD diagnosis which findings in this study support. Mosconi et al. (2007) and Clark et al. (2005) assured that a timely diagnosis of AD is pertinent and would allow for a treatment plan for the patient to possibly slow disease progression and supportive resources for caregivers during the transition.

Finding related to Conceptual Framework

HBM and Attribution Theory

This study utilized the health belief model (HBM) in conjunction with the attribution theory as the conceptual framework to further investigate caregiver's perceptions to a timely diagnosis of AD in their loved ones. I have included an analysis and interpretation of the findings related to the conceptual framework. I have identified areas where the themes support particular aspects of the model, either construct of the HBM or attribution theory.

Theme 1: Early Alzheimer's Disease Detection

Most family caregiver's deemed early AD detection as unimportant because there is no cure for the illness, there are no guaranteed effective treatment or medications, and technology is not advanced enough to assist patients suffering from the degenerative disease. As it relates to the conceptual model, family caregiver's did not perceive AD risk to be serious and were unaware of how early detection could assist with better treatment for their loved ones. The HBM construct of perceived severity occurs when an individual's belief that a situation will have a serious outcome (Hughes et al., 2009; Leifer, 2009; Clark et al., 2005), however in this study some family caregiver's did agree that early detection was significant to prevent a serious onset of the disease supporting the HBM construct of perceived benefits. These family caregiver's thought that if they engaged in early AD detection for their loved ones, it would have resulted in positive outcomes and the benefits will be greater than the barriers (Glanz & Rimer, 1997; Strecher & Rosenstock, 1997; Burke, n.d.). The findings in this study all relate to the family caregiver's beliefs and understanding about AD and early detection based on prior knowledge about the illness.

Theme 2: Knowledge Level of Alzheimer's Disease.

The findings of this study showed that some family caregiver's expressed they were knowledgeable about AD only because of prior association with a close family member. However, they still did not know what the disease entails because of a lack of personal involvement with the sufferer on a consistent basis. These findings strongly support the HBM construct of perceived susceptibility, in which an individual will obtain information and seek medical assistance if they believe themselves to have a high susceptibility to a particular condition. Those family caregiver's who had somewhat or no knowledge of AD before their loved ones diagnosis also supports perceived susceptibility, in which they experienced low susceptibility because of personal belief that their vulnerability to obtaining the disease is small and, therefore, do not engage in preventative measures (Carpenter, 2010; Turner et al., 2004; Hochbaum, 1958). The findings also suggest that family caregivers who thought that obtaining knowledge about AD was important may have encountered both perceived susceptibility and perceived severity, resulting in a unified belief of perceived threat (Shamar, 2011). All these family caregivers shared that a close family member either a parent or grandparent had AD, therefore making them aware of a possible family history of the illness. It would then trigger family caregivers to learn about the disease in the hope of reducing their risk in comparison to those family caregivers who were somewhat or not knowledgeable about AD before their loved one's diagnosis.

Theme 3: Gender Differences Play a Role in Seeking Medical Assistance

The findings of this study showed that only two family caregiver's believed that gender was a factor in delaying seeking medical assistance for their loved ones. The attribution theory states that individuals give implicit judgments to an observable behavior or behavioral outcome (Weiner, 2008; Manusov and Harvey, 2001). One family caregiver that believed that gender played a role in not seeking medical assistance attributed their personal denial because she was the only child and her mother's best friend. This data supports the attribution or cognitive bias, in which the caregiver blamed herself for her mother's behavior due to personal denial and the decision not to seek medical assistance (Heider, 1958; Jones and Davis, 1965; Kelly, 1967). The other family caregiver stated that her father was honoree and a typical male not wanting to visits the doctor regularly. These findings support aspects of the FAE in which an individual seek to explain an adverse behavior in another person (Forsterling, 2001; Sabini et al., 2001; Weary & Reich, 2000; Weiner, 1979, 1985, 1986; Jones & Harris, 1967). Both family caregiver's attributed their loved one's abnormal behavior to other factors that delayed them to seek a medical diagnosis.

Theme 4: Communication with Loved One about Alzheimer's Disease

Family caregiver's shared that they used different tactics to communicate with their loved ones about noticed cognitive changes. In some instance, family caregiver's did not bother to communicate changes with their loved one due to personal denial or avoidance or erratic behavior. My findings revealed, based on the type of relationship family caregivers had with their loved ones influenced their communication technique to discuss cognitive changes. The theme of communication with loved one about AD relates to the subsequent addition the HBM, cues to action. Cues to action relate to internal and external factors that signal an individual to take steps to seek help for an illness (Hochbaum, 1958). Family caregivers in this study recognized at a given time that something was unusual with their loved ones and decided to communicate with them about the changes and take action to seek medical assistance. This theme also supports the HBM construct of perceived severity when individuals identify the seriousness of a given condition (Janz & Becker, 1984). Also, Jones and Davis (1965) correspondence inference theory concept of decisions supports this theme in which the family caregiver's negative judgment to abnormal behavior changes in their loved ones due to either internal or external factors triggered them to engage in a conversation about cognitive decline and seek medical advice.

Theme 5: Physician Support is Critically Important

The findings of this study showed that family caregiver's believed that the support of the physician is very vital when caring for a loved one with AD whether they received support during the diagnosis process or not. This theme support that family caregiver's think that having a supportive physician and healthcare team is very significant when obtaining a diagnosis. The findings from this theme support a socioeconomic factor related to the HBM, social support. According to Nauert (2010) and Schneider (2006), social support is when an individual receives assistance from an unfavorable situation, and it may have an impact on a person health behavior. Socioeconomic factors can influence the decision to engage in healthy behavior (CDC, 2014).

Theme 6: Seeking Medical Assistance for Loved Ones

Caregiver’s decision to seek medical assistance for loved ones was contingent upon factors of denial and regret. Family caregiver’s mentioned that they noticed signs of cognitive decline in their loved one but hesitated on seeking medical advice. The HBM states that a person is more likely to participate in screening behaviors and early detection if they perceive a problem (Glanz & Rimer, 1997). Most family caregiver’s did not experience any denial or regrets from not seeking medical assistance and attributed reasons to no cure and no effective treatment that supports the attribution theory. However, there were some family caregiver’s that did experience regret and denial when not seeking medical assistance when they first noticed early signs of AD that also supports the attribution theory. The attribution theory examines how an individual observes a particular behavior in another person and what they contribute the behavior to, either the person or an external factor (Fosterling, 2001; Jones & Davis, 1965; Heider, 1958). Family caregiver’s also discussed personal fear of developing AD which is supportive of the construct of perceived susceptibility, due to a possible family history of the disease (Glanz & Rimer, 1997).

Theme 7: Early Signs of Behavioral Changes

Several family caregiver’s mentioned that they noticed early signs of possible cognitive decline in their loved ones, but were unsure that the cause was AD. This theme correlates with the extended HBM and Bandura (1977) construct of self-efficacy. Self-efficacy is perceived when an individual is able to engage in another’s given behavior. In relations to AD, self-efficacy reflects family caregiver’s perceptions of early signs and symptoms of AD observed in their loved ones. Family caregiver’s were uncertain of the cause of their loved ones abnormal behavior which supports the attribution theory (Heider, 1958). Family caregiver’s reasoning for early signs and symptoms in relatives varied and impacted their decision on when to seek medical care as seen in several studies (Switzer & Boysen, 2009; Weigel, Langon, Collins, & O’Brien, 2006; Polk, 2005; Williamson et al., 2005; Cobb & Chabert, 2002; Follet & Hess, 2002; Tarrier et. al., 2002). Family caregivers used personal judgments, as depicted by the attribution theory, to decide why their loved ones were behaving abnormally (Tyran & Allen, 2002; Anderson, 2001; Weary & Reich, 2000; Fiske &Taylor, 1991). Findings from this theme also support Jones and Davis (1965) correspondent inference theory, extending from Heider (1958) work on the attribution theory, in which they noted several important concepts. The concept of unintentional or intentional behavior, suggests that the observer examines the connection between another person’s behavior and their personality. Some family caregiver’s stated that their loved one’s personality did change, but they attributed it to the behavior being intentional because what they know about the individual (a heuristic deviation), therefore, not acknowledging the behavior as unintentional which could contribute to a delay to seek medical assistance (Weiner, 2008, 1986; Jones & Davis, 1965).

Theme 8: Family Caregiver Emotions to Cognitive Changes in Loved One

The theme of family caregiver emotions to cognitive changes in their loved ones showed an array of emotions before and after a confirmed diagnosis. According to Heider (1958) attribution theory, a major concept of emotions and feelings support this theme. Heider (1958) stated that emotions and feelings include the observer’s feeling toward the observed person based on either positive or negative behavior influences. The findings of this study revealed that family caregiver’s were more upset, frustrated, confused, bitter, and resentful before a confirmed diagnosis in their loved ones. Whereas, after diagnosis, family caregiver’s were more empathetic and supportive after a confirmed diagnosis, although some caregiver still had feelings of sadness, bitterness, and resentment for their loved one’s condition.

Theme 9: Family Member Influence to Seek Medical Assistance

In the ninth theme, family caregiver’s discussed how they were the primary individual in seeking medical assistance for their loved one cognitive changes. As previously described, social support is very significant during unfavorable conditions. The modifiable variable in conjunction with the HBM asserts that social support may influence self-care for proactive health behaviors (Nauert, 2010; Schneider, 2006).

Theme 10: Delayed Diagnosis

In the last theme, delayed diagnosis, half of the family caregiver’s thought that there was a delayed AD diagnosis for their loved one. Their reasons were personal denial, which support the HBM construct of perceived severity, in which family caregiver’s deemed severity as low and chose not to acknowledge the cognitive changes that their loved one. Family caregiver’s also shared that the early signs of AD are so subtle, and they were unsure when to take action that supports a low self-efficacy and the attribution theory. Family caregiver’s noticed cognitive changes, but were unable to identify when to take action and seek medical assistance for their loved ones (Bandura, 1977). Family caregiver’s may have attributed early signs of AD to negative behavior in their loved ones that support the FAE of the attribution theory (Jones & Harris, 1967). Family caregiver’s that lacked adequate knowledge about early signs of AD would make causal judgments of the affected family member’s behavior and attribute to their reasoning without sufficient information (Jones & Harris, 1967). These rash judgments would then increase the delay of seeking a medical diagnosis.

Limitations to Study

The study was not focused on all African American family caregivers, but only individuals who were English speaking, 18 and older African American family caregivers that resided in Dallas, Texas metropolis. Therefore, the study was not generalizable to all African American caregivers or other races as I only collected data from participants who volunteered to participate in my study. I recruited from several places for this study which included a local university’s geriatric and memory clinic, and a local church in

Dallas, Texas. I did not expand recruitment to other geriatric and memory clinics, or churches in the metropolitan area. Some individuals contacted me who were not able to participate in the study due to their family member being either deceased or in a nursing facility. This study was limited to qualitative, grounded theory approach. For validity in this study, I engaged in one-on-one, face-to-face interviews with participants depending on participants honest responses. However, some participant's shared additional information about their caregiver experience after the interview was complete and the audiotape was turned off and did not want to me to collect additional information. These occurrences may have limited data collection and responses to interview questions. Therefore, that information was not included in the results section.

Recommendations for Future Study

The scope of was purposely limited based on my resources, however, future researchers may choose to widen the extent of the study. First, by either increasing the number of participants to broaden the knowledge about African American caregiver's perceptions to AD. Second, to determine if gender is an influencer on the decision to seek medical assistance or using another research method, such as quantitative approach. Thirdly, the research questions for this study could be in a quantitative study with a larger sample size as gender was not able to be fully explored and analyzed due to the study's sample size of only eight individuals. I recommend the following topics for future research in this study's area:

1. Acquire qualitative and quantitative data from a larger sample size in hopes of obtaining more male caregivers to understand better their experience as a family

caregiver. In this study, I only interviewed two males caring for a wife and mother. There is not a lot of AD research on African Americans males (Griffith and Lopez, 2009), especially those who served in the military. PTSD often shows similar cognitive changes as AD. If there is an adequate amount of female and male caregiver's participation, more knowledge can be collected and analyzed to determine if gender differences among caregiver's experience do exist and if so, what they are. Data from African Americans may provide knowledge on other minority groups (Barnes & Bennett, 2014).

2. This study recommends that there is an increase of knowledge about AD shared within African American communities. An increase in educational programs in African American communities would be beneficial in addressing the low levels of awareness (Cahill et al., 2015; Barnes & Bennett, 2014; Hughes et al., 2009); mainly for lay individuals to obtain adequate knowledge about the disease (Connell et al., 2009a). It is important to attract individuals without Dementia at community-based events to increase the knowledge level of the targeted population. This recommendation will hopefully lead to the development of new ways to inform African Americans about available resources that are critical to increasing knowledge levels. Although the AA (2016) has substantial information online, African Americans are not utilizing it to become knowledgeable about AD, which is the primary barrier. As suggested by Ayalon & Arean (2004) there is a need to evaluate why minority groups, such as African Americans lack knowledge about AD. There also may need to be further investigation into healthcare providers influence on delayed AD diagnosis and the how the patient-physician relationship plays a pivotal role (AA, 2013, 2012; CDC, 2013; Hughes et al., 2009; Clark et al., 2005).

3. Extend the study to evaluate other minority groups, such as Latinos to determine if family caregiver's perceptions of early diagnosis are similar or different to those of African Americans. Also, examine if gender differences exist in this group. There is a lack of literature in both African American and Latino groups, which suggest the requirement for more data to assist minority groups gain a better understanding, educational awareness and training on AD.

Social Implications

Positive Social Change

The positive social change for this research study was to identify if caregivers' perceptions and covert barriers and biases exist and determine if these obstacles and biases influence diagnosis delay and the decision-making process to investigate further the patient's cognitive health in regards to being susceptible to AD. There is a stigma associated with AD or other cognitive changes and promoting public awareness can diminish stigma associated with sufferers and caregivers (Navab, Negarandeh, Peyrovi, & Navab, 2013). This study will allow for more educational awareness programs to target African Americans in recognizing AD symptoms and signs early on. The results of this study support the advancement of more proactive planning for the AD sufferer's lifestyle transition before disease progression, which could help the family caregiver with proper preparations. My research findings will also assist health-care providers with information to help at-risk individuals with an early diagnosis of AD and reduce any delay.

The social change for this study is pertinent to the individual, family, organizational, and societal and policy levels as AD is steadily increasing in all communities and African Americans are diagnosed at later stages compared to Caucasians (AA, 2013). This study also suggests an implementation for global policy change for healthcare providers to perform mandatory testing for AD on individuals 55-60 years of age and earlier (45 years of age) if there is a family history of AD. This potential policy change could allow for proactive planning for the safety of the affected family members, in addition to, notifying family members of the possibility of developing AD as some individuals can mask early signs and symptoms that delay diagnosis. Family caregivers expressed that they noticed changes in their loved ones before a confirmed diagnosis; however, they were unsure on when to seek medical assistance. Therefore, deciding when to seek help is difficult for family caregivers because they are uncertain if their loved one’s changes should be attributed to AD or other factors. Consequently, there needs to be a policy established for mandatory AD testing in individuals just as routine tests are performed for various cancers, diabetes, STD’s, and heart disease (Bradford et al., 2009). As the ultimate aim of positive social change in this study, I hope the results will lead to increased knowledge of Alzheimer's disease in the African American community in Dallas, Texas metropolitan in addition to, leading to the development of materials to aid healthcare providers to reduce delays in AD diagnosis among African American patients. I hope that this will also allow for more proactive planning in AD sufferers and their families before disease progression.

Conclusion

Chapter 5 presents the conclusion of this research study. The findings produced ten themes that revealed family caregiver’s perceptions to an early AD diagnosis in loved ones; 1) early AD detection, 2) knowledge level of AD, 3) gender differences play a role in seeking medical assistance, 4) communication with loved one about AD, 5) physician support is critically important, 6) seeking medical assistance for loved ones,7) early signs of behavioral changes, 8) family caregiver emotions to cognitive changes in loved ones, 9) family member influence to seek medical assistance and 10) delayed diagnosis. The combination of all themes may support the development of a new grounded theory of family caregivers' diagnosis interpretation. Among all the themes that emerged, the most significant factor was caregiver's knowledge and understanding about the disease. If individuals lack proper knowledge about AD, it will influence diagnosis delay in loved ones in some aspect. There is a significant requirement for community outreach and educational awareness about AD within the African American population. The recommendations for this study invite all community stakeholders to participate in the awareness and educational involvement of AD and further suggest additional research to be conducted on AD diagnosis delay of AD in African Americans and other minority groups (Hughes et al., 2009; Clark et al., 2005).

References

Abraham, C., Sheeran, P., & Johnston, M. (1998). From health beliefs to self-regulation: Theoretical advances in the psychology of action control. *Psychology & Health, 13*(4), 569-591. doi:10.1080/08870449808407420

Adekeye, O., & Adeusi, S. (2011). Attribution patterns, attitude and knowledge of HIV/AIDS on sexual behavioral change among students of Covenant University Ota, Nigeria. *IFE PsychologIA: An International Journal*, *19*(1), 255-269. Retrieved from http://covenantuniversity.edu.ng/content/download/18547/119871/file/Ife%20PsycholoGia%202011.pdf.

Alzheimer's Association. (2016). *Know the ten signs*. Retrieved from http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp

Alzheimer's Association. (2016). Public Health Alzheimer's Resource Center. *Early detection*. Retrieved from http://www.alz.org/publichealth/early-detection.asp

Alzheimer's Association. (2015a). *Smell and eye tests show potential to detect Alzheimer's early*. Retrieved from http://www.alz.org/aaic/releases_2014/sun-830am-smell-eye-tests.asp.

Alzheimer's Association. (2015b). *Planning ahead*. Retrieved from http://www.alz.org/care/alzheimers-dementia-planning-ahead.asp

Alzheimer's Association. (2015c). *Alzheimer's and dementia testing for early diagnosis*. Retrieved from http://www.alz.org/research/science/earlier_alzheimers_diagnosis.asp

Alzheimer’s Association. (2014a). *Alzheimer’s disease facts and figures.* Retrieved from http://www.alz.org/downloads/Facts_Figures_2014.pdf

Alzheimer’s Association. (2014b). *Alzheimer’s disease. Stages*. Retrieved from http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

Alzheimer’s Association. (2014c). *Alzheimer’s disease. Treatments*. Retrieved from http://www.alz.org/alzheimers_disease_treatments.asp

Alzheimer’s Association of Greater Dallas. (2014). *Education programs. Family caregiver classes.* Retrieved from http://www.alz.org/greaterdallas/in_my _community_education.asp

Alzheimer’s Association. (2013). *African Americans and Alzheimer’s*. Retrieved from http://www.alz.org/africanamerican/

Alzheimer’s Association. (2012). *African Americans and Alzheimer’s disease: The silent epidemic*. Retrieved from http://www.alz.org/national/documents/report _africanamericanssilentepidemic.pdf

Alzheimer’s Association. (2011a). *What is Alzheimer’s disease?* Retrieved from http://www.alz.org/alzheimers_disease_what _is_alzheimers.asp

Alzheimer’s Association. (2011b). *Alzheimer’s disease and chronic health conditions: The real challenge for 21st century medicine*. Retrieved from http://www.alz .org/national/documents/report_chroniccare.pdf

American Psychological Association. (2015a). *Who are family caregiver’s?* Retrieved from http://www.apa.org/pi/about/publications/caregivers/faq/statistics.aspx

American Psychological Association. (2015a). *Understanding chronic stress.* Retrieved from http://www.apa.org/helpcenter/understanding-chronic-stress.aspx

Anderson, C. (1991). How people think about causes: Examination of the typical phenomenal organization of attributions for success and failure. *Social Cognition, 9*, 295-329. doi: 10.1521/soco.1991.9.4.295

Andrews, P. (2001). The psychology of social chess and the evolution of attribution mechanisms: Explaining the fundamental attribution error. *Evolutions and Human Behavior, 22,* 11-29. doi: 10.1016/S1090-5138(00)00059-3

Apesoa-Varano, E., Barker, J., & Hinton, L. (2011). Curing and caring: the work of primary care physicians with dementia patients. *Qualitative Health Research, 21*(11), 1469-1483. doi:10.1177/1049732311412788

Ayalon, L., & Arean, P. (2004). Knowledge of Alzheimer's disease in four ethnic groups of older adults. *International Journal of Geriatric Psychiatry, 19*(1), 51-57. doi:10.1002/gps.1037

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84,* 191–215.Retrieved from https://www.uky.edu/~eushe2/Bandura/Bandura1977PR.pdf

Barnes, L., & Bennett, D. (2014). Alzheimer's disease in African Americans: Risk factors and challenges for the future. *Health Affairs*, *33*(4), 580-586. doi:10.1377 /hlthaff.2013.1353

Barnes, L., Wilson, R., Everson-Rose, S., Hayward, M., Evans, D., & Mendes de Leon, C. (2012). Effects of early-life adversity on cognitive decline in older African

Americans and whites. *Neurology*, *79*(24), 2321-2327. doi:10.1212/WNL.0b013e318278b607

Barnes, L., Wilson, R., Li, Y., Gilley, D., Bennett, D., & Evans, D. (2006). Change in cognitive function in Alzheimer's disease in African-American and white persons. *Neuroepidemiology*, *26*(1), 16-22. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/pdfviewer/pdfviewer?sid=bf235a8c-98cf-4347-b1bf-5c3b70cf4376%40sessionmgr4005&vid=8&hid=4212

Beinhoff, U., Tumani, H., Brettschneider, J., Bittner, D., & Riepe, M. (2008). Gender-specificities in Alzheimer's disease and mild cognitive impairment. *Journal of Neurology*, *255*(1), 117-122. doi:10.1007/s00415-008-0726-9

Bradford, A., Kunik, M., Schulz, P., Williams, S., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. Alzheimer Disease and Associated Disorders, 23(4), 306-314. doi:10.1097/WAD.0b013e3181a6bebc

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217–228. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/

Buckley, L., & Schub, T. (2012). Alzheimer's disease. Retrieved from http://ehis.ebscohost.com/eds/pdfviewer/pdfviewer?sid=88332ffa-af8d-4bab-89f9-82dc94f2037d%40sessionmgr12&vid=2&hid=23

Bullock, R., & Hammond, G. (2003). Realistic expectations: the management of severe Alzheimer disease. *Alzheimer Disease and Associated Disorders, 17 Suppl 3*S80-S85. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/14512821

Burke, E. (n.d.). The Health Belief Model. Retrieved from http://www.iccwa.org.au/useruploads/files/soyf/2013_resources_videos/the_health_belief_model.pdfevan_burke.pdf

Burwell, B. & Jackson, B. (1994). The Disabled Elderly and Their Use of Long-Term Care. U.S. Department of Health and Human Services. Retrieved from http://aspe.hhs.gov/daltcp/reports/diseldes.htm

Cahill, S., Pierce, M., Werner, P., Darley, A., & Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. Alzheimer Disease & Associated Disorders, 29(3), 255-275 21p. doi:10.1097/WAD.0000000000000102

Callone, P., Vasiloff, B., Brumback, R., Manternach, J., Kudlacek, C., & Pfeifer, C. (2006). Chapter V: Alzheimer's disease: changes in the brain. In, *Alzheimer's disease (9781932603132)* (pp. 91-109). New York, NY: Demos Medical Publishing. Retrieved from http://connection.ebscohost.com/c/book-chapters/39773957/chapter-v-alzheimers-disease-changes-brain

Carlesimo, G., Cherubini, A., Caltagirone, C., & Spalletta, G. (2010) Hippocampal mean diffusivity and memory in healthy elderly individuals: a cross-sectional study. Neurology 74(3): 194–200. doi:10.1212/WNL.0b013e3181cb3e39

Carpentier, N., Ducharme, F., Kergoat, M., & Bergman, H. (2008). Social representations of barriers to care early in the careers of caregivers of persons with Alzheimer's disease. Research on Aging, 30(3), 334-357. doi:10.1177/0164027507312113

Centers for Disease Control and Prevention. (CDC). (2014). Social Determinants of Health. Retrieved from http://www.cdc.gov/socialdeterminants/Definitions.html

Centers for Disease Control and Prevention. (2013). Black or African American Populations. Retrieved from http://www.cdc.gov/minorityhealth/populations/REMP/black.html

Charmaz, K. (1990). ‘Discovering’chronic illness: using grounded theory. *Social science & medicine*, *30*(11), 1161-1172. Retrieved from https://student.cc.uoc.gr/uploadFiles/1110-%CE%93001%CE%9A/Charmatz_1990.pdf

Clare, L., Marková, I., Roth, I., & Morris, R. (2011). Awareness in Alzheimer's disease and associated dementias: Theoretical framework and clinical implications. Aging & Mental Health, 15(8), 936-944 9p. doi:10.1080/13607863.2011.583630

Clark, P., Kutner, N., Goldstein, F., Peterson-Hazen, S., Garner, V., Zhang, R., & Bowles, T. (2005). Impediments to timely diagnosis of Alzheimer's disease in African Americans. *Journal of the American Geriatrics Society*, *53*(11), 2012-2017. doi:10.1111/j.1532-5415.2005.53569.x

Cobb, M., & De Chabert, J. (2002). HIV/AIDS and care provider attributions: Who's to blame? *AIDS Care*, *14*(4), 545-548. doi: 10.1080/09540120208629672

Connell, C., Scott Roberts, J., McLaughlin, S., & Akinleye, D. (2009a). Racial differences in knowledge and beliefs about Alzheimer disease. Alzheimer Disease and Associated Disorders, *23(2),* 110-116. doi:10.1097/WAD.0b013e318192e94d

Connell, C., Roberts, J., McLaughlin, S., & Carpenter, B. (2009b). Black and white adult family members' attitudes toward a dementia diagnosis. *Journal of the American Geriatrics Society, 57(9),* 1562-1568. doi:10.1111/j.1532-5415.2009.02395.x

Craig, M., & Murphy, D. (2009). Alzheimer's disease in women. *Best Practice & Research: Clinical Obstetrics & Gynecology*, *23(1),* 53-61. doi:10.1016/j.bpobgyn.2008.10.004

Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd Ed.). Thousand Oaks, CA: Sage.

Crosby, R., DiClemente, R., & Salazar, L. (2006). *Research methods in health promotion* (1st Ed.). San Francisco, CA: Jossey-Bass.

Dai, B., Mao, Z., Wu, B., Mei, Y., Levkoff, S., & Wang, H. (2015). Family Caregiver's Perception of Alzheimer's disease and Caregiving in Chinese Culture. Social Work in Public Health, 30(2), 185-196 12p. doi:10.1080/19371918.2014.969858

Donabedian, A. (1973). Aspects of Medical Care Administration: Specifying Requirements for Health Care. Harvard University Press for the Commonwealth Fund, Cambridge, MA.

Depressive symptoms and cognitive decline: A longitudinal analysis of potentially modifiable risk factors in community dwelling older adults. (2016). *Journal of Affective Disorders*, 190235-240 6p. doi:10.1016/j.jad.2015.09.046

Evans, R., Emsley, C., Gao, S., Sahota, A., Hall, K., Farlow, M., & Hendrie, H. (2000). Serum cholesterol, APOE genotype, and the risk of Alzheimer's disease: a population-based study of African Americans. *Neurology*, *54*(1), 240-242. doi: 10.1212/WNL.54.1.240

Fiske, S., & Taylor, S. (1991). *Social cognition (2nd Ed.)*. New York: McGraw-Hill.

Flicker, L. (2010). Modifiable lifestyle risk factors for Alzheimer's disease. *Journal of Alzheimer's disease, 20(3), 803-811.* doi: 10.3233/JAD-2010-091624.

Follett, K., & Hess, T. (2002). Aging, cognitive complexity, and the fundamental attribution error. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *57*(4), P312-P323. Retrieved from https://www.researchgate.net/profile/Thomas_Hess2/publication/11290179_Aging_Cognitive_Complexity_and_the_Fundamental_Attribution_Error/links/53d40b6b0cf2a7fbb2e9f8d0.pdf

Forgas, J. (1998). On being happy and mistaken: Mood effects on the fundamental attribution error. *Journal of Personality and Social Psychology*, *75*(2), 318-331. doi:10.1037/0022-3514.75.2.318

Försterling, F. (2001). *Attribution: An introduction to theories, research, and applications*. Hove [u.a.]: Psychology Press.

Frankfort-Nachmias, C., & Nachmias, D. (2008). Research methods in the social sciences (7th Ed.). New York: Worth

Frick, E., Fegg, M., Tyroller, M., Fischer, N., & Bumeder, I. (2007). Patients' health beliefs and coping prior to autologous peripheral stem cell transplantation. *European Journal of Cancer Care*, *16*(2), 156-163. doi:10.1111/j.1365-2354.2006.00725.x

Frieze, I. H., & Weiner, B. (1971). Cue utilization and attributional judgments for success and failure. *Journal of Personality*, 39, 591-605. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/pdfviewer/pdfviewer?sid=75897d70-0e0f-4191-a9c0-3ad10d913e13%40sessionmgr4003&vid=4&hid=4107

Ghebranious, N., Mukesh, B., Giampietro, P. F., Gluhch, I., Michel, S. F., Waring, S. C., & McCarty, C. A. (2011). A Pilot Study of Gene/Gene and Gene/Environment Interactions in Alzheimer Disease. *Clinical Medicine & Research, 9(1),* 17-25. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/pdfviewer/pdfviewer?sid=bf235a8c-98cf-4347-b1bf-5c3b70cf4376%40sessionmgr4005&vid=28&hid=4212

Gilbert, D., & Jones, E. (1986). Perceiver induced constraint: Interpretations Of social judgment. *Journal of Personality and Social Psychology, 50,* 269-280. Retrieved from http://dx.doi.org/10.1037/0022-3514.50.2.269

Gilbert, D., & Malone, P. (1995). The correspondence bias. *Psychological Bulletin, 117,* 21-38. Retrieved from http://heatherlench.com/wp-content/uploads/2008/06/gilbert.pdf

Gil-Lacruz, M., & Gil-Lacruz, A. (2010). Health attributions and health care behavior interactions in a community sample. *Social Behavior and Personality, 38*(6), 845-858. doi:10.2224/sbp.2010.38.6.845

Glanz, K., Rimer, B.K., & Lewis, F.M. (2002). Health Behavior and Health Education. Theory, Research and Practice. San Francisco: Wiley & Sons. Retrieved from http://202.74.245.22:8080/xmlui/bitstream/handle/123456789/362/Health%20behavior%20and%20health%20education%20by%20Karen%20Glanz.pdf?sequence=1

Glanz, K. and Rimer, B.K. (1997). Theories at a Glance. A Guide for Health Promotion Practice. National Cancer Institute, National Institutes of Health, U.S. Department of Health and Human Services. NIH Pub. No 97-3896. Washington, DC: NIH, Revised September 1997. Retrieved from http://www.sbccimplementationkits.org/demandrmnch/wp-content/uploads/2014/02/Theory-at-a-Glance-A-Guide-For-Health-Promotion-Practice.pdf

Glaser, B. G., & Strauss, A. L. (2009). *The discovery of grounded theory: Strategies for qualitative research*. Transaction Publishers.

Gong, Y., Chang, L., Viola, K., Lacor, P., Lambert, M., Finch, C., & Klein, W. (2003). Alzheimer's disease-affected brain: presence of oligomeric A beta ligands

(ADDLs) suggests a molecular basis for reversible memory loss. *Proceedings of the National Academy of Sciences of the United States of America*, *100*(18), 10417-10422. doi: 10.1073/pnas.1834302100

Grant, C., Davis, J., Rivers, B., Rivera-Colón, V., Ramos, R., Antolino, P., & Green, B. (2012). The men's health forum: An initiative to address health disparities in the community. *Journal of Community Health: The Publication for Health Promotion and Disease Prevention*, *37*(4), 773-780. doi: 10.1007/s10900-011-9510-3

Griffith, P. A., and Lopez, O.L. (2009). Disparities in the Diagnosis and Treatment of Alzheimer's disease in African American and Hispanic Patients: A Call to Action. *Generations*, *33*(1), 37-46. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/pdfviewer/pdfviewer?sid=bf235a8c-98cf-4347-b1bf-5c3b70cf4376%40sessionmgr4005&vid=34&hid=4212

Griffith, P., Lichtenberg, P., Goldman, R., & Payne-Parrish, J. (2006). Safety and efficacy of donepezil in African Americans with mild-to-moderate Alzheimer's disease. *Journal of the National Medical Association, 98*(10), 1590-1597. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2569765/pdf/jnma00197-0032.pdf

Gurland, B., Wilder, D., Lantingua, R., Stern, Y., Chen, J., Killeffer, E. & Mayeux, R. (1999). Rates of dementia in three ethnoracial groups. *International Journal of Geriatric Psychiatry, 14(6),* 481-493. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/pdfviewer/pdfviewer?si d=bf235a8c-98cf-4347-b1bf-5c3b70cf4376%40sessionmgr4005&vid=39&hid=4212

Hall, S., French, D. P., & Marteau, T. M. (2003). Causal attributions following serious unexpected negative events: A systematic review. *Journal of Social and Clinical Psychology*, 22(5), 515 – 536. doi: 10.1521/jscp.22.5.515.22924

Hargrave, R. (2006). Caregivers of African-American elderly with dementia: a review and analysis. *Annals of Long Term Care*, *14*(10), 36. Retrieved from http://www.annalsoflongtermcare.com/article/caregivers-african-american-elderly-dementia

Harvard Health (2005). In search of Alzheimer's disease. *Harvard Mental Health Letter*, *22*(4), 3-5. Retrieved from http://www.health.harvard.edu/press_releases/alzheimers_disease_research

Harvey, J., & Weary, G. (1981). *Perspectives on attributional processes*. Dubuque, IA: Wm. C. Brown.

Hebert, L., Scherr, P., McCann, J., Beckett, L., & Evans, D. (2001). Is the risk of developing Alzheimer's disease greater for women than for men? *American Journal of Epidemiology*, *153*(2), 132-136. doi: 10.1093/aje/153.2.132

Heider, F. (1958). *The psychology of interpersonal relations*. New York: Wiley.

Henshaw, E. J., & Freedman-Doan, C. R. (2009). Conceptualizing mental health care utilization using the health belief model. *Clinical Psychology: Science and Practice*, *16*(4), 420-439. doi:10.1111/j.1468-2850.2009.01181.x

Herbert, L., Weuve, J., Scherr, P., & Evans, D. (2013). Alzheimer’s disease in the United States (2010-2050) estimated using the 2010 census. *Neurology, 80(19)*, 1778-1783. doi:10.1212/WNL.0b013e31828726f5

Hewstone, M. (1983). Attribution theory and common-sense explanations: An introductory overview. In M. Hewstone (Ed.), *Attribution theory: Social and functional extensions.* (pp. 1-26). Oxford: Basil Blackwell.

Hinton, L., Franz, C., Yeo, G., & Levkoff, S. (2005). Conceptions of dementia in a multiethnic sample of family caregivers. *Journal of the American Geriatrics Society*, *53*(8), 1405-1410. doi:http://dx.doi.org.ezp.waldenulibrary.org/10.1111/j.1532-5415.2005.53409.x

Hochbaum, G. (1958). *Public Participation in Medical Screening Programs: A Socio-psychological study.* (Public Health Service Publication No., 572). Washington, D.C: Government Printing Office.

Holmes, S., & Adler, D. (2005). Dementia care: critical interactions among primary care physicians, patients and caregivers. *Primary Care*, *32*(3), 671. doi: http://dx.doi.org/10.1016/j.pop.2005.07.001

Hughes, T., Tyler, K., Danner, D., & Carter, A. (2009). African American caregivers: an exploration of pathways and barriers to a diagnosis of Alzheimer's disease for a family member with dementia. *Dementia (14713012)*, *8*(1), 95-116. doi: 10.1177/1471301208099048

Husaini, B., Sherkat, D., Moonis, M., Levine, R., Holzer, C., & Cain, V. (2003). Racial differences in the diagnosis of dementia and in its effects on the use and costs of health care services. Psychiatric Services (Washington, D.C.), 54(1), 92-96. Retrieved from http://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.54.1.92

Isamah, N., Faison, W., Payne, M., MacFall, J., Steffens, D., Beyer, J., & Taylor, W. (2010). Variability in frontotemporal brain structure: the importance of recruitment of African Americans in neuroscience research. *Plos One*, *5*(10), e13642. doi:10.1371/journal.pone.0013642

Janz, N., & Becker, M. (1984). The Health Belief Model: a decade later. *Health Education Quarterly*, *11*(1), 1-47. doi: 10.1177/109019818401100101

Jellison, J., & Green, J. (1981). A self-presentation approach to the fundamental attribution error: The norm of internality. *Journal of Personality and Social Psychology*, *40*(4), 643-649. doi:10.1037/0022-3514.40.4.643

Jeong, S. (2007). Effects of news about genetics and obesity on controllability attribution and helping behavior. *Health Communication*, *22*(3), 221-228. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/pdfviewer/pdfviewer?sid=bf235a8c-98cf-4347-b1bf-5c3b70cf4376%40sessionmgr4005&vid=47&hid=4212

Jones, E., & Davis, K. (1965). From acts to dispositions: the attribution process in social psychology, in L. Berkowitz (ed.), *Advances in experimental social psychology, 2,* 219-266. New York: Academic Press.

Jones, E. & Harris, V. (1967). The attribution of attitudes. *Journal of Experimental Social Psychology* 3, 1–24.

Jones, E. (1979). The rocky road from acts to dispositions. *American Psychologist, 34,* 107-117.

Jones, E. (1990). *Interpersonal perception.* New York: Macmillan.

Kada, S. (2015). Knowledge of Alzheimer's disease Among Norwegian Undergraduate Health and Social Care Students: A Survey Study. Educational Gerontology, 41(6), 428-439 12p. doi:10.1080/03601277.2014.982009

Kahneman, D. (2011). Thinking, Fast and Slow. 18 West 18th Street: New York, New York, 10011: Farrar, Straus, and Giroux.

Kahneman D., Slovic, P., and Tversky, A. (Eds.) (1982) *Judgment under Uncertainty: Heuristics and Biases*. New York: Cambridge University Press.

Kawas, C., & Corrada, M. (2006). Alzheimer's and dementia in the oldest-old: a century of challenges. *Current Alzheimer Research, 3*(5), 411-419.

Kelley, H. (1967). Attribution theory in social psychology. In D. Levine (ed.), *Nebraska Symposium on Motivation, 15*, 192-238. Lincoln: University of Nebraska Press.

Kelley, H. (1972). *Causal schemata and the attribution process.* Morristown, NJ: General Learning Press.

King, J. (1982). The impact of patients' perceptions of high blood pressure on attendance at screening: An extension of the health belief model. *Social Science & Medicine, 16*(10), 1079-1091.

King, J. (1983). Illness attributions and the health belief model. *Health Education & Behavior*, *10*(3-4), 287-312. doi: 10.1177/109019818301000309

Knopman, D., Donohue, J., & Gutterman, E. (2000). Patterns of care in the early stages of Alzheimer's disease: impediments to timely diagnosis. *Journal of the American Geriatrics Society, 48(3),* 300-304 5p. doi: 10.1111/j.1532-5415.2000.tb02650.x

Krull, D. (2001). On partitioning the fundamental attribution error: Dispositionalism and the correspondence bias. In G. B. Moskowitz (Ed.), *Cognitive social psychology* (pp.211-227). Mahwah, New Jersey, USA, Lawrence Erlbaum Associates. Retrieved from http://books.google.com/books?hl=en&lr=&id=DE-cJ8F4rSMC&oi=fnd&pg=PA211&dq=On+partitioning+the+fundamental+attribution+error:+Dispositional+ism+and+the+correspondence+bias&ots=jseQPHG5B4&sig=kSZVdvRwcn1_vU-chQmX4zS4cUs#v=onepage&q&f=false

Koos, E. (1954). The Health of Regionville. Columbia University Press, New York, New York.

Langdridge, D., & Butt, T. (2004). The fundamental attribution error: a phenomenological critique. *British Journal of Social Psychology, 43* (3), 357-369.

Lee, A., Kiyu, A., Milman, H., & Jimenez, J. (2007). Improving health and building human capital through an effective primary care system. *Journal of Urban Health: Bulletin of the New York Academy of Medicine, 84*(3 Suppl), i75-i85. Retrieved from http://link.springer.com/article/10.1007/s11524-007-9175-5/fulltext.html

Leifer, B. (2009). Alzheimer's disease: seeing the signs early. *Journal of the American Academy of Nurse Practitioners*, *21*(11), 588-595. doi:10.1111/j.1745-7599.2009.00436.x

Leritz, E., Salat, D., Milberg, W., Williams, V., Chapman, C., Grande, L., & McGlinchey, R. (2010). Variation in blood pressure is associated with white matter microstructure but not cognition in African Americans. *Neuropsychology*, *24*(2), 199-208. doi:10.1037/a0018108

Lerner, M., & Miller, D. (1978). Just world research and the attribution process. Looking back and ahead. *Psychological Bulletin* 85, 1030–1051. Retrieved from http://dx.doi.org/10.1037/0033-2909.85.5.1030

Leung, K., Finlay, J., Silvius, J., Koehn, S., McCleary, L., Cohen, C., & Drummond, N. (2011). Pathways to diagnosis: exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. Health & Social Care in the Community, 19(4), 372-381. doi:http://dx.doi.org.ezp.waldenulibrary.org/10.1111/j.1365-2524.2010.00982.x

Local College. (2014). Geriatrics. Retrieved from: http://www.localcollege.edu/patientcare/medicalservices/geriatrics.html

Long, M. (1994). The Medical Care System: A Conceptual Model. AUPHA Press/Health Administration Press, Ann Arbor, Michigan.

Lowe, D., Balsis, S., Hughes, M., Shine, H., & Carpenter, B. (2015). Misconceptions of Alzheimer’s disease. Clinical Gerontologist, 38(2), 149-156 8p. doi:10.1080/07317115.2014.990600

Luchsinger, J., Tang, M., Stern, Y., Shea, S., & Mayeux, R. (2001). Diabetes Mellitus and Risk of Alzheimer's disease and Dementia with Stroke in Multiethnic Cohort. American Journal of Epidemiology, *154*(7), 635-641. Retrieved from http://aje.oxfordjournals.org/content/154/7/635.full

Mahoney, D., Cloutterbuck, J., Neary, S., & Zhan, L. (2005). African American, Chinese, and Latino Family Caregivers' Impressions of the Onset and Diagnosis of Dementia: Cross-Cultural Similarities and Differences. The Gerontologist (2005) 45(6), 783-792. doi:10.1093/geront/45.6.783

Malone, D., McLaughlin, T., Wahl, P., Leibman, C., Arrighi, H., Cziraky, M., & Mucha, L. (2009). Burden of Alzheimer's disease and association with negative health outcomes. *The American Journal of Managed Care*, *15*(8), 481-488. Retrieved from http://www.ajmc.com/journals/issue/2009/2009-08-vol15-n8/AJMC_09augMalone_481to488/

Manly, J., Touradiji, P., Tang, M., & Stern, Y. (2003). Literacy and Memory Decline among Ethically Diverse Elders. *Journal of Clinical and Experimental Neuropsychology*, *25*(5), 680-690. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/pdfviewer/pdfviewer?sid=bf235a8c-98cf-4347-b1bf-5c3b70cf4376%40sessionmgr4005&vid=52&hid=4212

Manusov, V. L., & Harvey, J. H. (2001). *Attribution, communication behavior, and close relationships*. Cambridge: Cambridge University Press.

Mayo Clinic. (2015). Mild Cognitive Impairment (MCI). Definition. Retrieved from http://www.mayoclinic.org/diseases-conditions/mild-cognitive-impairment/basics/definition/con-20026392

Mayo Clinic. (2014). Alzheimer’s disease. Symptoms. Retrieved from http://www.mayoclinic.org/diseases-conditions/alzheimers-disease/basics/symptoms/con-20023871

McDonald, P., & Wykle, M. (2003). Predictors of health-promoting behavior of African-American and white caregivers of impaired elders. *Journal of National Black Nurses' Association: JNBNA*, *14*(1), 1-12. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15259993

McLeod, S. (2010). Attribution Theory. Retrieved from http://www.simplypsychology.org/attribution-theory.html

Mittleman, M., Roth, D., Haley, W., & Zarit, S. (2004). Effect of a Caregiver Intervention on Negative Caregiver Appraisals of Behavior Problems in Patients with Alzheimer’s disease: Results of a Randomized Trial. Journal of Gerontology, *59B* (1), 27-34. Retrieved from http://psychsocgerontology.oxfordjournals.org/content/59/1/P27.long

Mosconi, L., Brys, M., Glodzik-Sobanska, L., De Santi, S., Rusinek, H., & de Leon, M. (2007). Early detection of Alzheimer's disease using neuroimaging. *Experimental gerontology*, *42*(1), 129-139. Retrieved from http://ac.els-cdn.com.ezp.waldenulibrary.org/S0531556506001355/1-s2.0-

S0531556506001355-main.pdf?_tid=00e97e56-f528-11e5-ba41-00000aab0f27&acdnat=1459198966_b17385462df2e8a67d2c1872e63c2982

Mowday, R. (1987). Beliefs about the Causes of Behavior: The Motivational Implications of Attribution Processes. Retrieved from http://dsmgt310.faculty.ku.edu/SuppMaterial/KelleyAttributionTheory.htm

Mulnard, R., Cotman, C., Kawas, C., van Dyck, C., Sano, M., Doody, R., Koss, E., Pfeiffer, E., Jin, S., Gamst, A., Grundman, M., Thomas, R., & Thal, L. (2000). Estrogen replacement therapy for treatment of mild to moderate Alzheimer disease: a randomized controlled trial. Alzheimer's disease Cooperative Study. *The Journal of the American Medical Association, 283(8)*, 1007-15. Retrieved from: http://jama.ama-assn.org/content/283/8/1007.full.pdf+html

Murry, L. (2002). Cognitive distinctions between early depression and early Alzheimer’s disease in the elderly. Aphasiology, 16(4-5-6), 573-585. doi: 10.1080/02687030244000293

Musicco, M. (2009). Gender differences in the occurrence of Alzheimer's disease. *Functional Neurology*, *24*(2), 89-92. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19775536

National Institute on Aging (NIA). (2013). Alzheimer’s disease Fact Sheet. Retrieved from http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet

National Public Radio (NPR). (2016). Medicare Pays for Alzheimer's Screening, but do you want to know? Retrieved from http://www.npr.org/sections/healthshots/2014/05/06/309834180/medicare-pays-for-alzheimers-screening-but-do-you-want-to-know

Nauert, R. (2010). Social Support, Friends Can Help Our Health. *Psych Central.* Retrieved from http://psychcentral.com/news/2010/10/25/social--support-friends-can-help-our-health/20106.html

Navab, E., Negarandeh, R., Peyrovi, H., & Navab, P. (2013). Stigma among Iranian family caregivers of patients with Alzheimer's disease: A hermeneutic study. Nursing & Health Sciences, 15(2), 201-206 6p. doi:10.1111/nhs.12017

Ortiz, F., & Fitten, L. (2000). Barriers to healthcare access for cognitively impaired older Hispanics. Alzheimer Disease and Associated Disorders, 14(3), 141-150. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10994655

Parker, S., Clarke, C., Moniz-Cook, E., & Gardiner, E. (2012). The influence of ‘cognitive busyness’ on causal attributions of challenging behaviour in dementia: A preliminary experimental study. *Aging & Mental Health*, *16*(7), 836-844. doi:10.1080/13607863.2012.684668.

Paton, J., Johnston, K., Katona, C., & Livingston, G. (2004). What causes problems in Alzheimer's disease: attributions by caregivers. A qualitative study. *International Journal of Geriatric Psychiatry*, *19*(6), 527-532. doi:10.1002/gps.1118

Pierron-Robinet, G. (2012). For an integrative approach of Alzheimer's disease. Relevance and limits. National Institutes of Health: *Geriatric Psychology Neuropsychiatry Vieil. 10(1)*:73-81. doi: 10.1684/pnv.2012.0321.

Pike, C., Carroll, J., Rosario, E., & Barron, A. (2009). Protective actions of sex steroid hormones in Alzheimer's disease. *Frontiers in Neuroendocrinology*, *30*(2), 239-258. doi:10.1016/j.yfrne.2009.04.015

Pinn, V. (2003). Sex and gender factors in medical studies: implications for health and clinical practice. *JAMA: The Journal of the American Medical Association*, *289*(4), 397-400. doi:10.1001/jama.289.4.397.

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging*, *18*(2), 250-267. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12825775

Pocnet, C., Rossier, J., Antonietti, J., & von Gunten, A. (2013). Personality traits and behavioral and psychological symptoms in patients at an early stage of Alzheimer's disease. *International Journal of Geriatric Psychiatry, 28*(3), 276-283. doi:10.1002/gps.3822

Polk, D. M. (2005). Communication and family caregiving for Alzheimer's dementia: Linking attributions and problematic integration. *Health Communication, 18*(3), 257-273. doi:10.1207/s15327027hc1803_4

Ptok, U., Barkow, K., & Heun, R. (2002). Fertility and number of children in patients with Alzheimer's disease. *Archives of Women's Mental Health, 5*(2), 83-86. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12510204

QSR International. (2008). NVivo 8 getting started, 1-47. Victoria, Australia. Retrieved from http://www.qsrinternational.com

Rapp, T. (2014). Patients' diagnosis decisions in Alzheimer's disease: The influence of family factors. Social Science & Medicine, 1189-16 8p. doi:10.1016/j.socscimed.2014.07.052

Ray, C. (2011). An Overview of Jones and Davis Correspondent Inference Theory. Sciences 360. Psychology. Retrieved from http://www.sciences360.com/index.php/an-overview-of-jones-and-davis-correspondent-inference-theory-2-4204/

Riggio, H. R., & Garcia, A. L. (2009). The power of situations: Jonestown and the fundamental attribution error. *Teaching Of Psychology*, *36*(2), 108-112. doi: 10.1080/00986280902739636

Rosenstock, I. (1974). Historical Origins of the Health Belief Model. *Health Education Monographs, 2*(4). Retrieved from http://heb.sagepub.com/content/2/4/328.extract

Rosenstock, I. M. (1966). Why people use health services. *Milbank Memorial Fund Quarterly,* 44, 94-127. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/detail/detail?vid=7&sid=ab8cd86a-bb01-4d29-a826-e1eb3191e21d%40sessionmgr4001&hid=4207&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#AN=5967464&db=mnh

Rosenstock, I., Strecher, V., & Becker, M. (1988). Social learning theory and the health belief model. *Health Education Quarterly, 15,* 75-183. Retrieved from https://deepblue.lib.umich.edu/bitstream/handle/2027.42/67783/10.1177_109019818801500?sequence=2

Ross, L. (1988). The intuitive psychologist and his shortcomings: Distortions in the attribution process. In Berkowitz, L. *Advances in experimental social psychology*, *10*, 173-220. New York: Academic. Retrieved from http://web.mit.edu/curhan/www/docs/Articles/15341_Readings/Social_Cognition/Ross_Intuitive_Psychologist_in_Adv_Experiment_Soc_Psych_vol10_p173.pdf

Rudestam, K., and Newton, R. (2007). *Surviving your dissertation: A comprehensive guide to content and process*. Thousand Oaks: CA: Sage.

Sabini, J., Siepmann, M., & Stein, J. (2001). The really fundamental attribution error in social psychological research. *Psychological Inquiry*, *12*(1), 1-15. doi:10.1207/S15327965PLI1201_01

Schiavo, R. (2007). Health Communication: From Theory to Practice. San Francisco: Jossey-Bass.

Schmidt, R., Kienbacher, E., Benke, T., Dal-Bianco, P., Delazer, M., Ladurner, G., & Wehringer, C. (2008). [Sex differences in Alzheimer's disease]. *Neuropsychiatrie: Klinik, Diagnostik, Therapie Und Rehabilitation: Organ Der Gesellschaft Österreichischer Nervenärzte Und Psychiater*, *22*(1), 1-15. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/18381051

Schneider, M.J. (2006). Introduction to Public Health. Sudbury: MA: Jones & Bartlett.

Senior Journal. (2007). African-American, Hispanic Caregivers Too Often Dismiss Alzheimer's as 'Old Age'. Retrieved from http://seniorjournal.com/NEWS/Alzheimers/2007/7-03-14-AfricanAmerican.htm

Seneff, S. (2009). APOE-4: The Clue to Why Low Fat Diet and Statins may Cause Alzheimer's. Retrieved from: http://people.csail.mit.edu/seneff/alzheimers_statins.html

Senior Journal. (2007). African-American, Hispanic Caregivers Too Often Dismiss Alzheimer's as 'Old Age'. Retrieved from http://seniorjournal.com/NEWS/Alzheimers/2007/7-03-14-AfricanAmerican.htm

Sharma, M. (2011). Health belief model: Need for more utilization in alcohol and drug education. *Journal of Alcohol and Drug Education*, *55*(1), 3-6. Retrieved from https://www.researchgate.net/publication/273573916_Health_belief_model_Need_for_more_utilization_in_alcohol_and_drug_education_Editorial

Shadlen, M., Larson, E., Gibbons, L., McCormick, W., & Teri, L. (1999). Alzheimer's disease symptom severity in blacks and whites. *Journal of the American Geriatrics Society*, *47*(4), 482-486. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10203126

Shaw, C. (1999). A framework for the study of coping, illness behavior and outcomes. *Journal of Advanced Nursing, 29*(5), 1246-1255. doi:10.1046/j.1365-2648.1999.01010.x

Sinforiani, E., Citterio, A., Zucchella, C., Bono, G., Corbetta, S., Merlo, P., & Mauri, M. (2010). Impact of gender differences on the outcome of Alzheimer's disease. *Dementia & Geriatric Cognitive Disorders, 30*(2), 147-154. doi:10.1159/000318842

Small, J., & Ann Perry, J. (2012). Training family care partners to communicate effectively with persons with Alzheimer's disease: The TRACED program. *Canadian Journal of Speech-Language Pathology & Audiology*, *36*(4), 332-350. Retrieved from http://connection.ebscohost.com/c/articles/87346639/training-family-care-partners-communicate-effectively-persons-alzheimers-disease-traced-program

Soliday, E., & Hoeksel, R. (2001). Psychosocial predictors of pediatric patients' emergency room and hospital service utilization. *Psychology, Health, and Medicine, 6,* 1-12.

Souder, E., & Terry, T. (2009). Use of lay educators to overcome barriers to research with Black older adults: a case study using an Alzheimer's disease center. *Research in Gerontological Nursing*, *2*(4), 235-242. doi:http://dx.doi.org.ezp.waldenulibrary.org/10.3928/19404921-20090731-04

Stoeckle, J. and Barsky, A.J. (1980). Attributions: uses of social science knowledge in the 'doctoring' of primary care. In L. Eisenberg and A. Kleinman (Eds), *the relevance of social science for medicine.* Mass.: D. Reidel.

Strauss, A., & Corbin, J. (1998). Action research: A handbook for practitioners (2nd Ed.). Thousand Oaks, CA: Sage.

Strecher, V., Champion, V., & Rosenstock, I. (1997). The health belief model and health behavior. In D. S. Gochman (Ed.) *Handbook of health behavior research I: Personal and social determinants* (pp.71-91). New York: Plenum Press.

Strecher, V., Rosenstock, I. (1997). "The health belief model". In Andrew Baum. *Cambridge handbook of psychology, health and medicine*. Cambridge, UK: Cambridge University Press. pp. 113–117.

Swtizer, B., & Boysen, G. (2009). The impact of religiosity and attribution theory on attitudes toward addiction and cancer. *Mental Health, Religion & Culture, 12,* 241-245. doi: 10.1080/13674670802428449

Tang, M., Cross, P., Andrews, H., Jacobs, D., Small, S., Bell, K., & Mayeux, R. (2001). Incidence of AD in African-Americans, Caribbean Hispanics, and Caucasians in northern Manhattan. *Neurology, 56*(1), 49-56. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11148235

Tarrier, N., Barrowclough, C., Ward, J., Donaldson, C., Burns, A., & Gregg, L. (2002). Expressed emotion and attributions in the carers of patients with Alzheimer's disease: The effect on carer burden. Journal of abnormal psychology, 111. Retrieved from http://www.biomedsearch.com/nih/Expressed-emotion-attributions-in-carers/12003455.html

Taylor, S., & Fiske, S. (1975). Point of view and perceptions of causality. *Journal of Personality and Social Psychology, 32*(3), 439-445. doi: 10.1037/h0077095

Texas Department of State Health Services. (2011). Alzheimer’s disease. Retrieved from http://www.dshs.state.tx.us/alzheimers/qanda.shtm

Tongco, M. (2007). Purposive sampling as a tool for informant selection. Retrieved from https://scholarspace.manoa.hawaii.edu/bitstream/10125/227/4/I1547-3465-05-147.pdf

Turner, L., Hunt, S., DiBrezzo, R., & Jones, C. (2004). Design and implementation of an osteoporosis prevention program using the health belief model. *American Journal of Health Studies, 19(2),* 115-121. Retrieved from http://www.jblearning.com/samples/0763743836/chapter%204.pdf

Trochim, W. (2006). Qualitative measures. *Research Measures Knowledge Base,* 361-9433.

Tversky, A. & Kahneman, D. (1974). “Judgment Under Uncertainty: Heuristics and Biases”, Science. New Series, *185*(4157).

Tynan, H., & Allen, D. (2002). The Impact of Service User Cognitive Level on Carer Attributions for Aggressive Behaviour. *The Journal of Applied Research in Intellectual Disabilities, 15,* 213-223. Retrieved from http://onlinelibrary.wiley.com/doi/10.1046/j.1468-3148.2002.00120.x/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage=

U.S. Administration on Aging. (2008). Serving African American Families: Home and Community Based Services for People with Dementia and their Caregivers. Retrieved from http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/docs/Toolkit4_AfricanAmericans.pdf

U.S. National Library of Medicine. (2015). Type of health care providers. Retrieved from http://www.nlm.nih.gov/medlineplus/ency/article/001933.htm

U.S. National Library of Medicine (2012). Dementia. Medline Plus. Retrieved from http://www.nlm.nih.gov/medlineplus/dementia.html

Viña, J., & Lloret, A. (2010). Why Women Have More Alzheimer's disease Than Men: Gender and Mitochondrial Toxicity Amyloid Beta-Peptide. Department of Physiology. *Journal of Alzheimer's disease, 20*, S527-S533. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/20442496

VonDras, D., Loewen, A., & Tabordan, E. (2004). The Influence of Personal Characteristics on The Identification of Alzheimer's Disease Symptoms, Recommendation to Seek Medical Care, and Counterfactual Attributions. *The Gerontologists, ProQuest Central, 44*(1), *318.* Retrieved from http://www.uwgb.edu/vondrasd/Identifying_AD_Symptoms.htm

Wade, J. C. (2008). Masculinity ideology, male reference group identity dependence, and African American men's health-related attitudes and behaviors. *Psychology of Men & Masculinity*, *9*(1), 5-16. doi:10.1037/1524-9220.9.1.5

Wadley, V., & Haley, W. (2001). Diagnostic attributions versus labeling: impact of Alzheimer's disease and major depression diagnoses on emotions, beliefs, and helping intentions of family members. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *56*(4), P244-P252. Retrieved from https://www.researchgate.net/publication/11895073_Diagnostic_Attributions_Versus_Labeling_Impact_of_Alzheimer's_Disease_and_Major_Depression_Diagnoses_on_Emotions_Beliefs_and_Helping_Intentions_of_Family_Members

Watkins, Y., Bonner, G., Wang, E., Wilkie, D., Ferrans, C., & Dancy, B. (2012). Relationship among Trust in Physicians, Demographics, and End-of-life Treatment Decisions Made by African American Dementia Caregivers. *Journal of Hospice and Palliative Nursing: JHPN: The Official Journal Of The Hospice And Palliative Nurses Association, 14*(3), 238-243. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/24353477

Weary, G., & Reich, D. (2000). Attribution Theories. In A. E. Kazdin (Ed.), *Encyclopedia of psychology, Vol. 1* (pp. 320-325). Washington, DC New York, NY USUS: American Psychological Association. doi: 10.1037/10516-111

Weigel, L., Langdon, P. E., Collins, S., & O'Brien, Y. (2006). Challenging behaviour and learning disabilities: The relationship between expressed emotion and staff attributions. *British Journal of Clinical Psychology, 45*(2), 205-216. doi: 10.1348/014466505X67510

Weiner, M., Hynan, L., Beekly, D., Koepsell, T., & Kukull, W. (2007). Comparison of Alzheimer's disease in American Indians, whites, and African Americans. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 3*(3), 211-216. doi:10.1016/j.jalz.2007.04.376

Weiner, B., Frieze, I., Kukla, A., Reed, L., Rest, S., & Rosenbaum, R. (1971). *Perceiving the causes of success and failure.* New York: General Learning Press.

Weiner, B. (2008). Reflections on the history of attribution theory and research: People, personalities, publications, problems. *Social Psychology, 39*(3), 151-156. doi:10.1027/1864-9335.39.3.151

Weiner, B. (2000). Intrapersonal and interpersonal theories of motivation from an attributional perspective. *Educational Psychology Review*, *12*(1), 1-14. doi: 10.1023/A: 1009017532121

Weiner, B. (1986). An attributional theory of motivation and emotion. New York: Springer.

Weiner, B. (1985). An attribution theory of achievement motivation and emotion. *Psychological Review,* 92, 548-573.

Weiner, B. (1979). A theory of motivation for some classroom experiences. *Journal of Educational Psychology*, *71*(1), 3-25. doi:10.1037/0022-0663.71.1.3

Werner, P., Goldberg, S., Mandel, S., & Korczyn, A. D. (2013). Gender differences in lay persons' beliefs and knowledge about Alzheimer's disease (AD): A national representative study of Israeli adults. *Archives of Gerontology & Geriatrics*, *56*(2), 400-404. doi:10.1016/j.archger.2012.11.001

Werner, P. (2004). Beliefs about memory problems and help seeking in elderly persons. *Clinical Gerontologist: The Journal of Aging and Mental Health*, *27*(4), 19-30. doi:10.1300/J018v27n04_03

Werner, P. (2003). Factors influencing intentions to seek a cognitive status examination: A study based on the Health Belief Model. *International Journal of Geriatric Psychiatry*, *18*(9), 787-794. doi:10.1002/gps.921

Whitlatch, C., Judge, K., Zarit, S., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. The Gerontologist, 46(5), 688-694. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/17050761

Williams, C., Tappen, R., Buscemi, C., Rivera, R., & Lezcano, J. (2001). Obtaining family consent for participation in Alzheimer's research in a Cuban-American population: strategies to overcome the barriers. *American Journal of Alzheimer's Disease & Other Dementias, 16*(3), 183-187. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11398568

Williamson, G., Dooley, W., Martin-Cook, K., Weiner, M., Svetlik, D., Saine, K., & ... Schulz, R. (2005). Caregiver resentment: explaining why care recipients exhibit problem behavior. *Rehabilitation Psychology, 50*(3), 215-223. Retrieved from https://www.researchgate.net/publication/232555207_Caregiver_Resentment_Explaining_Why_Care_Recipients_Exhibit_Problem_Behavior

Willner, P., & Smith, M. (2008). Attribution theory applied to helping behaviour towards people with intellectual disabilities who challenge. *Journal of Applied Research in Intellectual Disabilities, 21*(2), 150-155. Retrieved from http://web.a.ebscohost.com.ezp.waldenulibrary.org/ehost/pdfviewer/pdfviewer?sid=bf235a8c-98cf-4347-b1bf-5c3b70cf4376%40sessionmgr4005&vid=67&hid=4212

Wolff, J., Roter, D., Barron, J., Boyd, C., Leff, B., Finucane, T., & Gitlin, L. (2014). A tool to strengthen the older patient-companion partnership in primary care: results from a pilot study. *Journal of the American Geriatrics Society, 62*(2), 312-319. doi:10.1111/jgs.12639

Wong, P., & Weiner, B. (1981). When people ask “why” questions, and the heuristics of attributional search. *Journal of Personality and Social Psychology, 40,* 650-663.

Retrieved from https://www.researchgate.net/publication/232503853_Why_People_Ask_Why_Questions_and_the_Heuristics_of_Attributional_Search

Appendix A: Interview Call Log and Schedule

Caregiver Unique Identifier	Date	Time	Confirmed Interview Date & Time	Location of Interview
0001-A	8/01/15	3:28p.m.	8/14/15; 2:30p.m.	Home
0002-B	8/25/15	6:20p.m.	8-26-15; 6:30p.m.	Home
0003-C	9/10/15	3:05p.m.	9-14-15; 2:00p.m.	Work
0004-D	9/21/15	1:00p.m.	9/25/15; 1:00p.m.	Home
0005-E	9/29/15	9:13a.m.	10/05/15; 12:30p.m.	Public library study room
0006-F	10/01/15	1:42p.m.	10/08/15; 1:30p.m.	Home
0007-G	10/12/15	4:26p.m.	10/15/15; 6:00p.m.	Home
0008-H	10/13/15	12:43p.m.	10/16/15; 11:00a.m.	Work

Appendix B: Consent Form

CONSENT FORM

You are invited to take part in a research study of "Caregivers' Perceptions to An Early Diagnosis of Alzheimer's Disease in African Americans". This study focuses on personal judgments and beliefs that family caregiver's may experience that may delay an early Alzheimer's disease diagnosis in the patient. The researcher is inviting African-American male and female family caregivers 18 years and older who are primary family caregivers to be in the study. This form is part of a process called "informed consent" to allow you to understand this research before deciding whether to take part.

This study is being conducted by a researcher named Stanita Jackson, who is a Public Health doctoral student at Walden University.

Background Information:
The purpose of this study is to understand if family caregivers' thoughts, judgments, and beliefs have an influence on the delay of an early Alzheimer's disease diagnosis for their loved ones. This study hopes to gather more information to create more awareness for African American family caregivers of the early signs and symptoms that their loved ones may experience to get an early diagnosis.

Procedures:
If you agree to be in this study, you will be asked to:

- Volunteer between one-hour and one-hour and a half for this study.
- Be audiotaped with informed consent during the interview to enhance transcription and learn more about your experiences as a family caregiver for a person with Alzheimer's disease.
- The interview will only be conducted one time.
- The interview may be held at your home or a location of your choice that guarantees confidentiality and protection of data.

Here are some sample questions:

- Demographic: Name, Age, Educational level.
- At the time of diagnosis, what stage of Alzheimer's disease was confirmed for your loved one?

- What feelings did you have towards your family member before a confirmed diagnosis?
- Did you notice early signs and symptoms of Alzheimer’s disease in your loved one?
- What is the gender of your afflicted family member?
- What are your perceptions or thoughts towards Alzheimer’s disease before your loved one’s diagnosis?

Voluntary Nature of the Study:
This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one in your community will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:
Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as becoming upset, sadness or guilt. Being in this study would not pose a risk to your safety or well-being.

The potential benefits of participating in this study could help diagnose African Americans early on for Alzheimer’s disease and increase awareness and educational programs in the community. If counseling is needed, I will refer you to the Greater Dallas Alzheimer’s Association chapter for free to low-cost counseling. There is a 24/7 helpline to call for any assistance. The number is 1-800-272-3900. They will refer you to free to low-cost counseling near your residence.

Payment:
Volunteers for this study that participate in the one-hour to one-hour and a half interview and will receive a $10.00 Walmart gift card from the researcher to show appreciation. The $10.00 gift card will be given to participants after the interview.

Privacy:
Any information you provide will be kept confidential within the limits of the law. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by Stanita Jackson in her home locked safe. Data will be kept for at least 5 years, as required by the university.

Contacts and Questions:
You may ask any questions you have now. Or if you have questions later, you may contact the researcher via phone or email. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 612-312-1210

Walden University’s approval number for this study is **06-05-15-0158986** and it expires on **June 4, 2016.**

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information, and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Printed Name of Participant ___________________________

Date of consent ___________________________

Participant’s Signature ___________________________

Researcher’s Signature ___________________________

Appendix C: Interview Protocol

I will greet participants with a friendly smile stating that I am Stanita Jackson, a doctoral student at Walden University and hand shake thanking them for participating in this study. I will inform them of the purpose for this study and ask preliminary information that will be needed for data collection. I will then sit with participants at a confidential and comfortable location. I will review the confidentiality agreement and consent form with participants before signing occurs.

Preliminary Demographic Information

Unique Identifier: _________________

Participant's Name: ______________________________

Participant's Address: ____

City_________________State______ Zip code___________

Participant's Age: ___________ Participant's Gender: Male_____ Female_____

Is Participant the Primary Caregiver? Yes____ No ____

Caregiver Status: Spouse/Significant Other __________ Adult Child _______ Grandchild _________ Other family member (aunt, uncle, niece, nephew, cousin) ____________

Marital Status: Single______ Married_______ Divorced______ Widowed______

Participant's Educational Level of Completion: High school________ Some college______ 4-year degree_______ Graduate school________

Appendix D: Email to Geriatric Physician

Date: 01-14-2014

To: Geriatrician
Subject: Possible Recruitment for Alzheimer's disease Research Study

Dear Geriatrician,

My name is Stanita Jackson and I am a doctoral candidate at Walden University. We met in 2013 at the Fort Worth Alzheimer's Disease African American Caregiver's Conference. I am conducting dissertation research on the "Cognitive Barriers to an Early Diagnosis of Alzheimer's Disease in African Americans". There are a numerous studies detailing information that contributes to the delay of an early diagnosis in this population. What is not known, however, are personal biases, health beliefs, attitudes, and gender of the afflicted family member associated with reasons that family caregivers delay to seek an early medical diagnosis. This research will provide more insight into what factors contribute to the delay of an early diagnosis of Alzheimer's disease in African Americans which may create more awareness and educational programs.

Your assistance in conducting this much needed research is important. If willing, after IRB approval I will need to supply flyers to you to distribute at your clinic for recruitment. The participants for this study need to be African American family caregivers that are 18 years and older, male or female, and speaks English. The participants are free to choose whether or not to participate and can discontinue participation at any time. Information provided by the participants will be kept strictly confidential.

I would welcome a telephone call or email from you to discuss any questions you may have concerning this study and your role in recruiting research participants. I can be reached via phone or email. Thank you.

Sincerely,

Stanita Jackson
Doctoral Candidate
Walden University

Appendix E: Interview Questions

Participant Name: ______________________ Unique Identifier: ______________________

Interviewer Name: ________________________________ Location: _____________

Semi-structured Interview

Before AD Diagnosis Questions:

1. What negative characteristics did you see and feel toward your loved one before a confirmed AD diagnosis?

2. Did you notice signs and symptoms of AD in your loved one before a diagnosis? If so what were the signs and symptoms? Do you think your loved one's behavior was due to his or her personality?

3. Did you first notice changes in your loved one or did the physician? What changes were seen?

4. What were the reactions of the physician to your observations?

5. When did you communicate with your loved one about the changes you were noticing before diagnosis? How did you communicate with your loved one about the changes you were seeing?

6. Do you think there was a delay in AD diagnosis for your loved one? If so, who or what factors contributed to the delay?

7. What were thoughts towards AD before your loved one diagnosis? Were you knowledgeable about AD before your loved one's diagnosis?

After AD Diagnosis Questions:

8. At the time of diagnosis, what stage of AD was confirmed for your loved one?

9. What negative characteristics did you notice and feel toward your loved one after a confirmed diagnosis?

10. Did you experience any denial about the signs and symptoms your loved one was displaying? Do you have any regrets from not seeking medical assistance when you first noticed cognitive changes in your loved one?

11. Did any other family members influence or delay your decision to seek a medical diagnosis for your loved one?

12. With hindsight, do you feel that a confirmed medical diagnosis early-on for your loved one would have helped with better treatment for AD?

13. What is the gender of you afflicted family member? Did this play a role in delaying medical assistance?

14. How did you feel after knowing your loved has AD? How did your loved one feel after telling them about the cognitive decline?

15. What is the current stage of AD for your loved one?

16. What were your experiences with the entire process of diagnosis for your loved one?

17. What would you change in the process if you could go back in time?

Appendix F: Recruitment Flyer

Did you know that African Americans are diagnosed at later stages of Alzheimer's disease?

You're invited to Participate

"Alzheimer's disease: Caregivers' Perceptions to an Early Diagnosis Study"

Would you like to be part of an important Alzheimer's disease research study?

Are you between 18 years of age and older?
Are you an African American male or female?
Are you a primary caregiver for your loved one diagnosed Alzheimer's disease?
Do you want to have a possible impact on early diagnosis for those at risk for Alzheimer's disease?

- If you answered YES to these questions, you may be eligible to participate in an Alzheimer's disease research study.

- The purpose of this study is to understand if family caregivers' thoughts, judgments, and beliefs have an influence on the delay of an early Alzheimer's disease diagnosis for their loved ones. This study hopes to gather more information to create more awareness for African American family caregivers of the early signs and symptoms that their loved ones may experience to get an early diagnosis.

Volunteers for this study that participate in the one hour to an hour and a half interview will receive a $10.00 Walmart gift card from the research to show appreciation. The $10.00 gift card will be given to participants after the interview. Participation in this study could possibly impact future research and create more educational awareness programs in the African American community.

Participants are allowed to choose the location of the conduction of the interview when contacting the researcher for participation in this study. Enrollment in the study means that you will agree to participate in a one-hour to a one hour and a half interview. Any information you provide will be kept confidential within the limits of the law.

If you are interested in learning more about the study or volunteering your time, please contact the researcher at the number below.

Please call Stanita Jackson, a doctoral student at Walden University at (XXX) XXX-XXXX for more information. Thank you!

Appendix G: Permission to use Alzheimer’s Data

Stanita Jackson **<stanita.jackson@waldenu.edu>**

Apr 5 (2 days ago)

to copyright

Hello,

My name is Stanita Jackson and I am currently working on my PhD in Public Health specializing in Epidemiology. My dissertation topic is "Cognitive Barriers to an Early Diagnosis of Alzheimer's Disease in African Americans". In my Epidemiology section I would like to ask permission to use figures and tables from your 2014 Facts and Figures data sheet for my study. I am currently at the proposal stage and will begin collecting my data in June 2015. I hope to finish my study by November 2015. Please let me know if I need to include additional information. Thank you in advance. My contact information is as follows.

Sincerely,

Stanita Jackson

copyright (sent by mhickey@alz.org)

Apr 7 2:40 PM (3 hours ago)

to me

Hello, you have permission for this request provided the Association is properly credited. We also have a 2015 version of the report found herehttp://alz.org/facts

Appendix H: Participant's Recommendations

- 0001-A: "Yes, I think it's a lot of resources, but I think it's identifying where they are and who they are. I think we as African Americans don't know that they exist. I think like you said, like your dissertation, we just got to educate the community. Because we, we want to pray it away, you know, or we want to ignore it or we just want to put the loved one in the back room and just hope they don't wander out and just let them you know, they just old and senile, that's another one myth that we have to dispel. That's part of it, that's natural and so that's why you don't get the early diagnosis because we are too quick to say it's normal. So, education is critical, it's real critical. Yeah, I really hope that whatever comes out of this as a part of the education that people reach out to caregivers, especially other family members and so-called close friends, because I think the assumption is because caregivers don't complain when it's your loved one you do everything for them, but that does not mean they don't need help."

- 0002-B: "Uhhh, I knew about medical resources, but nothing else. Yeah and that's the most difficult part, is just trying to figure out how to, uh get assistance. Umm, probably, umm, like how to navigate the financial system, you know. How to plan, plan more accordingly, financially. You have to have no money to get any kind of help, so you have to, you know. Umm, just that it's really hard trying to find caretakers. I mean, you, not caretakers, but assistance in uh, care to avoid having to be in a nursing home, you know, so that's one of the hard parts, you know. You basically have to do everything out-of-pocket, you know. Cause there are not a lot of resources, unless you on Medicaid, you know. Umm, I guess that's about the hardest part, you know, just trying to avoid sending them to a nursing home and umm you know."

- 0003-C: "Just have to be knowledgeable enough to ask the right questions and, and especially know, know your parent, that this is not quite normal umm. I would be disturbed to find out that I had diagnosis uh or any early signs. I told my kids watch me, watch everything I do (laughs) and bring it up to me and let's see and then of course you know you've got a lot of good supplements out there, not to say that they'll cure anything, but it certainly helps hopefully slow down the process if it's gonna happen. Proactive with myself (laughs). Yeah, because it's there, it's in the family history, so.

- 0004-D: "So that was my experience, that has been my experience with this, with this whole thing and just umm, trying to help family members understand. Cause family members still don't understand or some go ahhh, it's, he's not that bad (laughs). And you know, it's like yeah if you were here you would see something different, because you can talk to him on the phone and sound fine but you stay with him for a couple of days and then that's when you will see there's something different here. So, I think if we really educate our community on what's the norm, what's not the norm, so that there's not fear. Umm, especially with the kids and grandkids when they see grandma's not, why does she forget, why does she keep asking questions, things like that. They kind of have a better sense about this is what's going on with the brain, but these are things that could happen even though we don't know exactly what causes it. So, I think then that can bring about a conversation about healthy living, healthy eating, taking care of your body, only doing what we can do, you know."

- 0005-E: "Yeah. I'm the only one out of all of us that that help her like that. No one else is around like that, yeah. I've given up my entire life by myself and ya'll, nobody even gives me a break. I didn't know who to call, like I said had it not been for, I asked that lady could she always raved about her doctor and it just so happen that her doctor was a Geriatric doctor. I really wanna find a way to convey our stories better, umm and what we need. I still find that there's no real help for caregivers at this point like I've had to take a hiatus from work, which means I'm missing money which means and then my savings was blown and anything I was going through. There's no outside of, you know, insurance giving us money for a few hours which doesn't equate to anything, umm. Emotionally, mentally, physically, you just can't bounce back up, you can't leave them alone. There are many many many many African Americans being affected by this disease but no one wants to tell anybody about it. And that, and that bothers me. I have so many family members that you know, now I'm learning all these other cases that came about you know that they were dealing with."

- 0006-F: "And so the children and I decided that we need to look for a place where we could go, where she could be comfortable and, and have all of the uh, uh amenities that we need to have of, of life and, and so we formed a team. I would love to be able to umm to know uh maybe earlier than we did and, and, and where I could, where I maybe, may could get information that would be useful in trying to help her umm before she got into this state, yeah. I think if you have enough information, umm that leads you to, to that decision that this is what it is and you have it early enough, you probably could be able to, you know to, to help umm the loved one, uh a little bit better than if it hits you kind of all at once, uh you know. Umm, I think, I think having other family members, close family members uh as a part of uh, uh, the team to look out for the family for the loved one, I think that helps.

- 0007-G: “Again because Alzheimer's isn't a topic, a major topic or something that the African American community had been exposed to, so my mother's sisters who are a lot older than her, umm, had never heard of that. So, they felt that wasn't her issues, you know, that people just forget, she's just getting old and that uh we were just neglecting her. Now, resources I used my church, like again, my, we have a caregiver's uh ministry and umm, so they're linked with the (undisclosed organization) umm and I read a lot, I'm a reader. So I'll go and look at stuff online and I get their literature and I umm gone to the library and checked out books and read upon it. Umm, so I, I but I do have a good support system. I have good friends who have umm, one of my girlfriends lost her mom to it and so a lot of times it's just talking about it, you know. And I do do a lot of community things umm that like we do the fundraisers for uh the (undisclosed organization) walk to help the research. I've done survey where they have other drugs that they are testing uh and wanting to try it on her but I refuse to because uh, the accelerated risks and she can't all the, the, uh effects of using a new thing. She can't afford that, you know. But I, I mean as much as I can get support I do, I do. I think support is, is very key, it's very vital for a caregiver, even though they’ll deny that they need the support but, you know, but they do.”

- 0008-G: “I would force all my siblings to learn about Alzheimer's, not you know, not listen to what somebody else tells you because that may have been good for that person that they're talking about, but each individual is different, you know. I know in our community there's a lot of people out there who are probably suffering from this who haven't been diagnosed and may never be. There's gonna be somebody out there that they'll listen to, it's kind of like up to you to find that person even if it's not you, and whoever that caregiver is gotta realize that they're not the center just because of what they're doing. Now, and I'm pretty sure, I just wonder how many of those cases were Alzheimer's or Dementia or something like that, a mental case that we just locked away until the person died, you know. What could we have done way back when if we, you know, it's all about the education, you know, educating ourselves and you know, not accepting that that's just the way someone is, it's that way for a reason.”