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Alzheimer's Disease Literacy In The African American Community

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Alzheimer’s Disease Literacy in the African American Community

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North Carolina A&T State University

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Major Professor: Dr. Rosalyn Lang

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School of Graduate Studies
North Carolina Agricultural and Technical State University
This is to certify that the Master's Thesis of

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Greensboro, North Carolina
2013

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Biographical Sketch

Angel McKenzie Chardre' Watson was born on December 22, 1988 in Kings Mountain, North Carolina to Jewel and Selena Watson. She received her Bachelor of Science in Biology from Winston Salem State University on May 14, 2011. As an undergraduate at Winston Salem State, Angel was a member of the Honor's Program and a member of the STEMS (Science, Technology, Engineering, and Mathematics Scholars) Program. She also received the Dean's List recipient award each semester of her undergraduate career.

Angel also enjoys serving her community and home church, Vestibule AME Zion Church in Kings Mountain, North Carolina. Some of the many volunteer opportunities that Angel is involved in includes: school supply distribution for underserved children in the areas surrounding Kings Mountain, NC; Off the Street's Ministry for women's shelter in Gastonia, NC; Pre-K Christmas Gift Distribution for Underserved Children in Cherryville, NC; as well as Operation Christmas Child.

Upon receiving a Bachelor's degree in Biology, Angel enrolled in the Master of Science in Biology Program at North Carolina Agricultural and Technical State University in August 2011. She chose to work with the Alzheimer's disease research study team at NC A&T State University. Her hard work, perseverance, dedication, and enthusiasm for her research led to her to the completion of the requirements for the Master of Science degree in two years. Angel plans to utilize her knowledge in the workforce, before returning to school to earn a degree as a Doctor of Dental Surgery.

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Abstract

Alzheimer's disease (AD) is a public health crisis in the African American (AA) community, as evidenced by both increased prevalence and familial risk among African Americans. African Americans are two times as likely to suffer with this disease, are diagnosed later in the disease process, and are considered to have less factual information about AD when compared to their white counterparts. Late diagnosis has been associated with significantly higher dementia-related morbidity and health care costs. Moreover, studies have shown that patients with increased health literacy have better health outcomes. Therefore, we want to assess how well African Americans understand Alzheimer's disease with the long-term goal of improving health outcomes and decreasing prevalence of AD in the African American community. We designed a novel AD literacy survey instrument to assess knowledge, perception, and attitudes about AD in both caregivers and non caregivers in an AA cohort. The target population was African American adults with or without knowledge of Alzheimer's. We selected a convenience sample of adults to complete the survey at several different community events and on a university campus in the Southeastern United States. We found that many of our African American participants were aware of how Alzheimer's disease may affect lifestyle. However, we found decreased knowledge with more critical questions as: Is there a drug cure for the disease, and is AD considered normal memory loss. African Americans (37.3%, and 66% respectively) answered these questions incorrectly or responded that they were unsure of the correct answer, indicating a literacy deficit in these areas of AD knowledge. This study found evidence that confirms the need for more outreach in the African American community to further increase AD literacy.

CHAPTER 1

Introduction

Alzheimer's disease is the sixth leading cause of death and the only disease in the top ten without a good treatment or cure. Alzheimer's disease is the most common form of dementia, accounting for 50 to 80 percent of dementia cases diagnosed. Dementia is a term that refers to the decline of memory and other cognitive functions to a level below the patient's previous level of function [1]. Cognitive functions that are disturbed in dementia cause problems with memory, thinking, and behavior, which in many cases begin slowly and worsen over time. Alzheimer's disease is a public health issue and is estimated to affect more than 5.4 million older adults throughout the nation [2].

African Americans are twice more likely to be diagnosed with AD than other ethnic groups. One reason that African Americans are believed to be at a greater risk for suffering from AD is due in part to African Americans' increased rates of cardiovascular diseases. Current studies suggest that cardiovascular conditions are major risk factors for AD [3]. Although African Americans are disproportionately affected with AD, African Americans are diagnosed later in the disease process than older whites, which leads to significantly higher dementia-related morbidity and health care costs [4]. A study performed by Roberts and colleagues [5] observed the role of race in explaining differences in illness perception. Their results showed that African Americans illustrate less awareness of facts regarding AD, have fewer numbers of sources of information about AD, and perceive AD as less of a threat than whites. These individuals also associated age with memory loss and viewed the symptoms as role performances. The participants' perceptions about dementia, especially those formed from myths, negatively affect early access, diagnosis, and treatment of Alzheimer's disease (AD).

Studies have shown that cultural values and beliefs among ethnic groups affect the meanings assigned to dementia which assist in creating barriers to individuals seeking aid outside the family system [6]. The researchers also found that white participants were more likely than African American participants to recognize behaviors as a sign of serious illness and showed that African Americans viewed AD symptoms as normal part of aging [5].

In addition to race, poverty, inadequate education, lack of health insurance coverage and limited availability of medical care [7]. All of these factors either indirectly or directly impact health literacy and support the need to provide adequate health care services that will support all peoples [8], despite income, education, geographic location, and racial identification. The nation's primary policies in health care increase this urgency for America's elderly minority population. The Healthy People 2010 recognizes removing health disparities and improving quality and years of life as the two central goals of the nation's health care agenda. One way of improving quality of life would be to improve health literacy and increase health access [9].

Studies have shown that unfairness in stipulations of medical needs is more common among older African Americans, older women, and individuals with incomes below the poverty line [9]. These data support the need to eliminate health disparities and improve health education, literacy and access in order to improve overall health of individuals and communities

Health disparities are differences in treatment provided to members of different racial or ethnic groups. Some examples of health disparities include a higher mortality rate for African Americans as it relates to heart disease and stroke; lower health insurance coverage for Latinos and African Americans; and poorer HIV care and survival rates for African Americans when compared to whites [10]. Our focus is on Alzheimer's disease as a health disparity. Recently, the President, Barack Obama, established a national Alzheimer's Plan to address issues surrounding relevant AD research, interventions and community outreach [11]. Unfortunately, Alzheimer's is not recognized as a health disparity by North Carolina; North Carolina and many other states do not have a plan for how Alzheimer's disease should be managed [12]. This lack of planning supports the need for more grass roots efforts in helping communities to understand the warning signs, better manage this disease and care for their loved ones. Our study is an attempt to begin to understand where the gaps in AD knowledge may occur in underserved communities and among elderly populations.

When observing elderly Americans, health status differs by race, income, and gender. Elderly minority African Americans have constantly expressed worse health outcomes than whites of the same age group across measures of disease, disability, and self-assessed health [13]. African Americans have more chronic conditions when compared to whites [14]. More importantly, age is the number one risk factor for AD. Although there is no known cure for AD, AD and other chronic diseases have shown to be closely associated with obesity, diabetes, living a sedentary lifestyle, and lack of access to healthcare professionals and specialist at early stages in the condition.

Elderly African Americans are more susceptible to AD than white Americans [15] and in some cases have several barriers to AD screening, diagnosis, and testing. These barriers include living in an inequitable geographical/ regional location, poverty, and health illiteracy [16]. These different barriers often result in limited access to care and discrimination against older minority populations, which further intensifies inequalities in AD care [17]. Cultural differences in interpretation of disease, lack of culturally-appropriate health care, normalization of illness, and delay in seeking proper diagnoses and care are also important factors that must be addressed in decreasing disparities in AD [18].

There is a need for the scientific community to work towards interventions, treatment, and cures for AD due to more Americans providing health care to a growing and increasingly diverse elderly population. The U.S. elderly population, age 65 years and older, is expected to double by the year 2030, accounting for 71 million elderly Americans. The proportion of elderly Americans belonging to racial and ethnic groups is expected to increase drastically. More importantly, increase in age is a prominent risk factor for developing Alzheimer's disease, and is expected that the U.S. will spend approximately $1.1 trillion on treating Alzheimer's by the year 2050 [2].

Knowledge of a disease is important for disease management and for decreasing behaviors that increase disease risk [19]. According to the Health Belief Model (HBM), in order for an individual to change his or her behaviors, they must feel susceptible to the disease and recognize their perceived risk of developing the disease [20,21]. In order for this behavior change to occur, an individual must perceive a disease as serious, recognize their vulnerability of developing the disease, and recognize the positive outcomes associated with disease diagnosis while removing the stigma associated [20]. Health literacy plays a vital role in helping individuals to understand and recognize disease risk. Disease risk for Alzheimer's is becoming an even greater public health issue. According to the Alzheimer's Association, by the year 2050, there may be more than 15 million people diagnosed with AD.

Alzheimer's disease affects African Americans at a disproportional rate than those of other ethnic groups. Unfortunately, African Americans are thought to be diagnosed later in the disease than their white counterparts, which impedes their opportunities of accessing early interventions and available treatment [22-25]. In order to improve the chance of African Americans receiving early AD diagnosis and treatment, it is critical that knowledge and understanding of AD is increased in African American communities. An increase in AD literacy may have a tremendous impact on disease awareness and management, as well as possibly eliminating stigmas associated with AD.

The objective of this study is to determine African Americans' understanding, perceptions, and behaviors of Alzheimer's disease. The purpose of this study is to assess specific knowledge of warning signs, symptoms, and treatment options associated with AD in African American participants. Alzheimer's disease literacy data was collected in this study using a survey methodology. This survey tool can be used at several diverse venues to examine the knowledge of our participants about AD. Our survey instrument was used as a means to identify educational needs in our community as they relate to Alzheimer's disease, memory loss, and dementia.

Our long-term goals are to improve healthy aging in minority populations and to eventually reduce the prevalence of AD in the African American community. An immediate use of this information will allow us to understand current misconceptions about AD in underserved communities. Study results will be used to design necessary educational workshops, outreach programs, and interventions that will impact elderly populations throughout North Carolina. The need for accurate information on AD to improve early diagnosis and decrease the stigma associated with this devastating disease is critical. Therefore, we will also use this information to design workshops to address provider interactions for the elderly population. It is our hope that these educational programs and interventions will improve Alzheimer's disease management and care in the African American community.

CHAPTER 2

Literature Review

2.1 Alzheimer's Disease Overview

Alzheimer's disease is a disorder that most often begins to occur in individuals in middle or late life. Alzheimer's disease, the sixth leading cause of death in the U.S., is a progressive form of dementia that has several characteristics including degeneration of specific nerve cells, presence of neurotic plaques, and neurofibrillary tangles. A person's previous level of function, before dementia begins, is determined by clinical examination and neuropsychological tests that observes the history of decline of memory and other cognitive functions. Dementia is a diagnosis that is based on the behavior of the patient. Dementia cannot be diagnosed when a patient's consciousness is impaired by factors such as delirium, drowsiness, stupor, coma, or when other clinical abnormalities prevent adequate evaluation of mental status. Dementia also cannot be diagnosed by computerized tomography, electroencephalography, or other laboratory instruments [26].

Signs and symptoms of the disease include: difficulty recalling recent events, an inability to recognize familiar people and places, difficulty expressing thoughts or naming objects, difficulty performing calculations, trouble with time planning and carrying out tasks, trouble exercising judgment, failure to control moods or behavior, withdrawal from work and social activities, problems understanding visual images and spatial relationships, and lack of personal care [27].

There are seven stages of Alzheimer's disease. Not everyone with this disease will experience the same symptoms or progress at the same rate. Stage one of AD involves no impairment [28]. In this stage the individual is able to perform normal functions, without experiencing any memory problems. Stage two is classified by very mild cognitive decline. In this stage the person may feel as though they are having memory lapse such as forgetting familiar words or locations of everyday objects. Stage three is known as mild cognitive decline (early stage AD in some but not all individuals). Friends and family members take notice in the individual's difficulties in communicating, remembering names, performing tasks, and losing or misplacing objects. Moderate cognitive decline (moderate or early-stage AD) is stage four of AD, and should be able to be detected by a medical professional. Individuals tend to forget recent events, have problems with numbers, greater difficulty performing complex tasks such as paying bills or managing finances, and changes in mood or behavior. Moderate severe cognitive decline (moderate or mid-stage AD) is stage five. Gaps in memory and thinking are noticeable in this stage, as well as the individuals' need of assistance with day-to-day activities. Stage six, is where severe cognitive decline (moderately severe or mid-stage AD) occurs with continuously worsening memory, personality changes, and a need of extensive help with day-to-day activities. The final stage is very severe cognitive decline (severe or late-stage AD). In the final stage of AD, individuals lose the ability to respond to their environment, to carry of conversations, and eventually, to control movement [28].

2.1.1 Genetics of Alzheimer's disease. Many diverse diseases including AD, Parkinson's disease, frontotemporal dementia, and amyotrophic lateral sclerosis have been seen to demonstrate molecular similarities. These three diseases show intracellular and extracellular deposits of abnormally misfolded proteins [29]. Many shared molecular mechanisms are generally a result of overlapping genetic factors such as that of frontotemporal dementia and amyotrophic lateral sclerosis [29]. Both of these diseases included an underlying mutation which involves repeat expansion in the C90RF72 gene [29]. The clinical overlap of frontotemporal dementia with AD, led to a study by Kohli et al (2013) to hypothesize that C90RF72 expansions might contribute to AD. This hypothesis was supported from their data which resulted in their conclusion that large C90FR72 expansions does lead to a phenotypic spectrum of neurodegenerative disease including AD [29].

Alzheimer's disease involves degradation of neuronal cells in areas of the brain which are essential for learning, memory, and emotional behavior. In additional to neuronal death, the presence of beta amyloid plaques and neurofribillary tangles are a necessity of a definitive diagnosis [30]. Therefore, a true diagnosis of AD can only be confirmed post mortem. Plaques are formed from an insoluble deposit of a protein called beta amyloid derived from the large transmembrane protein β-amyloid precursor protein (APP) through proteolytic processing [31]. The process of APP cleavage is performed by α-secretase trailed by γ -secretase. Beta-amyloid peptides are produced when APP is cleaved. Beta-amyloid proteins are heterogeneous in length with the major peptides 40 and 42 amino acids long [32]. Certain studies of brains from Down syndrome individuals have shown that deposits of beta-amyloid are an early step in AD neuropathology. Plaques are suspected to be a result from elevated levels beta-amyloid 42 due to its soluble aggregation into fibrils that are indistinguishable from those found in vivo [31].

An additional known hallmark of AD is neurofibrillary tangles which results from the deposit of the protein tau. These tangles are thought to occur when tau becomes hyperphosphorylated causing it to dissociate its attachment from tubulin. This dissociation leads to the production of an abnormal version of tau-aggregates called paired-helical filaments and are thought to disrupt the transport network inside the neuron [33]. In AD, deposition is limited to neurons. Death in neurons seems to correlate with the formation of neurofibrillary tangles [34].

Alzheimer’s disease is a multifactorial disease that is caused by both genetic and non genetic factors [35]. Genetic variation is a critical contributor to increased risk of this disease [36]. Studies have associated the inherited risk of AD with four prominent genes: amyloid precursor protein, apolipoprotein E, presenilin 1, and presenilin 2. These four genes are suspected to account for approximately half of the genetic risk factors for AD [35].

Two genetically distinct subtypes in which we can divide AD are familial AD (FAD) and sporadic AD. The subtype FAD occurs when the disease is transmitted as an autosomal dominant trait. It also has an earlier age of onset and sometimes shows additional neurological features. Sporadic AD shows lower familial clustering [37-39]. Large multigenerational genetic linkage studies in FAD kindreds had provided evidence that early onset FAD is a genetically heterogeneous disorder that can be caused by mutations in β-amyloid protein precursor gene (APP) on chromosome 21, presenilin 1 (PS1) gene on chromosome 14, and presenilin 2 (PS2) gene on chromosome 1 [40-42]. The pathogenesis of AD is understood better by scientist due to the results of genetic and cell biology studies of FAD. The problem is that 99% of AD cases do not have a mutation in these genes. Currently, studies to link genetics and association are being performed to identify risk factors of late-onset AD [43].

2.1.2 Genetics of Alzheimer’s disease in minorities. Until recently, very little was known of the pathogenesis of AD in the African American elderly population. Examining gene variations may be a critical method in explaining the pathophysiological and clinical symptoms observed in minorities with AD. Alzheimer’s disease is genetically heterogeneous, which means that multiple gene mutations, or genotypes, result in similar disease characteristics or phenotypes making it difficult to completely understand this disease [44].

There are genetic variants that are associated with the susceptibility of developing late-onset AD in people of European decent. Previously, scientists were unaware if the same or different variants are genetic risk factors of AD in African Americans. Identification of disease associated variants plays a role in identifying genetic testing, prevention, and treatment. Recently, a paper by Reitz and his colleagues (2013) performed a study to identify genetic loci in African Americans associated with late-onset AD. This group observed in their meta-analysis of data from African American participants that AD was significantly associated with variants in ABCA7 as well as with APOE-4, genes that had been previously associated with AD in those with European ancestry [45]. This study is a part of ongoing efforts within our group to find genes that make African Americans more susceptible to AD than other ethnic groups.

2.1.3 Alzheimer's disease: the silent epidemic. According to the Alzheimer's Association, African Americans are at a higher risk of having AD and dementia when compared to non-Hispanic whites. This increased risk of prevalence is decreased when factors such as age, sex, and years of education. Several different studies have shown that knowledge and attitudes about AD plays a role in family decision-making about symptoms, diagnosis, treatment, and participation in dementia research [26]. In a study performed by Roberts et al (2003), examining racial differences in knowledge and attitudes about AD, in comparison to whites, African Americans know less factual information, fewer information sources about the disease, and lower levels of perceived risk of AD [18]. African Americans were also shown to consider AD as a term for normal memory loss associated with aging and also expressing more confidence about potential future advances in AD research [26]. These results support the need for more AD and health education in minority populations.

The U.S. population contains a larger percentage of older individuals with AD than it has ever had before, but there is still a high level of stigma and silence about this disease and its devastating effects on families. These issues must be addressed in order to increase understanding of the disease as well as to promote early diagnosis. Medical advances are extending the lifespan of our elders and increasing chances of living with chronic illnesses for a longer period of time. Therefore, it is imperative to increase the likelihood that individuals, their caregivers, and patients have appropriate information to make the best decisions possible about care management. More education and awareness will also be needed to reduce the stigma and silence about AD in underserved communities in order to lessen its sometimes devastating effects on family. Historically, African Americans have had less access to health care, less access to specialist, and less awareness of chronic illnesses. Socio-economically, disadvantaged African Americans are less likely to receive care and the less educated are less likely to receive care or have knowledge about chronic illnesses [18].

A previous study by Boise et al (1999), found that a mere 50% of dementia cases are diagnosed by physicians. This group was also able to identify four diverse barriers to dementia diagnosis which included: the failure to recognize and respond to symptoms of dementia, lack of the need to determine a specific diagnosis, limited time constraint, and negative attitudes toward the importance of assessment and diagnosis. It is very important that friends and family of people with any type of dementia are able to detect memory loss. These barriers inhibit physicians from diagnosing dementia and offering help for individuals that are experiencing certain symptoms of dementia or for the families that care for them [46]. These findings highlight the need to educate the whole family along with the patient.

The benefits of obtaining a specific diagnosis of dementing illness include providing a sense of relief by letting the individual know what is wrong with them, ruling out other reversible causes of memory or behavior problems, facilitating access to community-based information and support services, promoting adaptation and coping, helping to plan for the future, and enhancing communication during health care visits [47]. Caregivers surveyed in this study reported that the major benefit of obtaining a diagnosis was that it assisted them in being more patient and understanding with affected family members, as well as enabling them to make decisions on their behalf [47].

Most adults in the United States have some awareness about AD, but in general the public lacks specific detailed information about AD and its treatments. It has been reported that the general public does not feel very knowledgeable about AD [48]. Scientific literature lacks consistent or validated measures regarding perceptions about AD. In addition, we have not completely understood the public's perceptions of cognition across various social, cultural perspectives, or ethnic groups; therefore, extreme generalizations must be avoided until more inclusive research can be completed [49]. These results substantiate the need to better understand how AD is perceived and understood in underserved populations. In this way, we will be able to better assess the specific needs of different populations

2.1.4 Minority recruitment. There is a huge issue in recruiting and retaining willing participants in clinical research trials [50]. Studies have shown that participation rates for certain clinical research trials, such as epidemiological studies, has decreased so drastically that the levels may have a tremendous effect on successful conduction of some types of research. This decline in participation includes populations that were once traditionally overrepresented [51]. The decline in clinical research trials is even more noticeable in low economic and minority populations [50]. There is lack of consistent evidence that the elderly are less than younger populations to participate in clinical research [51].

In 1984, the National Institutes of Health required that clinical research trials must include women and minorities [52]. The National Institutes of Health requires increased participation of racial & ethnic minorities in biomedical research in 1984 and by the NIH Revitalization Act of 1993 [52-54]. There are still inequalities in clinical research in minority populations. African Americans are less likely to participate in research studies when compared to their white counterparts [50, 53]. Limited enrollment of African Americans in these clinical trials raises problem because the lack of research participation affects generalizability of study findings [53].

The difficulty of obtaining and retaining minorities in clinical research has been shown in many literature studies [55]. There has been ample evidence that demonstrates significant barriers that hinder minorities from participating in clinical research trials [50, 52-54, 56-57]. Some barriers include individual-based barriers to participation, community-based barriers to participation, barriers of minority elders, barriers at the institutional level, and researcher barriers [50,52-54]. Several studies have identified these barriers and are trying to develop a strategy that addresses these barriers [52]. Some studies have turned their primary focus on recruitment for prevention or health promotion studies that has been shown to have less recruitment participation than other studies [58].

Mistrust of government entities, because of past experience, fear of a vulnerable population being exploited or harmed may be barriers that hinder minority recruitment in clinical research trials [54, 59]. Mistrust of the medical community such as doctors, researchers, and medical and academic institutions, and negative experience with the health care system may be a barrier for research participation [60]. The lack of knowledge surrounding the disease being studied, as well as the lack of family or church member support, and prioritizing other requirements, such as paying bills as opposed to health needs, may all play a role in the decline in clinical trial research participation [60, 61]. There may be special barriers that are associated with the elderly population such as, unwillingness to participate in lengthy appointments, lack of transportation, parking, repeated phlebotomy, and unwilling to participate in neuropsychological testing [62, 63].

There have been several studies that address many of the described barriers to increase minority participation in clinical trials [52]. One study suggests that establishing personal relationships with formal and informal community leaders is great way to address the barrier of mistrust. Direct contact with potential participants for a research study is also a good strategy to address these barriers [64]. Other ways to address these barriers that have an effect on clinical research participation is to match the gender and race of the research staff to the target population while being flexible to the needs of the potential participants [65]. What may seem minor to some may have a huge effect on the recruitment of some groups, such as addressing the older population by their formal name [66].

Some studies used indirect and direct methods to observe which recruitment style would gather the most participants. Indirect forms of recruitment included word of mouth (people spreading the word with others they come in contact with), flyers, radio announcements, television commercials, and newspaper ads. Direct forms of recruitment included face to face interactions, health fairs, and presentations at areas that were highly populated by potential participants. Ellish et al (2009) found that direct methods of recruitment are more beneficial than indirect methods of recruitment [34].

In order to retain participants, research has shown that monetary incentives have been useful [67]. Byrd et al (2011) observed the importance of using a multifaceted community-based approach for minority recruitment that builds trust and provides services along with other incentives as an effective way of increasing the enrollment of minority in clinical research trials. This study also accentuated the need to use different strategies for addressing time, costs, and relevance to improve recruitment of intergenerational African Americans [68]. Lang et al (2013) observed ways to increase willingness of African Americans participation in health-related research studies. The manner in which Lang et al (2013) described to increase willingness of African Americans included: providing appropriate incentives to decrease the costs of participation, increasing convenience, improving information access, and raising awareness of research opportunities [69].

2.2 Health Literacy

A nationally representative household survey, the National Adult Literacy Survey (NALS), conducted in 1992, studied the functional English language literacy skills of over 26,000 American adults. According to results from the NALS, 66% of the United States elderly population (60 years and over) demonstrated a level of inadequate or marginal literacy skills. Moreover, 40% of the study population that demonstrated inadequate or marginal literacy skills was African Americans; they were reported as having reading problems. This study also reported that half of United States adults have limited or low literacy skills [70]. This observation demonstrates that American adults with average literacy skills have difficulty using complex texts to accomplish everyday tasks and lack the skills needed for full participation in our current society [71]. Good health is needed for full participation in society, so adequate health literacy is also needed for good health promotion. Health literacy is a necessity not only in this society, but around the world as isolated diseases can in some cases become epidemics and then pandemics.

Health literacy is a term that describes an individual's ability to read, understand, and use health care materials provided. Health literacy is also a prominent factor in poorer knowledge and understanding of an individual's health conditions [72-75]. Levels of low literacy have been shown to play a role in worse health outcomes of a patient [76], poorer health status [77,78], declined levels of satisfaction with health care [79], and lower rates of participation in preventive health services [80] when compared to people having higher literacy levels. A variety of medical and public health literature has emphasized the high reading demands made on people in need of important health information. Over 300 articles are published documenting that most health materials are beyond the comprehension skills of most Americans [71].

2.3 Minorities and Health Literacy

Previous studies in impoverished populations have shown that patients with chronic diseases and with low literacy also have little knowledge of their disease and treatment options, including accurate self-management skills compared to literate patients [74, 75]. It is possible that low literacy that is linked with poor disease management may explain higher hospitalization rates for this patient population [81]. From this standpoint, it is easy to understand how low health literacy may also be linked to higher mortality and greater susceptibility to health disparities overall.

Several studies have suggested a specific link between low education and higher risk of dementia. This link is noted as cognitive reserve [82-85]. Cognitive reserve is the ability of the brain to bear the effects of the pathology of dementia. Reserve is measured by such variables as years of education, occupational level, or IQ measures, but racial, economic, and cultural factors may affect the role of these different factors [86].

It is possible that the number of years of education can be a sign of lifetime experiences that modify the brain during childhood or even adult life. This brain modification may create a reserve against the development of dementia. The problem is that there cannot be a direct link to represent the years of education to the effect of experience on the brain or cognition when observing ethnic minorities, because of the disagreement between years of education and quality of education among ethnic minorities [86].

Lower educational levels have been shown to be an important risk factor for dementia, more specifically AD [87]. There have been several studies of populations of normal aging that have shown a brisk decline in both functional and cognitive capabilities in individuals with lower educational attainments [88-93]. Various studies show that African Americans in particular have reading skills below the education level than they reported having [94-96]. This can be due to the fact of the quality of education provided to the African Americans in the study.

Literacy has the potential to be of extreme importance for cognitive reserve than years of education because of the reflection of the quality of the educational experience provided to ethnic minority groups, in particular African Americans. Literacy does not attempt to assume that all individuals obtain the same amount of learning from a certain grade level, because individuals learn in different environments and from different contextual experiences beyond the classroom [86].

2.4 Alzheimer's Disease Health Literacy

It is extremely important to disseminate knowledge of AD to the community. It is believed that the more an individual knows about AD, the more likely one is to seek help for the disease. Studies show that the likelihood of seeking medical attention increases as a population learns more about a disease. In HIV and hypertension, education and dissemination programs have shown that an increase in community awareness of a disease, its causes, and presentation can have a positive impact on the rate at which community members request diagnostic testing and treatment. With this in mind, it is suggested that older adults may be more likely to discuss AD with their personal physician, family member, and friends and to start treatment early if presented with accurate and current information on the disease [97].

2.5 Minorities and Alzheimer's Disease Health Literacy

Alzheimer's disease is more prevalent among ethnic minorities [22], but elderly ethnic minorities are likely to receive the diagnosis of AD at later stages of the disease, usually following a long and debilitating course [23-25] and, therefore, are less likely to access early interventions and benefit from available treatments. A study done by Ayalon and Areάn (2004) evaluated knowledge of AD in four ethnic groups (Whites, African Americans, Asians, and Hispanic) of older adults with the goals of evaluating ethnic group differences in knowledge of AD by the use of a close-ended AD questionnaire and to identify the role of education and level of acculturation plays in knowledge of AD. Their results indicated a significant difference in the knowledge of white Americans when compared to African American, Asian, and Latino older adults. This group concluded that African Americans, Asians, and Latino adults do not have sufficient information about AD which may explain a lack of AD service usage by the minority community [97]. Extensive research is needed to further evaluate minorities and AD literacy.

CHAPTER 3

Materials and Methods

3.1 Survey Development and Design

The methodology of this study was based on previous work done by Byrd et al (2011) and Lang et al (2013). The survey study was designed to ascertain a clear understanding of the knowledge and perception of African Americans on the health disparity Alzheimer's disease. This survey also sought to determine if qualitative factors such as gender, ethnicity, level of education, and whether a person is a professional caregiver or family caregiver influenced the knowledge, awareness, and attitude of Alzheimer's disease.

The survey instrument used in this study consisted of twenty-three questions that documented age, sex, educational level, ethnicity, and perception of AD from the survey participant. The perception of AD included questions examining whether the participants knew of anyone with the disease, symptoms of the disease, if there is a cure for the disease, what type of specialist handles AD, and who is at risk of developing AD. These series of questions were designed on a middle school reading level and pilot tested on a particularly small group of North Carolina Agricultural &Technical State University students and faculty for readability and content. After making the necessary modifications, we determined that our survey instrument was validated to achieve the objectives of this study.

3.2 Study Participants

The sample population for this study was African American adults, 18 years of age and older, of different socioeconomic status and gender. The sample populations were members of the Triad region which consist of Greensboro, Winston Salem, and High Point, North Carolina. To reach a broad diverse array of African Americans in the Triad community, groups which represented different demographic clusters such as age, gender, and education were identified. African American adults in hospitals, health clinics, or Physicians' offices were excluded from this study, due to the convenience sample gathered at other venues.

3.3 Research Compliance

The survey entitled, "Alzheimer's Disease Literacy among African Americans- An Intergenerational Survey" was reviewed by the Institutional Review Board (IRB) at North Carolina Agricultural and Technical State University. The IRB determined that our survey met all requirements. The seal of approval was granted on October 3, 2012 by North Carolina A&T State University.

3.4 Survey Administration Protocols

An interdisciplinary team of trained African American public health specialists was responsible for administering the surveys. These public health specialists were experienced in overseeing educational and outreach activities in the Triad community. The survey was disseminated to people who have zero to little knowledge of AD, as well as AD caregivers, both professional and nonprofessional. Volunteers within the TRIAD were gathered at different venues, including community health fairs, women's conferences, and church gatherings and events. Voluntary participants were instructed to complete the survey forms in an independent manner, but administrators were present to answer any question of the participant regarding the survey instrument or study.

A fairly small sample of survey participants were able to complete the survey in an online instrument known as Qualtrics. The online version of the survey was composed of teachers from North Elementary School in Kings Mountain, NC and gerontology students at the University of North Carolina at Greensboro in Greensboro, NC. These surveys were emailed to all individuals in these particular groups with a brief description of our study as well as a request of their participation in this study through completion of the AD literacy survey. The participants that volunteered for this study, regardless of where and how they completed the survey, were not given any incentive or reimbursed in any way for voluntarily completing the survey.

3.5 Statistical Analysis

The data collected from the surveys were entered into Microsoft Excel and then analyzed using the tool IBM SPSS (v19). To gain a better understanding of the perception and knowledge of AD in the African American community, multivariate statistical methods were used to analyze the data for this study. The statistical analyses included both inferential and descriptive data which observed frequencies. The significance level used for this study was set at 5% (alpha = 0.05).

CHAPTER 4

Results

4.1 Characteristics of the Study Population

A total of 292 surveys were collected from volunteers attending health fairs and other church and community events as seen in Figure 1. The largest number of survey participants attended health fairs across North Carolina (70.5%). Survey participant attendance at from community YMCAs represented 14%. Voluntary participants in the online version of the survey were composed of teachers from North Elementary School in Kings Mountain, NC and gerontology students at the University of North Carolina at Greensboro in Greensboro, NC, represented 6.5% and educational forums and galas followed closely at 5.4%. The lowest number of respondents attended AD caregiver conferences (3.4%).

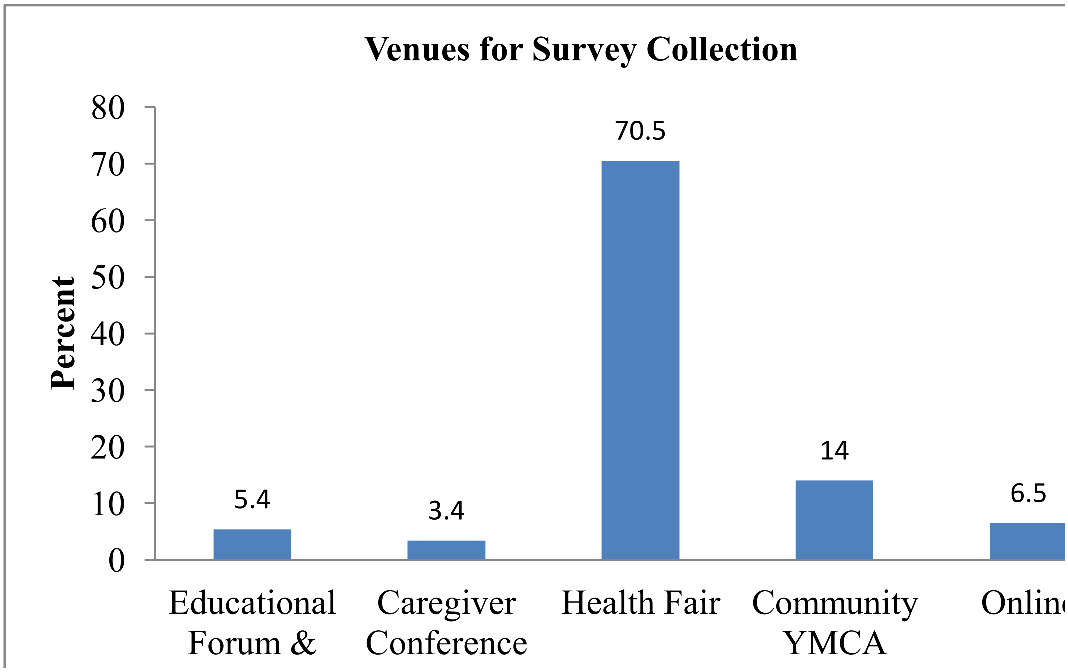

Figure 1. Distribution of Participants at the Five Selected Venues.

4.1.1 Gender. The majority of volunteer survey participants in this study were female. Females accounted for 79.7% of the total number of people surveyed, with 20.3% participants representing males.

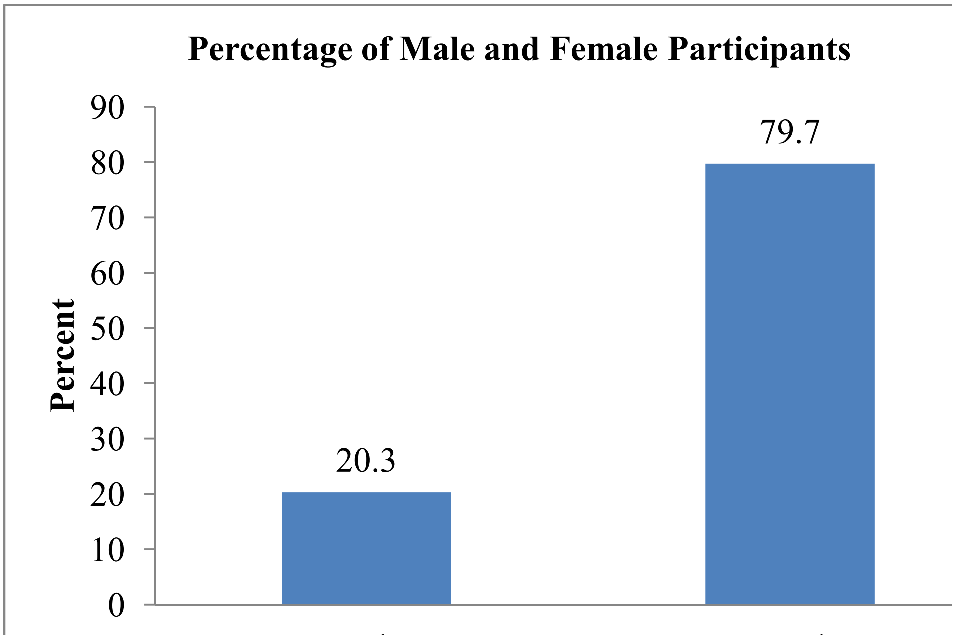

Figure 2. Genders of Participants at the Five Selected Venues.

4.1.2 Ethnicity. African Americans made up the largest (71.6%) ethnic group surveyed as seen in Table 1. The percent of whites that participated in this study was 26.4%. Other ethnicities and those of mixed ethnicities accounted for approximately 2.0%. Non African American and White ethnic groups were not included in further analyses due to low participant rates. This study focused on African Americans and Caucasian/Whites.

Table 1

Ethnic Distribution of the Participants

Ethnicity	Percent %
African American/ Black/African Descent	71.6

Table 1

cont.

Caucasian/ White	26.4
Other	2.0
Total	100.0

4.1.3 Age group. The age group of 40 years of age to 60 years of age accounted for 48.4% of the participants. Those participants less than 40 years of age trailed behind the 40 to 60 year olds at 28.7%. Finally, those individuals ages 60 year of age and older accounted for 22.8%. Table 2 demonstrates the age percentages of this study. There were no expectations on the age groups in which surveys would be gathered from due to the wide range of venues that were attended.

Table 2

Age Distributions of the Participants

Age Group	**Percent %**
Less Than 40	28.7
40 to 60	48.4
60 and Over	22.8
Total	100

4.1.4 Education demographic. Figure 2 shows the distribution of educational achievement amongst the participants in this study. For the majority of the participants, the highest level of educational achievement was no college degree (51%). The number of participants that had a four year degree was 29.7%. The remaining 19.3% of survey participants had a graduate or professional degree. Within ethnicity, we found similar findings with about half of those surveyed with at least a Bachelor's degree regardless of ethnicity.

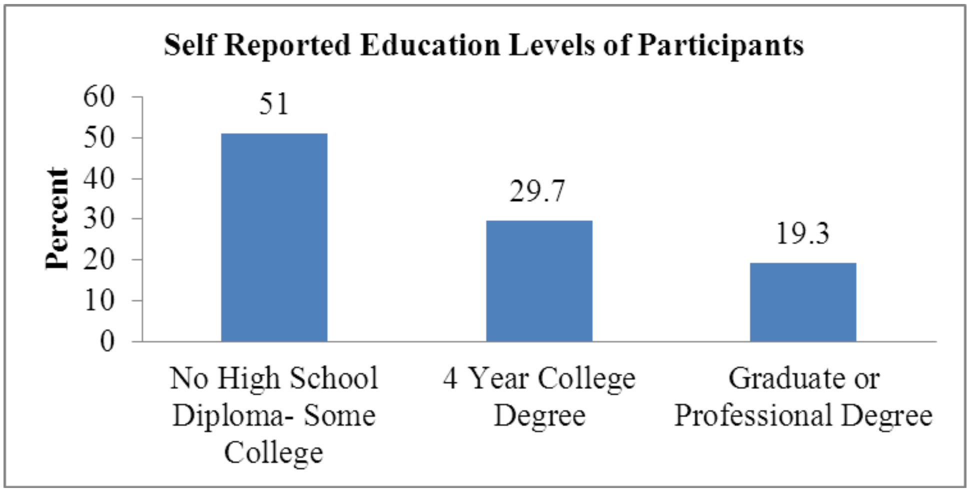

Figure 3. Education Demographic

4.1.5 Immediate family member diagnosed with Alzheimer's disease. Participants were asked if they had an immediate family member that had been diagnosed with AD. The majority (59.1%) of the participants responded that they did not have an immediate family member with AD, whereas 37.1% of the participants had an immediate family member with AD. Very few of our respondents (3.8%) did not know if any immediate family member was diagnosed with Alzheimer's disease.

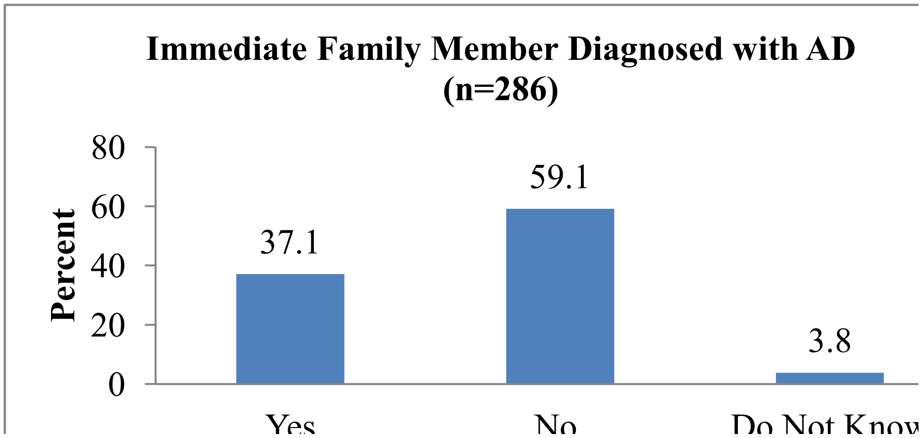

Figure 4. Immediate Family Member Diagnosed with AD

4.1.6 Current caregivers versus non caregivers. Over half (52.6%) of the survey participants were caregivers to another individual, not excluding those caregivers that did not provide care for an individual with Alzheimer's disease, the remaining 47.4% were not caregivers. Of the 153 participants that were caregivers, the majority (35.3%) of the participants was family members, 27.5% of the participants were professional caregivers, 9.2% were friend caregivers, and 28.1% were caregivers of some other type not listed. We will only focus on professional and family members that are caregivers for the duration of this paper. The vast majority (80.2%) of our participants claimed they were not currently providing care to someone with Alzheimer's disease; the remaining 19.8% of our participants were caregivers to someone with AD.

4.2 Knowledge of Alzheimer's Disease

The knowledge of Alzheimer's disease facts among participants, such as prevalence, statistical data, signs and symptoms, treatment options, and risk factors, was assessed. We compared the responses by ethnicity, caregiver status, age, educational level, and gender.

4.2.1 Immediate family member and Alzheimer's diagnosis. Of the individuals that participated in this study, 38.9% of African Americans and 36.5% of Whites had an immediate family member diagnosed with this disease. The vast majority of African American participants (57.1%) and Whites (60.8%) did not have an immediate family member diagnosed with AD. Less than 5% of African Americans and Whites did not know if they had an immediate family member diagnosed with this disease.

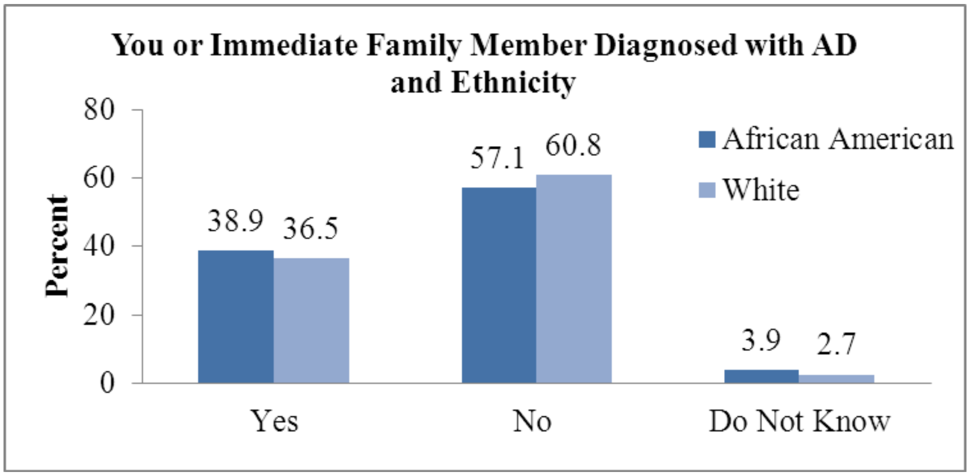

Figure 5. Immediate Family Member Diagnosed with AD and Ethnicity

4.2.2 Caregiver to patient with Alzheimer's. As previously mentioned, there were few (55) participants that are currently providing care to an individual suffering from Alzheimer's disease. In order to gain a better understanding of who were the individuals providing this care, we looked at gender, ethnicity, age, and educational level of these caregivers. In Table 3, we find that the majority of AD caregiver participants were females, African American, between the ages of 40 and 60, and did not have a 4 year college degree or higher.

Table 3

Current AD Caregivers Demographics

	Percent of Current AD Caregiver (n=55)
Gender (n=55)	
Female	87.3

Table 3

cont.

Male	12.7
Ethnicity (n=54)	
African American	64.8
White	35.2
Age (n=55)	
Less than 40	29.1
40 to 60	49.1
60 and older	21.8
Educational Level (n=54)	
No High School Diploma - Some College	55.6
4 Year College Degree	25.9
Graduate or Professional Degree	18.5

4.2.3 Describe Alzheimer's disease. Most participants (85.9%), across categories, understand AD as a form of memory loss or dementia; a few (14.1%) people refer to AD as normal old age, senility, or that they are unsure of what this disease is. Response to this question was compared across ethnicity, gender, caregivers, non caregivers, professional caregivers, and family caregivers. Table 4 demonstrates the responses from each of the groups observed. There does not appear to be any significant difference in the way each group responded to this question. This suggests that understanding of AD is not related to any of the parameters we observed.

Table 4

Best Describes Understanding of AD

	Memory Loss or Dementia (%)	**Normal Old Age, Senility, Unsure (%)**
Ethnicity (p-value= 0.703, n= 275)		
African American	86.1	13.9
White	87.8	12.2
Gender (p-value= 0.887, n= 283)		
Female	85.7	14.3
Male	86.4	13.6
Caregiver vs Non Caregiver (p-value= 0.375, n= 284)		
Caregiver	84.2	15.8
Non Caregiver	87.9	12.1
Type of Caregiver (p-value= 0.514, n= 95)		
Professional	87.8	12.2
Family	87	13
Caregiver (p-value= 0.247, n=273)		
AD Caregiver	90.9	9.1
Non AD Caregiver	84.9	15.1

4.2.4 Age as a risk factor. Age is the number one risk factor in the development of AD; therefore, an 80 year old has a higher risk of developing AD than a 50 year old. Only 31.3% of the overall participants had the correct response to this true/false statement, while the remaining 68.7% answered this statement incorrectly. More Whites than African Americans (37.8%, 28.9%), more caregivers than non caregiver (33.8%, 29.4%), more professional than family caregivers (42.5%, 33.3%), and more AD caregivers than non AD caregivers (35.2%, 32%) correctly answered this question. However, the difference in correct responses was not statistically significant.

Table 5

True False: 80 year old has greater risk of AD than 50 year old

	True (%)	**False (%)**
Ethnicity (p-value= 0.156, n= 278)		
African American	28.9	71.1
White	37.8	62.2
Caregiver vs Non Caregiver (p-value= 0.428, n= 287)		
Caregiver	33.8	66.2
Non Caregiver	29.4	70.6
Type of Caregiver (p-value= 0.532, n= 94)		
Professional	42.5	57.5
Family	33.3	66.7
Caregiver (p-value= 0.652, n= 276)		
AD Caregiver	35.2	64.8
Non AD Caregiver	32	68

4.2.5 Most common symptom of Alzheimer's. One of the most common symptoms of Alzheimer's disease, is the inability to recall recent events. Again there was no significant difference between ethnic and caregiver groups. The majority of African Americans (66.7%) and Whites (64%) recognized the inability to remember recent events as the most common symptom of AD. Among the caregivers 66.2% answered the question correctly which is similar to the response given by those particpants who are non caregivers (65%). Most of the professional caregivers (67.5%) were aware of the common symptom of AD, however a slightly higher percentage of family members (70.4%) answered this question correctly. Among the current AD caregivers surveyed, 70.4% answered this question correctly compared to 64.9% of non AD caregivers. Again, we observed no significant difference in the way each group responded to this question.

Table 6

True False: Most Common Symptom is Inability to Remember Recent Events

	True (%)	**False (%)**
Ethnicity (p-value= 0.667, n= 279)		
African American	66.7	33.3
White	64	36
Caregiver vs Non Caregiver (p-value= 0.822, n= 288)		
Caregiver	66.2	33.8
Non Caregiver	65	35
Type of Caregiver (p-value= 0.274, n= 94)		
Professional	67.5	32.5

Table 6

cont.

Family	70.4	29.6
Caregiver (p-value= 0.444, n= 276)		
AD Caregiver	70.4	29.6
Non AD Caregiver	64.9	35.1

4.2.6 There are drugs that cure Alzheimer's disease. Currently, there are no drugs available to cure AD. The majority of the particiants of this study (70.9%) are aware that this statement is false, but 29.1% of the participants were unaware or unsure that there is no drug cure. A statistically significant (p-value < 0.001) percentage of the White cohorts, 93.2%, answered this question correctly compared to the 62.7% of African American participants. Among caregivers in general, 73.6% answered this question correctly, compared to the 69.5% of non caregivers that answered this question correctly with a significant difference between the two groups. Significant differences were seen in 90% of the professional caregivers and 75.5% of family caregivers know that there is no drug cure for this disease. Of the current caregivers to the a patient with AD, significantly more (92.6%) AD caregivers were aware that there is no drug cure for AD compared to 65.2% non AD caregivers.

Table 7

True False: There are Drugs that Cure AD

	True (%)	***False (%)***
Ethnicity (p-value= <0.001, n=275)**		
African American	36.3	63.7

Table 7

cont.

White	6.8	93.2
Caregiver vs Non Caregiver (p-value= <0.001, n= 284)**		
Caregiver	26	74
Non Caregiver	30.6	69.4
Type of Caregiver (p-value= 0.006, n= 95)**		
Professional	9.8	90.2
Family	24.1	75.9
Caregiver (p-value= 0.006, n= 273)**		
AD Caregiver	7.3	92.7
Non AD Caregiver	34.4	65.6

**= p-value<0.01 *= p-value<0.05

4.2.7 First contact with memory loss symptoms. This question explores who the participants would call first if experiencing memory loss. Overall, the majority (62.7%) said that they would call a doctor first, followed by those participants that would call a family member first (31.4%). Within ethnicity, we found that over half of the African American participants (57.4%) shared that they would call a doctor first, with 35% calling a family member first; this response is significantly different from the responses of the Whites in this study. The majority (77%) of Whites responded that they would call a doctor first if they experienced frequent memory loss. Gender distributions are similar, 62.9% of females and 63.2% of males indicate that they would call a doctor first, and 31.7% of females and 28.1% of males said that they would call a family member first. Similarly, no difference was observed across educational levels.

Table 8

Who Would You Call First for Memory Loss

	Family Member (%)	**Friend (%)**	**Pastor (%)**	***Doctor (%)***	**Other (%)**
Ethnicity (p-value= 0.058, n= 268)					
African American	35	3	1	57.4	3.6
White	21.6	-	-	77	1.4
Gender (p-value= 0.631, n= 274)					
Female	31.7	1.8	0.9	62.9	2.7
Male	28.1	3.5	-	63.2	5.3
Education Level(p-value= 0.428, n= 274)					
No High School Diploma - Some College	32.1	2.9	0.7	61.3	2.2
4 Year College Degree	28.2	1.2	1.2	68.2	1.2
Graduate or Professional Degree	30.4	1.8	-	60.7	1.8

4.2.8 Severe memory loss and doctor visits. It is extrememly important that a person experiencing frequent memory loss goes to the doctor to seek help. Overall, the majority (16%) of the participants indicated that they would go to a doctor if they were experiencing frequent memory loss. Less than 10% of those who participated said that they would not go to the doctor for memory loss that interferes with daily activities. More Whites (97.3%) indicated that they would go to the doctor compared to 90% of the African Americans surveyed. Females are more likely (93.3%) to go to the doctor, compared to males (89.5%). However, the differences were not significant.

Table 9

Would You Go To Doctor for Memory Loss

	Yes (%)	**No (%)**
Ethnicity (p-value= 0.074, n= 273)		
African American	91	9
White	97.3	2.7
Gender (p-value= 0.326, n= 281)		
Female	93.3	6.7
Male	89.5	10.5

4.2.9 Alzheimer's disease and African Americans. Recent studies have shown that African Americans are twice as likely to develop AD compared to their white couterparts [18]. Overall, only 39.6% of the participants were aware of this fact. The responses differed significantly by ethnicity. We observed that half of the African Americans and only a fourth of the White participants were aware that African Americans are most affected by AD. Only 43% of females and 25% of males responded that African Americans are more affected by AD. More general caregivers (44.4%) answered this question correctly than non caregivers (34.2%). Almost half of the professional and family caregivers know that African Americans are more affected by this disease. More AD caregivers (55.6%) answered this question correctly compared to 34% of non AD caregivers. There is a significant difference in the way in which AD caregivers and caregivers of someone without AD answered this question.

Table 10

Are African Americans More Affected by AD

	Yes (%)	**No (%)**
Ethnicity (p-value= 0.004, n= 134)**		
African American	50	50
White	25	75
Gender (p-value= 0.067, n= 139)		
Female	43	57
Male	25	75
Caregiver vs Non Caregiver (p-value= 0.218, n= 139)		
Caregiver	44.4	55.6
Non Caregiver	34.2	65.8
Type of Caregiver (p-value= 0.898, n= 42)		
Professional	47.1	52.9
Family	48	52
Caregiver (p-value= 0.040, n= 130)*		
AD Caregiver	55.6	44.4
Non AD Caregiver	34	66

**= p-value<0.01 *= p-value<0.05

4.2.10 Sources of Information on Alzheimer's disease. In order to improve literacy in AD, it is important to know where individuals receive AD information. We asked this question to gain insight of how most people in the community receive information on AD. Survey participants were allowed to choose as many sources as they needed; therefore the responses of this question were separated into the seven different sources asked in the survey. We observed the overall percentage of each source by all participants, as well as the percentage of each ethnic group to each source. The majority of the participants, 19.2%, received information about AD from sources that were not mentioned in the survey. Health fairs (14.8%) and family members or friends (11%) were the most popular ways our participants obtained AD information. We observed that at least 50% of the African Americans indicated that they received AD information from each of these sources indicated. We also found that 62.5% of the African American participants and 37.5% of the White participants do not receive any information regarding AD.

Table 11

Methods of Receiving Information on AD

Source for AD Information	**Overall (%)**	**African American (%)**	**White (%)**
Newspaper (n= 27)	9.3	56	44
Radio (n= 9)	3.1	50	50
TV (n= 27)	9.3	53.8	46.2
Health Fair (n= 43)	14.8	73.2	26.8
Family or Friend (n=32)	11	60	40
Other Sources (n= 56)	19.2	55.6	44.4
Do Not Receive any Information (n= 24)	8.2	62.5	37.5

4.3 Perception of Alzheimer's Disease as a Disease State

To assess the perception of participants, individuals were asked to answer the questions based on a Likard-type scale. A rank of one on the scale corresponded to an answer of Strongly Do Not Agree, a rank of two corresponded to Do Not Agree, a rank of three indicated Neutral, a rank of four indicated Agree, and a rank of five corresponded to Strongly Agree. For the purposes of analysis, we combined Strongly Do Not Agree and Do Not Agree, as well as, Strongly Agree and Agree.

4.3.1 Memory loss disrupts daily activities. Overall, the majority (90%) of the participants agree that memory loss may disrupt their ability to drive and perform daily activities. The majority of African American (89.5%) and White (92.8%) agreed that this statement was true. When observing how caregivers responded to this statement compared to participants who were not caregivers, 92% of our non caregivers agreed with this statement compared to the 88.5% of caregivers. Among caregivers, 88.2% of professionals and 87.5% of family members agreed that memory loss may disrupt ability to drive and perform daily activities. Within caregivers, 85.2% of AD caregivers and 91.2% of non AD caregivers agreed with this statement.

Table 12

Memory Loss May Disrupt Driving and Performing Daily Activities Abilities

	Do Not Agree (%)	**Neutral (%)**	***Agree (%)***
Ethnicity (p-value= 0.816, n= 131)			
African American	2.6	7.9	89.5
White	1.8	5.5	92.7

Table 12

cont.

Caregiver vs Non Caregiver (p-value= 0.777, n=136)			
Caregiver	3.3	8.2	88.5
Non Caregiver	2.7	5.3	92
Type of Caregiver (p-value= 0.119, n= 41)			
Professional	-	11.8	88.2
Family	8.3	4.2	87.5
Caregiver (p-value= 0.618, n= 129)			
AD Caregiver	3.7	11.1	85.2
Non AD Caregiver	2.9	5.9	91.2

4.3.2 Memory loss disrupts problem solving abilities. One of the signs of AD is being unable to think and solve problems. Here again, the majority of the participants (90.2%) agreed that this statement was in fact true. Within ethnicity, African Americans (89.7%) and Whites (90.9%) agreed that memory loss has the ability to disrupts an individual's ability to think and solve problems. A significant difference is observed in response of the caregivers and non caregivers, 82.5% of caregivers agreed to this statement, while 96% of non caregivers agreed to this statement. Amongst caregivers, 82.4% professionals and 80% family members agreed with this statement. Within caregivers, AD caregivers (85.2%) and non AD caregivers (91.3%) agreed with this statement.

Table 13

Memory Loss May Disrupt Thinking and Problem Solving Abilities

	Do Not Agree (%)	**Neutral (%)**	***Agree (%)***
Ethnicity (p-value= 0.154, n=133)			
African American	-	10.3	89.7
White	3.6	5.5	90.9
Caregiver vs Non Caregiver (p-value= 0.030, n= 138)*			
Caregiver	3.2	14.3	82.5
Non Caregiver	1.3	2.7	96
Type of Caregiver (p-value= 0.897, n= 42)			
Professional	-	17.6	82.4
Family	4	16	80
Caregiver (p-value= 0.210, n= 130)			
AD Caregiver	-	14.8	85.2
Non AD Caregiver	2.9	5.8	91.3

**= p-value< 0.01 *= p-value< 0.05

4.3.3 Frequent episodes in memory loss are a normal part of aging. A frequent episode in memory loss is not a normal part of aging. Overall, 40.6% of the participants disagreed with this statement. More Whites (58.7%) answered this question correctly when compared to their African American counterparts (34%), demonstrating a significant difference in the way in which ethnicities answered this question. Only 37.5% of all caregivers answered this question correctly compared to the 44.8% of non caregivers who answered correctly. Of the caregivers, 50% of the professional and 33.3% of family member caregivers answered this question correctly. From the data we see that 41.8% of AD caregivers and 40.9% of non AD caregivers answered this question correctly. There appears to be no relationship between the ways in the caregivers group answered this question.

Table 14

Memory Loss is a Normal Part of Aging

	Do Not Agree (%)	**Neutral (%)**	**Agree (%)**
Ethnicity (p-value= <0.001, n=278)**			
African American	34	31	35
White	58.7	25.3	16
Caregiver vs Non Caregiver (p-value= 0.269, n= 286)			
Caregiver	37.5	32.9	29.6
Non Caregiver	44.8	24.6	30.6
Type of Caregiver (p-value= 0.291, n= 96)			
Professional	50	33.3	16.7
Family	33.3	35.2	31.5
Caregiver (p-value= 0.852, n= 275)			
AD Caregiver	41.8	25.5	32.7
Non AD Caregiver	40.9	29.1	30

**= p-value< 0.01 *= p-value< 0.05

4.3.4 People as young as 30 years of age can develop Alzheimer's disease.

It is possible for a person as young as 30 years of age to develop AD, but the risk for a 30 year old is extremely low. It was observed that 51.7% of the overall participants believe that people as young as 30 can develop AD. Similar to the overall findings, we observe that approximately 50% of both ethnic groups agree with this statement. Also, similar to the overall findings, approximately 50% of professional and family caregivers agree with this statement.

Table 15

People as Young as 30 Years of Age can Develop AD

	Do Not Agree (%)	**Neutral (%)**	**Agree (%)**
Ethnicity (p-value=0.836, n= 277)			
African American	15.8	33.5	50.7
White	16.2	29.7	54.1
Caregiver vs Non Caregiver (p-value= 0.088, n= 284)			
Caregiver	16	37.3	46.7
Non Caregiver	14.9	26.1	59
Type of Caregiver (p-value= 0.840, n= 95)			
Professional	14.3	31	54.8
Family	18.9	37.7	43.4
Caregiver (p-value=0.246, n= 274)			

Table 15

cont.

AD Caregiver	9.1	38.2	52.7
Non AD Caregiver	17.4	30.1	52.5

4.3.5 Physical activity can lower the chances of experiencing memory loss. Physical activity is believed to decrease the risk of numerous diseases and adverse health conditions including Alzheimer's disease. Overall we observed that the majority of the participants (67.5%) agree that being physically active is a good way to lower the chances of experiencing memory loss. More than 65% of African American and White participants agreed with this statement. We found a significant difference in responses in the caregivers and non caregivers, with more non caregiver (74%) agreeing with the statement than caregivers (62.4%). We also observed that 58.5% of professional caregivers agree with this statement compared to 66% of family caregivers. More non AD caregivers (69%) agreed with this statement than AD caregivers (63%).

Table 16

Physical Activity is a Good Way to Lower Memory Loss

	Do Not Agree (%)	**Neutral (%)**	***Agree (%)***
Ethnicity (p-value= 0.305, n= 274)			
African American	8	26.5	65.5
White	9.4	17.6	73

Table 16

cont.

Caregiver vs Non Caregiver (p-value= 0.009, n= 280)**			
Caregiver	12.8	24.8	62.4
Non Caregiver	3.1	22.9	74
Type of Caregiver (p-value= 0.553, n= 94)			
Professional	12.2	29.3	58.5
Family	11.4	22.6	66
Caregiver (p-value= 0.180, n= 270)			
AD Caregiver	14.8	22.2	63
Non AD Caregiver	6.9	24.1	69

**= p-value< 0.01 *= p-value< 0.05

CHAPTER 5

Discussion

The goal of this study is to assess the understanding, perceptions, and behaviors related to Alzheimer's disease in African Americans. More specifically, this was a qualitative study conducted in a mostly African American community to assess specific knowledge about warning signs and symptoms associated with AD. A survey instrument was designed and used as a way to identify Alzheimer's educational needs in the community.

The results are based on data from 292, 23 question surveys that were completed by voluntary participants. Participation was sought at community events with the largest number of completed surveys received at community health fairs. The majority of the survey participants were African American females and almost half of the participants were ages 40 to 60 years of age with no high school diploma to some college. The majority of participants (62.9%) did not have or were unaware of an immediate family member diagnosed with AD. Although most of the participants are not caregivers, it is important to assess knowledge of AD in the general population as well as those that may potentially be caregivers. The vast majority, 80.2%, of the participants reported that they were not currently a caregiver to someone with AD.

Although there were some participants providing care for someone with AD, there were still many participants that considered themselves caregivers of some type. We found that 27.5% of these caregivers, not excluding those that are AD caregivers, were professional caregivers while 35.3% were family members providing care for a loved one. From the knowledge gained in our literature review, we expected to see that the vast majority of Alzheimer's disease caregivers are not professional. According to the Alzheimer's Association 2012, the majority of Alzheimer's disease caregivers are women over the age of 50, who are providing unpaid care to a family member. There were no specification of the term “other” as it relates to caregiving and the percentage of friends providing care were low, therefore we decided to only look at caregivers who were professionals and family members.

Several AA participants gave an incorrect response to the question asking if there is a drug cure for AD. These results support the findings by Ayalon and Areάn (2004) which highlight racial differences in knowledge about AD. The results also highlight the need to dispute possible myths about AD in the African American community. Inaccurate health information and myths, may explain why stigma related to AD is widespread in minority communities. Future interventions should be designed to address the best way to identify AD, stages of AD along with incorporating information that directly addresses myths in order to eventually lower stigma in minority communities.

Although the majority of participants understand AD as memory loss or dementia, results from this survey also found individuals who referred to this disease as normal old age, senility, or were unsure as to how the disease should be identified. These results are similar to those found in McKhann and colleagues (2011) in which African Americans considered AD as a term for normal memory loss associated with aging. In addition, our results indicate that individuals will contact a doctor first if experiencing frequent memory loss. This information is in contrast to findings by Husaini et al (2003) that African Americans are generally diagnosed at later stages in the disease than older Whites, which may be the leading factor in significantly higher dementia-related mortality and health care costs. It is likely that individuals that state that memory loss is a part of normal aging may not be able to recognize symptoms, will be less inclined to seek medical attention for their symptoms and therefore, they may miss opportunities to participate in clinical trials of interventions that may impact their level of care.

There were significant differences in the way in which individuals in different ethnic groups answered the disparity question which assessed the knowledge of participants' awareness of African Americans' disproportionate susciptibility of developing AD, as well as the way in which AD caregivers and caregivers of someone without AD answered the disparity question. These results substantiate the need to provide AD education across cultures and highlights the need to have the appropriate classification of AD as a health disparity. It is now important to creat policies that will underscore AD's role as a chronic disease and health disparity if we want to combat the devastating effects of this disease on families. Having policies that address this issue will also help eliminate stigma by bringing necessary attention and resources to a growing issue.

This survey only represents two ethnic groups in North Carolina. Our goal is to gain more participation from other ethnic groups throughout the state. Future studies will be designed to include more male participation by conducting outreach activities at male dominated events. Our future plans involve gathering more information from communities in the Eastern part of the state of North Carolina and beyond. An expansion of our collection sample will provide us with information on where the deficit about Alzheimer's disease is in the community, and it will allow us to impact communities that are underserved by the medical community, have less health education and access to adequate health care.

CHAPTER 6

Conclusion

Alzheimer's runs in our families. In this study we were able to recognize an Alzheimer's literacy deficit in the African American community. African Americans incorrectly responded to questions that directly addressed knowledge about signs, symptoms and nomenclature of AD. Results from this study support the need for more Alzheimer's disease outreach, education and awareness in minority communities. We also noticed that there are opportunities to educate the general population outside of just the African American community. It is necessary to design interventions and continue translational research that will improve disease knowledge and management.

We conclude that understanding how African Americans understand AD is a first approach to designing policies, interventions and symptoms that can reduce prevalence of AD in minority communities. Being able to use appropriate nomenclature, identify warning signs and symptoms of AD will help to improve patient-provider communication and hopefully improve early diagnosis and patient care and disease management. Knowing the correct information may also help with the caregiver's confidence in discussing this disease with support agencies, family members and friends and in this way increase awareness about AD in communities nationwide.

Our goal is to use this pilot data to create a culturally appropriate survey that will serve to assess AD knowledge and educate communities about AD signs and symptoms across North Carolina. Our ultimate goal is to increase AD literacy and decrease disease prevalence and improve patient-provider interactions in underserved, elderly communities.

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Appendix

Alzheimer's Disease Literacy among African Americans
- An Intergenerational Survey

Alzheimer's disease is one of the most common forms of dementia in the US and according to the Centers for Disease Control and Prevention (CDC) African Americans are more likely to develop the disease than any other populations. The purpose of this study is to gain insight into the African American community's knowledge and overall understanding of Alzheimer's disease. This study is being conducted by the AD research staff at NC A&T State University and the results will be used to educate the community about AD symptoms, risk factors and care management.

The Institutional Review Board of NC A&T State University has approved this survey for dissemination. Participation in this survey is voluntary, and your responses will remain completely confidential and anonymous. It will take approximately 10 minutes for you to complete this survey.

Place a check in the corresponding box.

1. Gender: Female ☐ Male ☐

2. Ethnicity: ☐ African American ☐ White ☐ Hispanic ☐ Native American

☐ Mixed Ethnicity

3. Age: ☐ 18-29 ☐ 30- 39 ☐ 40-49 ☐ 50- 59

☐ 60 -69 ☐ 70 -79 ☐ 80 and above

4. Level of Education completed:

___ No High School Diploma
___ High School Diploma/GED
___ Associate's Degree
___ Bachelor's Degree
___ Master's Degree
___ Doctoral Degree
___ Professional Degree
___ Certificate

___ Other_____________

Please choose the best answer.

5. Have you or an immediate family member (parent, grandparent, sibling, spouse) been **diagnosed** with Alzheimer's disease by a physician or health care provider?

☐ YES ☐ NO ☐ I do not know

6. Are you currently a caregiver to someone with Alzheimer's disease? **If NO, go to #8**

☐ YES ☐ NO

7. Are you a professional caregiver (i.e. nurse, doctor, etc.) or as a family member or friend?

☐ Professional ☐ Family member ☐ Friend ☐ Other

8. Which of the following best describes your understanding of Alzheimer's disease? (Check only one box)

☐ Memory Loss ☐ Dementia ☐ Normal Old Age

☐ Senility (Senile) ☐ Not sure ☐ Other __________

9. An 80 year old has a greater risk of developing Alzheimer's disease than a 50 year old.

☐ True ☐ False ☐ I do not know

10. The most common symptom of Alzheimer's disease is being unable to remember recent events.

☐ True ☐ False ☐ I do not know

11. There are drugs that cure Alzheimer's disease.

☐ True ☐ False ☐ I do not know

12. If you (or a loved one) were experiencing frequent memory loss that interferes with daily activities, **who would you call first**?

☐ Family member ☐ Friend ☐ Pastor ☐ Doctor ☐ Other________

13. If you (or a loved one) were experiencing frequent memory loss that interferes with daily activities **would you go to the doctor? If your answer is no, go to #15**

☐ Yes ☐ No ☐ I do not know

14. If yes, what kind of doctor would you visit?

☐ **Primary care doctor** ☐ **Neurologist** ☐ **Gerontologist**

☐ **Other__________**

15. If you (or a loved one) were experiencing frequent memory loss that interferes with daily activities, would you go to a church member, church nurse or pastor first?

☐ Church member ☐ Church Nurse ☐ Pastor ☐ Other_________

☐ I do not know

16**.** Are African Americans more affected by Alzheimer's disease than any other ethnic group?

☐ Yes ☐ No ☐ I do not know

17. How do you get information about Alzheimer's disease?

☐ Newspaper ☐ Radio ☐ Television ☐ Health Fair

☐ Family member/Friend ☐ Other________

☐ I do not receive Alzheimer's information

TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENTS? CIRCLE THE APPROPRIATE NUMBER.

18. In some people, memory loss may disrupt their ability to drive and perform daily activities.

Do Not Agree		**Neutral**		**Strongly Agree**
○	○	○	○	○
1	**2**	**3**	**4**	**5**

19. In some people, memory loss may disrupt their ability to think and solve problems.

Do Not Agree		**Neutral**		**Strongly Agree**
○	○	○	○	○
1	**2**	**3**	**4**	**5**

20. Frequent episodes in memory loss are a normal part of aging.

Do Not Agree		**Neutral**		**Strongly Agree**
○	○	○	○	○
1	**2**	**3**	**4**	**5**

21. People as young as 30 years of age can develop Alzheimer’s disease.

Do Not Agree		**Neutral**		**Strongly Agree**
○	○	○	○	○
1	**2**	**3**	**4**	**5**

22. Females are more likely to be diagnosed with Alzheimer’s disease.

Do Not Agree		**Neutral**		**Strongly Agree**
○	○	○	○	○
1	**2**	**3**	**4**	**5**

23. Being physically active (ex. Walking, Zumba, weight lifting, jogging, sexual behavior, etc.) is a good way to lower the chances of experiencing memory loss.

Do Not Agree		**Neutral**		**Strongly Agree**
○	○	○	○	○
1	**2**	**3**	**4**	**5**