A Study of the social barriers leading to the disproportionately higher incidence of Alzheimer's disease in the African American population

Edna Andrews-Rose
Clark Atlanta University

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ABSTRACT

SCHOOL OF SOCIAL WORK

ANDREWS-ROSE, EDNA B.S.N. KENNESAW UNIVERSITY, 1986
M.S.W. CLARK ATLANTA UNIVERSITY, 2002

A STUDY OF THE SOCIAL BARRIERS LEADING TO THE

DISPROPORTIONATELY HIGHER INCIDENCE OF ALZHEIMER’S DISEASE

IN THE AFRICAN AMERICAN POPULATION

Advisor: Richard Lyle, Ph.D.

Dissertation dated May 2008

This study examines social factors associated with the disproportionately higher incidence of Alzheimer’s disease in the African American population. Ninety participants were selected for the study utilizing non-probability convenience sampling. The survey participants were composed of primary care givers of Alzheimer’s clients. The findings of the study indicated that socio-economic factors were a significant variable in the diagnosis of Alzheimer’s disease. Respondents 65.9% reported that participation in research was not equally shared by all ethnicities. The results of the study revealed that 56.8% of respondents allowed patients to remain in the home due to support of other family members. The finding of access to health care was measured by information on medication and health care alternatives being provided to the care giver at the time of the diagnosis. Respondents (61.2%) reported no information given at the time of the diagnosis. The research findings related to stressors of caregivers of Alzheimer’s patients were not found to be significant.
A STUDY OF THE SOCIAL BARRIERS
LEADING TO THE DISPROPORTIONATELY HIGHER
INCIDENCE OF ALZHEIMER’S DISEASE IN THE
AFRICAN AMERICAN POPULATION

A DISSERTATION
SUBMITTED TO THE FACULTY OF CLARK ATLANTA UNIVERSITY
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR
THE DEGREE OF DOCTOR OF PHILOSOPHY

BY
EDNA ANDREWS-ROSE

WHITNEY M. YOUNG, JR., SCHOOL OF SOCIAL WORK

ATLANTA, GEORGIA
MAY 2008
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To my father who art in Heaven, I give thanks. I acknowledge my parents Ellie and Lula Andrews, who taught me that all things are possible if you only believe. I acknowledge my husband, Stanley Rose, who taught me that there are always three choices -- the good, the best, and the excellent choice -- and motivating me to always make the excellent choice. Thanks for encouraging me to keep going in times of doubt, I love you. I acknowledge my friend Shirley Brooks-Wilson who helped to make these last two years possible. I acknowledge my “Dream Team” Dr. Richard Lyle, chairman of my dissertation committee; Dr. Robert Waymer and Dr. Harper who worked tirelessly as committee members. I acknowledge Mrs. Claudette Rivers-King for always being there in times of need and direction. I acknowledge the many caregivers of those diagnosed with Alzheimer’s disease and for your contributions in the fulfillment of my dissertation. To my Mother: Though Alzheimer’s had taken your memory, I was always able to look into your eyes and see and love your soul. To you my research has begun, for you it will continue. I am grateful for having had you as my mentor; you are the wind beneath my wings.
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CHAPTER I

INTRODUCTION

Alzheimer's is a progressive, degenerative disease of the brain, and the most common form of dementia. Alois Alzheimer, a German pathologist (1864-1915), discovered Alzheimer disease in 1907. Many years passed before the American Medical Association, Diagnostic and Statistical Manual of Mental Disorders accepted and applied this diagnosis to clients in the United States. Initially this disease was predominantly diagnosed among Jewish immigrants. There were many myths as to the causes of the disease. One such myth was the association of traces of aluminum on the brain of the Jewish population in Germany. The brains of Jews were autopsied after death. It was noted that a large number of those autopsied showed traces of aluminum in the cerebral cortex. It was also noted that many of those that were autopsied had endured the Holocaust. Due to the diagnosis of Alzheimer's disease in the Jewish population, many of the early studies focused on this ethnic group. During autopsies there were noted changes in brain configuration and lost of fluids that were needed to carry electrical impulses/signals to different parts of the body to initiate appropriate responses. There was also an obvious change in the size and weigh of the brain of those autopsied (Brookmeyer 2007).
Much has changed and new scientific findings and empirical research has aided in the early diagnosis and treatment of the disorder; however Alzheimer’s disease is now the fourth leading cause of death in adults. It is estimated that 4.5 million Americans and eight million more people worldwide have the disease. The biggest risk factor associated with this disease is age: however age factors, alone, are not the single most known cause for the diagnosis of Alzheimer’s disease. Studies in genetics have shown that certain diseases predispose many patients to the diagnosis. Those diseases are usually vascular diseases such as hypertension, diabetes and high cholesterol. Other research on Alzheimer’s disease points to the value of diagnosing the disease prior to progression to stages two and three. Early detection of Alzheimer’s disease decreases the cost of care to the client and society, improves the quality of life to the client, and associated stress to the caregiver. Detection at the pre-clinical stage or the Early Phase of Alzheimer’s disease in the African American population is the desired goal (Sampson 2004, Hoyt 1999, Bird 1989).

The three stages in the progression of the disease process as given in the Diagnostic and Statistical Manual of Mental Disorders are:

1. The Preclinical Stage is marked by very mild problems with memory, speed of processing and confrontation naming. The general cognitive abilities remain intact, however neuropathology has begun in the brain.

2. The Early Phase is best noted by memory problems. The patient begins to repeat questions with forgetfulness of short-term memory issues. Because the patient has periods of memory where they sense that something doesn’t “feel right” they
withdraw and often become depressed as gradual impairment in advanced living skills (i.e., activities of daily living) commences.

3. In the Moderate to End of Life Phase, profound cognitive problems take place. Aphasia, the inability to communicate through speech, written or signs, are the furtherance of brain dysfunction. Aphasia may be considered complete or total if both the sensory and motor areas of the brain are involved. When Agnosia occurs, which is the loss of comprehension of auditory, visual or other sensations, the patient is no longer able to conceptualize what is heard, seen or felt. The gradual loss of basic life care abilities occurs when the patient becomes apraxic. Apraxia is the inability to perform purposeful movements, although there is no sensory or motor impairment with the patients’ condition (DSMIII-R).

Although Alzheimer disease was described 100 years ago, the preponderance of knowledge of the disease has mostly accumulated since the 1970’s. The dramatic advances in research during the last three decades propelled the disease from near obscurity to the forefront of modern social, psychological and biomedical science. The remarkable study in the field of Alzheimer disease is reflected in the number of investigators, publications and funded projects. Multiple studies have created an atmosphere of optimism about the aspect of discovering effective interventions to delay the progression of the disease. The National Institute on Aging initiatives to promote interdisciplinary research programs by creating a nationwide network of collaborating investigators and a research infrastructure/resource influenced the pace of progress (Khachaturian 2007).
In 2006, the worldwide prevalence of Alzheimer disease was 26.6 million. By 2050, the prevalence will quadruple, by which time 1 in 85 persons worldwide will be living with the disease. It is estimated that about 43% of prevalent cases will need a high level of care, equivalent to that of a nursing home. If interventions could delay both the disease onset and progression by a modest one year, there would be nearly 9.2 million fewer cases of the disease in 2050 (Brookmeyer 2007).

Alzheimer's disease in the U.S. population is a devastating disorder that is often unrecognized or misdiagnosed in its early stages. Despite the current lack of unequivocally effective treatment, recognition of early-stage dementia may offer substantial benefits. At present there is no cure for the disease only preventive measurements to assist the patient with comfort measures and maintenance of memory functioning via medication therapy. The education of the caregiver and increased opportunities of African Americans to become a part of research studies may improve access to health care and improve opportunities to gain access to medications and decrease stressors on the caregiver (Brookmeyer, 2007).

Statement of the Problem

To overlook the cost on society of Alzheimer's disease is one atrocity that our society cannot bear. To date 75% of all cost for patient care is paid by the families of the Alzheimer's patient. Half of all nursing home residents have a diagnosis of Alzheimer's. The cost for nursing home care per year is $42,000 and can exceed $70,000 per patient. The average lifetime cost per patient is $174,000. Alzheimer's disease is the third most expensive disease in the United States, after heart disease and cancer (Bloom, 2003).
To meet the mission of the Alzheimer’s organization, “…to eliminate Alzheimer’s disease through the advancement of research: to provide and enhance care and support for all affected: and to reduce the risk of dementia through the promotion of brain health”; and the vision “…a world without Alzheimer’s disease” we must look at factors that affect early detection and treatment from a social perspective (Alzheimer Fact Sheet, 2007).

“Baby boomers” are the largest segment of the U. S. population. This age group is rapidly approaching the age for first onset diagnosis. Unless effective methods for prevention and treatment are discovered Alzheimer’s will reach epidemic proportions. Based on today’s progression rates, of diagnosis of the disease, it is likely that in fifty years from today the disease will afflict 14 million Americans if prevention or cures are not discovered. The 2006 population was 299,398,485 with greater than 10.1 % over the age of sixty-five. The percentage of African Americans’ in this population is 12.4% and Caucasians 73.9% (American Community Survey, 2006). With the aging of the African American population, the expenditures on health care for the diagnosis of Alzheimer’s disease will reach epidemic proportions. The global burden of Alzheimer’s disease without early diagnosis, treatment and appropriate medication regimes when necessary will cost billions of dollars (Bruton, 2007).

Disease progression is an important consideration in assessing the social, psychological, and financial burdens to the African American population and society as a whole. Delaying the disease onset into stages two and three by an average of two years would decrease the worldwide prevalence of Alzheimer disease by 22.8 million persons.
This decrease in diagnosis would lead to a decrease burden on society and the family members of all races (Brookmeyer, 2007).

Today the diagnosis of Alzheimer’s disease is striking African American’s who are more susceptible to the “brain-wasting” condition than any other group of Americans. Stephanie Johnson a research associate at Duke University Medical Center’s “Bryan Alzheimer’s Research Center” states “…dementia is anywhere from 14 percent to 100 percent more prevalent among African Americans.” According to the 2002 report by the Alzheimer’s Association, 65 percent of African American Medicare beneficiaries have hypertension compared to only half of the white beneficiaries. And Blacks have a 60 percent higher risk for type 2-diabetes than do whites (Type II diabetes is insulin dependent diabetes). These are the vascular diseases that lead to an increase prevalence of the diagnosis of Alzheimer disease in the African American population (Johnson, 2007).

These statistics in health care highlight that there is a significantly greater number of African American’s who are at a greater risk for vascular diseases such as high blood pressure, diabetes and high cholesterol than other populations. Though these medical diagnoses may increase the risk of African American’s, being diagnosed with Alzheimer’s diseases it does not include social factors that are germane to the African American population. What medial statistics fail to capture in their hypothesis is the social factors leading to late diagnosis of Alzheimer’s disease such as caregiver support and services, lack of access to medication and services, and the lack of African American’s participation in research. This lack of representation may be associated with less access to medical care. This could lead to late diagnosis when the disease has
progressed to a serious stage. The socioeconomic status as well, that may keep poor African Americans from the best health care. For many older Americans possibly the Tuskegee study still breeds’ distrust for the medical association (Washington, 2006).

Purpose of the Study

The purpose of the study was to explain whether clients with Alzheimer’s disease in the African American population had a higher incidence of the diagnosis due to social factors. The study was designed to explain social factors leading to the diagnosis of Alzheimer’s disease in the African American population in five areas that included the socio-economic status, participation in research, caregiver knowledge and support, access to health care/medication and caregiver stressors. The participants of the study were the caregivers of clients diagnosed with Alzheimer disease.

Research Questions

The research questions of the study were as follows:

1. Is there a relationship between socio-economic status and the diagnosis of Alzheimer’s disease?

2. Is there a relationship between African American participation in research and lack of trust in the medical/research field?

3. Is there a relationship between institutionalization of the client with Alzheimer disease and caregiver knowledge and support?

4. Is there a relationship between the late diagnosis of Alzheimer disease in the African American population and the access to health care/medication?
5. Is there a significant relationship between caregiver stressors and caring for the Alzheimer relative?

Hypotheses

The null hypotheses for the study were as follows:

1. There is no statistically significant relationship between low socio-economic status in the African American population and the diagnosis of Alzheimer’s disease.

2. There is no evidence of a relationship between African American participants in research and lack of trust in the medical/research field.

3. There is no relationship between institutionalization of the client with Alzheimer disease and the caregiver knowledge and support.

4. There is no statistically significant relationship between the late diagnosis of Alzheimer’s disease in the African American population and the access to health care/medication.

5. There is no statistically significant relationship between caregiver stressors and caring for the Alzheimer diseases relative.

Significance of the Study

With the disproportionately higher incidents of Alzheimer’s disease among African Americans, it is imperative that studies conducted include African Americans in research, and focus on the influence of social factors contributing to the higher incidence of this diagnosis. Historically, members of minority populations have been underrepresented in clinical trials. There are many difficulties associated with
enrollment of minority individuals in research studies and clinical trials. Cultural and language barriers must be overcome, and ways to inform individuals of the studies and trials available and their potential benefits for improvements in health must be found (Manly, 2005).

African Americans represent 12.4% of the U.S. population with 8.6% over the age of sixty, while Caucasians represent 73.9% of the population with 84.3% over the age of sixty. The African American represents a small portion of the U.S. population but has a higher incidence of Alzheimer disease diagnosis. Between 1946 and 1964, 76.2 million babies were born and were called the “Baby Boomers.” This population is quickly becoming the generation that will inherit the diagnosis of Alzheimer’s disease (U.S. Census Bureau, 2000).

This study purports to shed some light on social factors leading to the disproportionately higher incidence of Alzheimer disease in the African American population. It is therefore of great significance to demonstrate with these data whether social factors influence the disproportionately higher incidence of Alzheimer disease in the African American population.
CHAPTER II  
REVIEW OF THE LITERATURE

The purpose of presenting this review of the literature was to lay a scholarly foundation in order to establish the need for this study. This chapter is a review of the current literature on the recent efforts to improve culturally appropriate health care delivery to minority populations diagnosed with Alzheimer’s disease. The review covers the development prevention and intervention for healthy aging that is appropriate for the African American population.

Historical Review of Alzheimer’s Disease

The study of Alzheimer’s began in 1907 in Germany when the Jewish population began to have difficulty with recall and inability to maintain life skills. Today the spread of this disease has effected all populations. Few well-conducted studies have been utilized on the differences among population groups. The general studies have concluded African Americans and Hispanics have a higher risk than Caucasians for the diagnosis. In similar research it was noted that Alzheimer’s disease occurs less frequently in Native American Crees and Cherokees and Asians than in the general American population (NIA 2007).

There are myriads of literature regarding Alzheimer’s disease, treatment and causes. Some consider Alzheimer’s to be a natural part of the aging process. Other
theorists speculate on five areas that warrant further medical research. The Chemical Theory, the Toxic Chemical Excess, the Auto-immune, Slow Virus and the Blood Vessel Theories were all a part of earlier research studies (Carson & Arnold, 1999).

The Chemical Theory of neurotransmitters focuses on the diminishing of these transmitters in the brain and is associated with the diagnosis of Alzheimer’s. It was noted that decreases in functional abilities were related to the decrease in neurotransmitters. These transmitters did not relay information to organs and body parts of the patient in their environment, in order to obtain appropriate functioning or response from the patient (Carson & Arnold, 1999).

The Toxic Chemical Excess Theory has as its’ focus large deposits of aluminum being found on the autopsied brains of patients diagnosed with Alzheimer’s. This excess of aluminum interrupts the flow of transmitters to assist with the well being of the patient and decreases the functioning of the patients’ ability by ultimately poisoning the brain. This theory was one of the first theories used in the diagnosis of Alzheimer’s disease in Germany, by Alois Alzheimer. Little was known in 1907 of the role that the immune system would play in the diagnosis of Alzheimer’s (Carson & Arnold, 1999).

The Autoimmune Theory focuses on the immune system that serves to protect the body from harmful invaders. The system turns on itself and begins to attack its’ own tissues, and then produces antibodies that attacks its’ own cells. This theory is not considered a virus but decreases brain cells as the antibodies destroy brain tissue. The Slow Virus theory has been identified an associated with human virus.

The Slow Virus Theory is a slow-acting virus that has been identified in brain disorders similar to Alzheimer’s (i.e. Parkinson’s). This virus is found in spinal fluids of
those living, and allows for medicinal treatments to decease the signs and symptoms of the disease process. The last two theories, the Genetic and the Blood Vessel theory are more aligned with social and cultural factors affecting various populations (Carson & Arnold, 1999).

The Blood Vessel theory has as its’ focus the blood supply to the brain. The three most common vascular diseases to affect brain activity are hypertension, high cholesterol and diabetes I. These three diagnoses are highest among the African American and Hispanic populations; which predisposes these populations to the diagnosis of Alzheimer’s at a higher incidence than other populations. Along with this theory is the Genetic theory which links diagnosis to inherited traits.

The Genetic theory is associated with the production of apolipoprotein. This theory is associated with a mutation on chromosome 14, which accounts for 10% of the Alzheimer’s cases. Mutations on chromosomes 1 and 21 are linked to late-onset of Alzheimer’s. These chromosomal studies are not significant for African Americans. These chromosome mutations are significant genetic studies applicable to Caucasians, and yet the diagnosis of Alzheimer’s is more prevalent in the African American community (Carson & Arnold, 1999).

Genetic studies applicable to African Americans have as their primary focus genetic links the most commonly found diseases in the African American population are high cholesterol, hypertension and diabetes. With the research focus of African Americans being that of genetic predisposition many social concerns warrant a different approach to the higher incidence of this disease among African Americans.
National Policies on Alzheimer’s Disease

In 1965 the Older Americans Act, Medicare and the enactment of SSI, afforded major medical services for the older population. A huge portion of the federal budget was allocated to older persons, including the 29.4% of the 1990 federal budget ($341.4 billion) consumed by two programs, Medicare and Social Security. The elderly still had problems associated with the consumer fees attached with the use of Medicare. The elderly were to pay 50% of their cost for services. As a result many older citizens divested their savings to obtain funds from the means-tested Medicaid program. Many older persons and their families were heavily burdened in 1992 when Alzheimer’s disease became the fourth greatest killer of older persons (Jansson, 1997).

Alzheimer’s disease and related dementias present enormous demographic and financial challenges to society. Today, an estimated 4.5 million Americans, more than one in 10 persons over age 65 and nearly half of those over 85, have Alzheimer’s disease. In the midst of a growing budget deficit, the federal government has decreased its commitment to biomedical research funding and programs that support individuals with Alzheimer’s disease and now their caregivers are in jeopardy. Alzheimer’s disease is just not another item in the budget; …it is a national crisis in the making.” Because age is a known risk for Alzheimer’s disease, the demographics of our aging society demonstrates that decreasing funding for research and care in an attempt to reduce the deficits is penny-wise and pound-foolish” (National Public Policy, 2006).

The fiscal year 2006 budget approved by Congress reduced funding for biomedical research for the first time in more than 30 years and the third time in the history of the Alzheimer’s Association. Funding for Alzheimer’s disease research
declined by approximately $4 million dollars, an amount that may not appear alarming until it is considered alongside the projected growth in health care spending that Alzheimer’s disease will cause if it is not brought under control. The Deficit Reduction Act passed by Congress in 2005 places additional financial restrictions on who can qualify for Medicaid nursing home coverage, increasing the already heavy burden on family caregivers. In February 2006, President Bush released his 2007 budget proposal which further reduced the budget for Alzheimer’s disease research, eliminated all of the federally funded Alzheimer’s disease care programs and cut dollars for other programs that provided services to the frail elderly and their caregivers (National Public Policy, 2006).

Medicare Part A pays for hospital care, home healthcare, and hospice. Part B of Medicare pays for doctors’ visits, out patient hospital care and other medial services requiring hospitalization. Part B of Medicare must be purchased for a monthly premium of $50.00. Medicare does not pay for prescription drugs for Alzheimer’s, adult day care, board at assisted living facilities, or custodial care in nursing homes (U. S. Department of Health, 2003).

Contemporary Review

Recent empirical studies on Alzheimer’s disease have focused on aspects of the disease process in relationship to physiological aspects of the disease process. Environmental and social factors such as: socio-economic status, African American’s participation in research, caregiver knowledge, support and access to health care and medications and caregiver stressors may lend credence to the body of knowledge
available. Social factors affecting the diagnosis of Alzheimer’s disease in the African American population along with the rising numbers of Baby Boomers if not researched to the extent deemed necessary to decrease the highest diagnosis of Alzheimer’s disease in the African American population may lead to astronomical cost to society (Manly, 2004).

Socioeconomic Status

Although numerous studies have documented the importance of socio-economic status (SES) to a variety of health outcomes, comprehensive measures of SES are not routinely collected in the Unites States. In addition, most SES data that are obtained are not reported. This data deficiency was highlighted at a recent federally-sponsored health conference on SES and has been noted by the National Committee on Vital Statistics. In both cases, the recommendation was for regular collection of SES data and for the use of SES variables in studies of differential health outcomes (Daly, et al, 2000).

Despite growing awareness of the need for regular collection of SES measures, there remains little agreement on which SES measures should be gathered. One problem is that numerous measures of SES have been shown to affect health outcomes, e.g., occupation, education, and household income. Researchers have shown that these measures are not interchangeable, and that the impact of any particular SES measure on health varies across social groups, gender and age. Various measures of SES may summarize different components of overall health risk. A systematic evaluation of the explanatory power of various SES measure is required before an effective set of optimal indicators can be created (Daly, et al, 2000).
Years of completed schooling are reported with reasonable ease and reliability and are a meaningful indicator of SES for most adults. Occupation has also been an indicator of SES and is useful for persons who have had labor force experience. Income has been more widely used as a measure of SES in studies in the United States than elsewhere. The income reflects the value of human wealth or capital. Several studies in both the United States and the United Kingdom found that indicators of wealth are related to health, independent of the more traditional indicators of SES (Daly, et al, 2000).

According to Wilson et al in 2005 early life SES to incident of Alzheimer’s disease, level of cognition and rate of cognitive decline in old age was examined. For up to ten years, 859 older catholic clergy members without dementia at baseline completed annual clinical evaluations as a part of the Religious Orders Study. The evaluations included clinical classification of Alzheimer’s disease and detailed cognitive testing. At baseline, indicators of early life household SES level (e.g. parental education) and the county of birth were ascertained. SES features of the birth county (e.g. literacy rate) were estimated with data from the 1920 US census. Composite measures of early life household and community SES level were developed. In analyses that controlled for age, sex, education, higher household and community, SES levels in early life were associated with higher level of cognition in late life, but not with risk of Alzheimer’s disease or rate of cognitive decline. The results suggest that early life SES level is related to level of cognition in late life but not to rate of cognitive decline or risk of Alzheimer’s disease (Wilson, 2005).

Another study assessed the relationship of three measures of SES status, education, occupational prestige, and income, to risk of incident clinically diagnosed
Alzheimer’s disease. This cohort study was performed over a period of four years in Boston Mass. A stratified random sample of community residents, sixty-five years or older and who were free of Alzheimer’s disease at baseline were surveyed. Clinical diagnosis of probable Alzheimer’s disease according to standard criteria, using structured uniformed evaluation was utilized. The results of the study using logistic regression revealed that fewer years of formal schooling, lower income, and lower occupational status each predicted risk of incident of Alzheimer’s disease. The risk of Alzheimer’s disease decreased approximately 17% for each year of education. The analysis using all three measures showed that the effect of education on risk for disease remained approximately the same, but the effect of the other two measures, occupational prestige and income, were somewhat less and did not attain formal statistical significance, compared with separate analysis of each measure. The study concluded that markers of lower SES predict risk of developing incident of Alzheimer’s disease. The mechanism of the relationship was uncertain, but the possibility that it reflects unidentified and potentially reversible risk factors for the Alzheimer’s disease deserves more consideration (Evans, 2007).

Karp, et al., (2004) evaluated whether there was an association between low educational levels and increased risk of Alzheimer’s disease and dementia. They assessed occupational-based SES. A cohort of 931 non-demented subjects, aged seventy-five years or older, was studied for three years between 1997 and 1993. A total of 101 incident cases of dementia, 76 involving Alzheimer’s disease were detected. Less educated subjects had an adjusted relative risk of developing Alzheimer’s disease of 3.4 (05% confidence interval: 2.0, 6.0), and subjects with lower SES had an adjusted rate
relative risk of 1.6 (95% confidence interval: 1.0, 2.5). When both education and SES were introduced into the same model, only education remained significantly associated with Alzheimer’s disease. The combination of low education with high or low SES were associated with similar increased risks of Alzheimer’s disease, but well educated subjects with low SES were not as high risk. Low SES at 20 years of age, even when SES was high at age 40 or 60 years, was associated with increased risk; however, this increase disappeared when education was entered into the model. This study concluded that the association between low education and increased Alzheimer’s disease risk was not mediated by adult SES or SES mobility. This study suggested that early life factors may be relevant (Karp, et al., 2004).

Participation in Research

Flawed medical experimentation with African American’s since the time of the plantation has played a pivotal role in the lack of participation in research. Historically African American’s have been subjected to exploitative, abusive and involuntary experimentation at a rate far higher than other ethnic groups. This is neither a baseless fear of harm nor a fear of imaginary harm. The label of being paranoid is attached when African American’s refuse to participate in research (Washington, 2006).

Those who investigate the role of medical ethics and policy are attempting to analyze the aversion of African Americans to participate in research without understanding the history of the aversion. Researchers often focus on the Tuskegee Syphilis study without the many other experiments with African American’s. Some of the distrust dates back to the antebellum days of blood letting, the display of slave bodies
by physicians, experimentation in the use of radiology treatments, and the Norplant in
low economically disadvantaged communities. Researchers have exploited the African
American population. This was the norm for much of our nation’s history, when African
Americans were commonly regarded as fit subjects for nonconsensual, non-therapeutic
research (Washington, 2006).

Trust is an important element of communication and many ethnic elders lack trust
in health care professionals as well as the American health system. One of the most
famous examples of why trust is lacking, is the ethnic elders involved in the Tuskegee
study. The United States Public Health service tracked 399 African American men with
untreated syphilis from 1932-1972. The research participants were untreated despite the
discovery of penicillin in the 1940’s. The research participants were not treated with the
penicillin because the purpose of the study was to chart the natural history of syphilis.
This violation of trust could very well lend credence to the limited numbers of African
Americans in research. As the older population becomes more ethnically diverse, health
professionals will need to become more knowledgeable about the cultural backgrounds of
their clients to obtain subjects to participate Alzheimer’s research (Washington, 2006).

Green, et al., examined participation of adults (18 and older) who lived in
Jefferson County, Alabama, to determine the effects of the Tuskegee Syphilis Study on
African Americans’ willingness to participate in health studies. They found that African
Americans indicated less interest than white Americans in participating in health research
or health promotion activities because of the Tuskegee Syphilis experiment (22% vs.
10%), and African American males reported less interest than white males (27% vs.
11%). They concluded that the historical legacy of poor treatment by physicians had a
major implication on researchers’ ability to recruit research participants, especially African Americans (Green, et al., 1997).

Research pioneered by Shavers, et al., focused on the relative absence of minorities in medical research. The relative absence of racial/minorities among medical research subjects received considerable attention because of recent government mandates for their inclusion in all human subject research. They examined racial differences in the prevalence of socio-cultural barriers as a possible explanation for the underrepresentation of African Americans in research (Shavers, et al., 2002).

During 1998-1999, a total of 198 residents of the Detroit Primary Metropolitan Area participated in a survey that examined impediments to participation in research studies. Chi square tests and logistic regression analyses were used to examine the association between race, issues related to trust of medical researchers, and the willingness to participate in studies. Results indicated that African Americans and whites differ in their willingness to participate in research. Racial differences in the willingness to participate in research were primarily due to the lower level of trust of the medical research among African Americans. African Americans were also somewhat less willing to participate if they attributed high importance to the race of the doctor when seeking routine medical care, believed that minorities bear most of the risks of research, and if their knowledge of the Tuskegee Study resulted in less trust in medical researchers (Shavers, et al., 2002).

Participation of African Americans in research is required in order to answer many research questions correctly. It is important that normative studies include complete and accurate measurement of factors that not only underlie cognitive test
performance but are also the variables for which race/ethnicity serves as proxy. Jennifer Manly (2004) informs researchers "...in much research we are using measures that were originally developed by and for well educated Caucasians. Even the largest and most comprehensive normative sample would not improve the questionable construct validity of cognitive measures when used among African Americans." Despite recent and projected growth in racial and ethnic diversity within the population of the United States, few neuropsychological measures have been properly validated for use among ethnic minorities (Manly, 2004).

Caregiver Knowledge and Support

With the current aging of the population in the U.S. the number of those with Alzheimer disease is increasing rapidly, and along with it, the impact of the disease on society. The risk of Alzheimer's disease is four times higher for African Americans, and twice as high for Hispanics as for white Euro-Americans. Research is expanding both to prevent or delay the disease and to assist the caregiver in maintaining the patient in the home. More than 75% of those diagnosed with Alzheimer's disease are cared for in the home (Stanton, 2001).

Estimates of the number of frail older people living in the community who need care giving assistance with activities of daily living (ADL's), such as shopping and bathing are estimated to range from 1.8 million to 7.6 million older people in the United States. It has also been estimated that there are 13.3 million informal caregivers of disabled older adults in the United States. Most informal caregivers are spouses and
adult children, but other family members, friends, and neighbors also provide care (American Association of Retired Persons, 1999).

When a loved one begins to develop the early signs of Alzheimer's disease it is alarming to them and the caregiver. Alzheimer’s disease attacks the central organic core of the being, the brain. The changes and destruction to the brain fundamentally changes who they are and how the caregiver interacts with them. Personality changes and increasing dependence on family members, the gradual but increasing memory loss and changes in relationship dynamics are difficult to deal with no matter how strong the relationship was prior to the onset of Alzheimer’s disease. Even though a caregiver can understand the processes that are occurring, matching those changes and responding appropriately to the person with Alzheimer’s disease requires not only patience, but skills, knowledge and support (Alzheimer’s News Letter, 2007).

Previous research focused on the association of knowledge level of the caregiver regarding dementia Alzheimer’s disease, and institutionalization of a family member. Several factors influenced the decision. The study compared predictors of desire to institutionalize versus those who did not. Seventy-two caregivers completed the Desire to Institutionalize Scale (DIS) and several psychosocial measures, involving burden, dementia knowledge, self-efficacy, depression, health, and social support. The groups were then divided into “no desire for institutionalization” (No DI) and “desire for institutionalization” (DI). The results were that the DI caregivers had significantly higher burden, greater dementia knowledge, more family dysfunction, and decrease family support compared with No DI. Dementia knowledge was associated with higher desire to
institutionalize, suggesting that the knowledge and educational programs alone may not be helpful to delay institutionalization (Spitznagel, 2006).

Another study researched the effects of knowledge of Alzheimer’s disease with caregivers and the consequences of such knowledge. The study measured two items the amount of knowledge that the caregivers possessed. The second explored possible correlates of knowledge of Alzheimer’s disease. One hundred and one caregivers participated in the study. Participants’ were given a 30 item test which consisted of 15 multiple choice items and 15 true false items. The caregivers answered an average of 46 percent of the items correctly. Female caregivers answered more questions correctly compared to male caregivers. It appears that education about Alzheimer’s disease is needed, especially in caregivers of patients diagnosed with possible or probable Alzheimer’s (Hicks, 2004).

Family caregivers of older adults are faced with a variety of emotional and behavioral difficulties, such as dealing with persistent, repetitive questions, managing agitation and depression and monitoring hygiene. Although professional and governmental organizations have called for the creation of community-based education and support programs, most caregivers continue to receive little or no formal instruction in responding to these challenges (Hicks, 2004).

In yet another study related to lack of social support and stressors on the caregiver, Haley, et al., found that family caregivers of patients with Alzheimer’s disease commonly have high levels of psychological distress. African American caregivers often report less depression than white caregivers, but the process underlying this difference was poorly understood. With the use of a stress model, 123 white and 74 African
American family caregivers of patient with Alzheimer’s disease and other progressive dementias were studied. African American caregivers appraised patient problems as less stressful and reported higher self-efficacy in managing caregiver problems and less depression than did white caregivers. White and African Americans’ also differed significantly in coping responses but not in social support. Caregiver responses and race did not affect wellbeing through direct paths, but they were mediated by effects for appraisal, social support, activity, and coping (Haley, et al., 1996).

In a qualitative analysis, 51 participants responded to open-ended questions regarding the experiences of being family caregivers for a loved one affected with Alzheimer’s disease. The participants’ had been in the caregiver role for more than eight years. Results indicated that they were adapting successfully or unsuccessfully to the caregiver role experiencing initial caregiver burden finding relief in social support when available, and long term positive change. Memories and feelings were strong about individuals and institutions that had been helpful or indifferent many years earlier as the caregiver struggled to cope with their unplanned predicament (Karlin, et al., 2001).

In a telephone interview conducted in 2007, research documented notable differences in knowledge, awareness, and cultural beliefs about Alzheimer’s disease among groups defined by race and ethnicity. The study was conducted to assess racial differences in knowledge and attitudes about Alzheimer’s disease among a national sample of adults. Data from 1176 adults aged 35 years and over (48.6% white, 25.7% African American, and 25.8% Hispanic) were obtained, via telephone interview in this study. Although some notable group differences defined by race/ethnicity were observed, more similarities in patterns of responses were discovered than expected.
African American and Hispanic respondents were significantly more likely to believe that Alzheimer’s disease is a normal part of aging, but were more optimistic about future advances in research than white participants. Compared with white and African American respondents, Hispanics were more likely to report feeling well prepared for handling a diagnosis of Alzheimer’s disease in a family member. Overall, the results suggest that misconceptions about Alzheimer’s disease remain among large segments of the population that Alzheimer’s disease remains a source of significant concern, and that continued efforts are need to educate caregivers and the public about this disease process (Connell, et al., 2007).

**Access to Health Care and Medications**

Early identification of Alzheimer’s disease provides opportunities to initiate treatment that may slow a patient’s disease progression until the family member can connect and access health care providers and supportive services. As the need for services for people with Alzheimer’s disease grows, the benefits of early intervention becomes clear, it has become important to understand what factors may improve access to services for people with early-stage dementia (Pratt, 2005).

In a study, 30 key professionals were interviewed about access to services for people with early stage Alzheimer’s disease in order to explore how different models of access were reflected in their own understanding. When articulating the reasons they thought needs were unmet, participants focused on the impact of the framework within which services are delivered. The findings highlight the importance of considering relationships and socio-contextual factors, such as the impact of the framework of service
delivery, when attempting to understand variations in access to services. In order to improve access to services, it will be necessary to move beyond addressing individual factors relating to access, and to consider the impact of the framework for service delivery and the relationships that influence contact with services (Pratt, Claire & Kirchner, 2006).

A cohort study of African American patients and their caregivers presenting at a suburban memory assessment clinic and were diagnosed with probable Alzheimer’s disease were interviewed. Data was collected about the delay from noticing first Alzheimer’s disease signs until recognition that a problem existed and delay from problem recognition until first physician consult. Median delays in caregivers’ recognizing a problem and in consulting a physician were as long as seven years. Lack of physician contact is likely to be widespread in families caring for African American’s with Alzheimer’s disease. Intensive efforts are needed to connect African American families with physicians and to achieve more timely diagnosis of Alzheimer’s disease to enable families to understand the illness, plan for patient safety, make long term care plans and gain access to health care services (Clark, et al., 2005).

Although there is no cure for Alzheimer’s disease there are a number of drugs that are available globally that can help slow cognitive deterioration. The aim of Alzheimer’s disease medications is to improve cognitive ability to think, perceive, judge and recognize (Alzheimer’s Fact Sheet, 2007).

President Clinton underscored the need for a Medicare Prescription Drug Benefit plan in July 2000 in light of research prevention of Alzheimer’s disease. He stressed “…there must be a commitment to pursuing research possibilities equaled by our efforts
to provide an affordable, meaningful, prescription drug benefit option for all Medicare beneficiaries in order to obtain present medications for Alzheimer’s disease” (Whitehouse Backgrounder, 2000).

Most low-income elderly and disabled persons lack coverage for important medications, resulting in unavoidable deterioration of health among those with chronic illnesses and use of expensive institutional services. Rapidly escalating drug cost, more restrictive drug coverage policies, and a dramatic increase in the population of elderly persons will exacerbate these problems. With the current budget surplus, as well as bipartisan concern about health care needs and public concern about drug costs and coverage, the Harvard Medical School in Boston, MA feels that it is time to act responsibly and aggressively. The recommendation is that a national replication of the best features of a state pharmacy assistance program in a federal-state insurance program for low-income Medicare enrollees, either alone or in combination, with expanded Medicare coverage. Such a program would reduce the current inequitable situation in which the most vulnerable patients have the least access to medications, with serious medical and economic consequences (Soumerai & Ross-Degnan, 1999).

There are five prescription drugs currently approved by the U.S. Food and Drug Administration to treat people with Alzheimer’s disease. Treating the symptoms Alzheimer’s disease can provide patients with comfort, dignity and independence for a longer period of time and can encourage and assist their caregiver as well. Mild to Moderate Alzheimer’s disease is treated with Reminyl, Exelon, Aricept, and Cognex. To treat Moderate to Severe Alzheimer’s disease, Namenda is used and may help the patient maintain the ability to go to the bathroom independently for several more months,
a benefit for both patient and caregiver (Alzheimer’s Disease Medication Fact Sheet, 2007).

The cost for Alzheimer’s disease medication averages about $5.00 per day. Listed below are the average costs to the pharmacy. Aricept $142.00 per month, Exelon $134.00 per month and Reminyl $130.00 per month is the estimated average cost to the pharmacy prior to prescription filling fee. Namenda and Cognex bear a heavier monthly cost due to the new emergence of these drugs, which may be found in the neighborhood of $175-$250 per month prior to prescription filling fee, with no generics currently available for any of the medications listed above (Delagarza, 2003).

A cross sectional survey, of a national sample of 4050 adults aged 50 years or older who use prescription medications for at least five chronic health conditions were surveyed. The primary outcome measure was patient report of being asked by a doctor or nurse in the prior 12 months whether the patient could afford the prescribed medications. The measures of prescription cost burden were cost-related underuse of medications, cutting back on other necessities to pay for medications, and worries about medication costs. Adjustment was made for patient income, education, race/ethnicity, age, sex, and health status, number of prescribed medications, pharmacy benefits, and frequency of outpatient visits, having a regular health care provider and sampling weights. In the weighed analysis, 16% of the respondents reported that they had been asked about potential problems paying for prescribed medications. Only 24% of the 1499 respondents who reported one or more burdens from out-of-pocket medication costs reported being asked this question. After an adjustment was made for potential confounders, patients who had cut back on medications use or other necessities to cover
payments were no more likely than other patients to be asked about the ability to pay for prescription medications. Concerns about medication, being a racial/ethnic minority, taking seven or more prescription medications, and having no prescription coverage were independently associated with a greater likelihood of being asked about possible problems with prescriptions (Heisler, et al., 2003).

It is widely recognized that the ability to pay effects physicians care, hospitalizations and medications. It has been hypothesized that persons with higher incomes and better health insurance coverage are more likely to medicate common health problems than those with lower incomes and less comprehensive coverage. A landmark study in 1998 surveyed 4,066 elderly Pennsylvania Medicare beneficiaries. These beneficiaries were asked to complete a mail survey on health insurance, income and medicine use for 23 common health problems. The relationship between ability to pay and medication decisions was analyzed using Poisson logistic regression models with covariates for socio-demographic characteristics and health status. The results showed a strong and consistent relationship in the hypothesized direction.

Other things being equal, elderly persons with Medicare supplementation were between 6% and 17% more likely to use prescription medicine to treat their health problems than were persons with Medicare coverage alone. The elderly with annual incomes greater than $18,000 were 18% more likely to treat problems with prescription drugs than were persons with an annual income less than $6,000. This research concludes that economic factors appeared to play an important role in medication decisions by the elderly. The magnitude of the impact was sufficiently high so that it could have major negative consequences on the health of elderly persons who are poor
and lack drug coverage (Stuart & Grana, 1998). Though President Clinton understood the need for Prescription Drug Benefit plan, healthcare utilization and access must become more culturally sensitive in order to increase utilization of services by African Americans.

Research by George Rust (2004) utilized secondary data of 3,462 records of African American respondents to the 1999 Medical Expenditure Survey Household file. They concluded that there was a significant variation in the number of office visits, outpatient clinic visits, hospital discharges, and the number of days hospitalized and prescriptions filled among this population. There were three modifiable factors, poverty, insurance, and lack of a primary care physician as having a striking effect for African American patients. Barriers to utilization of services were noted as availability, accessibility and acceptability.

Availability of services was linked to sometimes not being able to obtain a primary care physician where ethnic elders lived. Even more difficult was specialty care physicians in the areas where many African Americans reside. Accessibility was determined by the African American as available care but the inability to use or access services for a number of reasons measured were: lack of knowledge, distrust of the system, fear of punitive action, inability to deal with bureaucracy, assumptions by providers of lack of motivation or trust and transportation difficulties. Acceptability of the patient was linked as another barrier to access and utilization of services and was based on patients’ satisfaction with having their expectations met. Acceptability was an aspect of access and utilization of services most affected by culture and the interaction between patient and provider performance. Trust needed to be developed between the
provider and patient in order to gain access to services. In order to gain access and utilize services, indigenous networks for education and outreach must be formulated. Utilization of churches, temples, lay leaders and non-professional advocates can be utilized to increase access to medication and services for African Americans with Alzheimer’s disease.

**Caregiver Stressors**

Some five million Americans care for loved ones with Alzheimer’s disease at home, in nursing homes or assisted living facilities. Many caregivers feel isolated from family, friends and their communities. Stress levels of caregivers rise as Alzheimer’s disease symptoms grow and become more severe. Social support is needed to help bear not only the financial burden, but the psychological and social aspects of those diagnosed with Alzheimer’s disease. Improving social support and reducing family conflict to help the caregiver withstand the hardships of care giving requires a multitude of social support systems. To help society and other family members understand the primary caregiver’s needs and how to best become helpful may postpone the institutionalization of patients diagnosed with Alzheimer’s disease (Fisher Center, 2006).

Caregivers who lack sufficient or appropriate social support are often put under heightened stress. Family conflicts, isolation, loneliness further exacerbate the stress of the caregiver. While social support may not affect primary stress caused by Alzheimer’s disease, it can change the caregivers’ response to the illness. Feeling supported by social/community services and family can improve the psychological response to stress and boost the caregivers sense of well being. Caregivers can benefit from formal support by community services such as in home respite or day care programs for the patient, and
support groups in conjunction with the informal support of family and friends (Alzheimer's Caregivers Fact Sheet, 2007).

More than 80% of Alzheimer's caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression. The National Family Caregiver Alliance terms caregiver depression as "...one of today's all-to-silent health crises". The alliance estimates that care giving spouses the ages of 66 to 96 who are experiencing mental or emotional strain have a 63% higher risk of dying than people the same age who are not caregivers (Abel, 2003).

Caregivers often experience feelings of guilt, believing they are not doing enough to help. Spouses and adult children feel grief and loss except for being sudden, it spreads over years. Alzheimer's is a progressively worsening disease, but the rate of progression from mild to advanced stages can vary from three to 20 years. As the disease progresses, the loss of brain function itself will cause death unless the patient has one or more other serious illnesses (Health Link Fact Sheet, 2003).

Financial strain from the disease process brings about problems that can also add to stress and depression. Caregivers will often give up paying jobs for the unpaid job of caring for the family member with Alzheimer's disease. Additional responsibilities are thrust upon them such as overseeing medication régime, taking on power of attorney along with living wills and advance directives that specify whether terminal patients should undergo extreme measures to keep them alive. In the book "The 36 Hour Day, Mace and Rabins made the first reference to caregiver stressors:

As the patient’s illness progresses and the person changes, you may experience the loss of a companion and a relationship that was important to you. You may grieve the way she used to be. We usually think of grief
as an emotional experience that follows death. However, grief is a natural emotional response to loss and so it is a normal experience for people who love a person with a chronic illness (p. 209).

Caregivers of individuals with Alzheimer’s disease are at an increased risk of mental and physical problems as a result of the strain that accompanies this role. Despite clear indications that caregiver grief and feelings of loss are normal, researchers did not begin to address the idea until late 1980’s and mid 1990’s. Two of the earliest researchers on this topic were Wasow and Coons. They indicated that the grief of caregivers of individuals with Alzheimer’s disease often remained undetected by society. Not recognized as normative behavior, grief and loss were combined with feelings of stigma which was often associated with the disease (Wasow & Coons, 1987).

In 1999, Boss coined the term “ambiguous loss” to define grief that has no clear starting point and no clear ending point. This type of grief experienced by Alzheimer’s disease caregivers is ambiguous because the care recipient is still physically present, but cognitively not the same person. Boss argued that the depression commonly noted in caregivers of individuals with Alzheimer’s disease probably has more to do with the ambiguity of their loss than their heavy work load. The feeling of being out of control commonly associated with ambiguous losses can lead to increase family conflict; problematic communication patterns an obsession with the day to day activities of caring for the patient (Boss, 1999).

There is also grief at different stages of the disease. The profound feelings of grief expressed following the diagnosis of Alzheimer’s disease. Grief becomes stronger when the patient no longer recognizes the caregiver which often occurs in the middle
stages of the disease progression. Other researchers suggest that the final stage and the
depth of the patient bring about the strongest display of grief. There are multiple losses
for the caregiver, the loss of the previous relationship, social interaction an support,
health status, resolution of pass issues, activities, previously established social roles,
intimacy and control (Sanders & Adams, 2005).

In another study, grief and depression was examined. A racially diverse sample
of caregivers was drawn from an urban setting on the east coast of the United States.
Results indicated not only that a significant proportion of caregivers experienced high
levels of grief that may place them at risk of other difficulties, but also that grief was a
significant predictor of increased depressive symptoms (Sanders & Adams, 2005).

Another study investigated the predictors of caregiver burden and depression.
The participants were 613 individuals with dementia, living in either the community or
an institution, and their informal caregivers. Structural equation models representing
four alternative pathways from care giving stressors (e.g., functional limitations,
disturbing behaviors, patients’ residence, and assistance given to caregiver) to caregiver
burden and depression was compared. The data provided the best fit to a model whereby
the effects on the caregivers well being are mediated by appraisals of burden. A higher
frequency of disturbing behavior, caring for a community-dwelling patient, and low
informal support were related to higher burden, which in turn led to more depressive
symptomatology. Caregivers of patients exhibiting more disturbing behaviors and
functional limitation received les help from family and friends, whereas those whose care
recipients resided in an institution received more informal support (Clyburn, et al., 2000).
Sleath, et al., examined the relationship between race and psychotropic drug use (antidepressants, anti-anxiety, sedative/hypnotics agents) in informal caregivers with symptoms of depression who provided care for elderly relatives with dementia. Whether racial differences in medication use relate to racial differences on predisposing, enabling, and need factors associated with use of these agents was also examined. There were 2,932 African American and white caregivers of elderly male veterans diagnose with probable Alzheimer’s disease or vascular dementia. Depressive symptoms were measured using a modified version of the Center for Epidemiological Studies Depressive Scale. Antidepressant, anti-anxiety, and sedative/hypnotic agents were indexed using the Veterans Affairs’ medication classification system. Of caregivers with depressive symptoms, 19% used anti-depressants, 23% anti-anxiety agents, and 2% sedative hypnotics. African American caregivers with depressive symptoms were significantly less likely than whites with depressive symptoms to use antidepressants’ and anti-anxiety medications. This study conclude that 81% of caregivers had depressive symptoms and were not taking medication and that African American caregivers were less likely than whites to take antidepressants (Sleath, et al., 2005).

Theoretical Framework

The theoretical framework for this study was based on Systems Theory; a means by which some resolutions to the myriad of problems facing our society and the family may be beneficial. Systems Theory is an approach to human behavior. There are two substantive assumptions in defining Systems Theory: 1) The state or condition of a system, at any one point in time is a function of the interaction between it and the
environment in which it operates; and 2) Change and conflict are always evident in a system (Longres, 1990).

Two basic components of Systems Theory are elements and processes. Elements are measurable things that can be linked together. They are called objects, event, patterns, or structures. Processes change elements from one form to another. They are also called activities, relations, or functions. The family system and the organizations needed to serve the myriad of problems facing the Alzheimer client, caregiver and society are part of complex social systems meeting the needs and the events that take place in the progression of Alzheimer disease (Pavard & Dugdale, 2004).

When utilizing Systems Theory for this dissertation the family is a smaller system with the involvement of multiple other larger systems of service. The communications between all systems must be open for services to meet the needs of the Alzheimer’s client and caregiver. Systems are most productive when conflict arises and alternatives are established. When the diagnosis of Alzheimer’s disease is established communication between all systems of services are needed. If systems are not in place to meet the needs of the client and caregiver then communication is developed between systems until a resolution can take place. The family as well as the larger systems must address the needs of the Alzheimer’s epidemic among African American. These needs are met by larger systems such as Federal and state funding for respite care, prescriptions, nursing homes, in home health care and assisted living (Gurman & Kniskern, 1979).

The impact of Alzheimer disease on the family and society are astronomical. African Americans are being diagnosed disproportionately higher than any other ethnicity. Integration of available resources and available services must be tapped into.
Systems theory will serve as an intervention, enabling social workers to advocate on the grounds of empirical research in the area of social dynamics; as opposed to multiple studies whose focus is on the physiological aspects (Bruton, 2007).

A secondary theoretical approach was incorporated into this paper. Behavior Cognitive Theory (BCT) is based on the concept that there is a reciprocal interaction between what we think, how we feel, and how we behave. This theory serves as an intervention for the caregiver. In BCT the problems are specified (i.e. aging, dementia, inability of the client to care for self, housing medications, access to health care, lack of participation in research etc). The challenge at hand is identified as the focus of change, which may be collectively or one situation at a time. The behaviors or attitudes that may be changed, altered or suppressed are identified by the caregiver the Alzheimer’s client and society. The system that is most likely to assist with the solutions of the problem is identified and ways are established with the help of social organizations to meet those needs (Cooper & Leer, 2005).

The caregiver is then requested to obtain knowledge regarding available resources to assist in the care, both psychologically, emotionally and financially of the client. The caregiver may also began to set goals as specified in CBT secondary to the progressive nature of the disease and the need for hospice, respite care and possibly the need for placement issues associated with the final stage. The client may not be able to remain in the home and the caregiver may be requested to do homework to practice future skills that may be needed in order to identify future services needed as the disease process continues (Corcoran, 2006).
CHAPTER III

METHODOLOGY

Chapter III presents the methods and procedures that were used in conducting the study. The following are described: research design; description of the site; sample and population; instrumentation; treatment of data; and limitations of the study.

Research Design

A descriptive and explanatory research design was employed in this study. The study was designed to ascertain data in order to describe and explain the higher diagnosis of Alzheimer’s disease in the African American population.

The descriptive and explanatory research design allowed for the descriptive analysis of the demographic characteristics of the respondents. Also, this research design facilitated the explanation of the statistical relationship between diagnosis of Alzheimer’s disease among African Americans and their socio-economic status, participation in research, caregiver knowledge and support systems, access to health care and medication and caregiver stressors for family members with the diagnosis of Alzheimer’s.

Description of the Site

The research study was conducted in Atlanta Georgia. Atlanta is the largest urban metropolitan city in the state of Georgia. The surveys were administered at Sadie G.
Mayes Nursing Home, Staff Builders Home Health Care and Ashton Hall Assisted Living Facilities. The assisted living facilities were selected due to the selection of both male and female clients and involvement in patients care. Caregivers that were not present during the session were interviewed by phone.

Sample Population

The target population for the research was composed of primary caregivers for patients diagnosed with Alzheimer’s disease. One hundred (100) respondents were selected utilizing non-probability convenience sampling from among the participants at the selected sites for the study.

Instrumentation

The research study employed a survey questionnaire entitled Alzheimer’s Awareness. The survey questionnaire consisted of 6 sections with a total of 30 questions. The questions were answered by the caregiver or family member of the client. The first section solicited demographic information about the characteristics of the patient or relative of the respondent.

Section I consisted of three questions numbers 1-3 as independent variables of the study. The questions in Section I were related to gender, age and ethnicity.

Sections II of the survey consisted of three questions numbers 4-6, and were independent variables to determine socio-economic status. The questions in Section II were income, occupation and educational level. Section I and II provided information for the presentation of a demographic profile on the respondents of the research study as well as serving as independent variables.
Section III of the survey consisted of four (4) questions numbered 7-10. The four (4) questions were related to research participation in Alzheimer’s disease studies. Items were responded to on a four point continuum Likert Scale. The scale was as follows: 1 = Disagree; 2 = Somewhat Disagree; 3 = Agree; 4 = Strongly Agree.

Section IV consisted of eight (8) questions numbers 11-18 related to caregiver knowledge using a “yes” “no” response. Participants’ answered questions related to their knowledge of Alzheimer’s disease and these responses served as independent variables.

Section V consisted of five (5) questions numbers 20-24 and were related to access to health care and medications. A “yes” “no” response was measured and questions served as independent variables. Two questions are open ended with suggested responses.

Section VI consisted of six (6) questions numbers 25-30 using a four point Likert scale to measure stressors related to care giving of an Alzheimer’s disease patient. The scale was as follows: 1 = Disagree; 2 = Somewhat Agree; 3 = Agree; 4 = Strongly Agree.

Treatment of Data

Statistical treatment of the data employed descriptive statistics, which include measures of central tendency, frequency distribution, and cross tabulation. The test statistics for the study were phi and chi square.

Frequency distribution was used to analyze each of the variables of the study in order to summarize the basic measurements. A frequency distribution of independent variables was used to develop a demographic profile and to gain insights about the respondents of the study.
delivery, when attempting to understand variations in access to services. In order to
improve access to services, it will be necessary to move beyond addressing individual
factors relating to access, and to consider the impact of the framework for service
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a benefit for both patient and caregiver (Alzheimer's Disease Medication Fact Sheet, 2007).

The cost for Alzheimer's disease medication averages about $5.00 per day. Listed below are the average costs to the pharmacy. Aricept $142.00 per month, Exelon $134.00 per month and Reminyl $130.00 per month is the estimated average cost to the pharmacy prior to prescription filling fee. Namenda and Cognex bear a heavier monthly cost due to the new emergence of these drugs, which may be found in the neighborhood of $175-$250 per month prior to prescription filling fee, with no generics currently available for any of the medications listed above (Delagarza, 2003).

A cross sectional survey, of a national sample of 4050 adults aged 50 years or older who use prescription medications for at least five chronic health conditions were surveyed. The primary outcome measure was patient report of being asked by a doctor or nurse in the prior 12 months whether the patient could afford the prescribed medications. The measures of prescription cost burden were cost-related underuse of medications, cutting back on other necessities to pay for medications, and worries about medication costs. Adjustment was made for patient income, education, race/ethnicity, age, sex, and health status, number of prescribed medications, pharmacy benefits, and frequency of out patient visits, having a regular health care provider and sampling weights. In the weighed analysis, 16% of the respondents reported that they had been asked about potential problems paying for prescribed medications. Only 24% of the 1499 respondents who reported one or more burdens from out-of-pocket medication costs reported being asked this question. After an adjustment was made for potential cofounders, patients who had cut back on medications use or other necessities to cover
payments were no more likely than other patients to be asked about the ability to pay for prescription medications. Concerns about medication, being a racial/ethnic minority, taking seven or more prescription medications, and having no prescription coverage were independently associated with a greater likelihood of being asked about possible problems with prescriptions (Heisler, et al., 2003).

It is widely recognized that the ability to pay effects physicians care, hospitalizations and medications. It has been hypothesized that persons with higher incomes and better health insurance coverage are more likely to medicate common health problems than those with lower incomes and less comprehensive coverage. A landmark study in 1998 surveyed 4,066 elderly Pennsylvania Medicare beneficiaries. These beneficiaries were asked to complete a mail survey on health insurance, income and medicine use for 23 common health problems. The relationship between ability to pay and medication decisions was analyzed using Poisson logistic regression models with covariates for socio-demographic characteristics and health status. The results showed a strong and consistent relationship in the hypothesized direction.

Other things being equal, elderly persons with Medicare supplementation were between 6% and 17% more likely to use prescription medicine to treat their health problems than were persons with Medicare coverage alone. The elderly with annual incomes greater than $18,000 were 18% more likely to treat problems with prescription drugs than were persons with an annual income less than $6,000. This research concludes that economic factors appeared to play an important role in medication decisions by the elderly. The magnitude of the impact was sufficiently high so that it could have major negative consequences on the health of elderly persons who are poor
and lack drug coverage (Stuart & Grana, 1998). Though President Clinton understood the need for Prescription Drug Benefit plan, healthcare utilization and access must become more culturally sensitive in order to increase utilization of services by African Americans.

Research by George Rust (2004) utilized secondary data of 3,462 records of African American respondents to the 1999 Medical Expenditure Survey Household file. They concluded that there was a significant variation in the number of office visits, outpatient clinic visits, hospital discharges, and the number of days hospitalized and prescriptions filled among this population. There were three modifiable factors, poverty, insurance, and lack of a primary care physician as having a striking effect for African American patients. Barriers to utilization of services were noted as availability, accessibility and acceptability.

Availability of services was linked to sometimes not being able to obtain a primary care physician where ethnic elders lived. Even more difficult was specialty care physicians in the areas where many African Americans reside. Accessibility was determined by the African American as available care but the inability to use or access services for a number of reasons measured were: lack of knowledge, distrust of the system, fear of punitive action, inability to deal with bureaucracy, assumptions by providers of lack of motivation or trust and transportation difficulties. Acceptability of the patient was linked as another barrier to access and utilization of services and was based on patients’ satisfaction with having their expectations met. Acceptability was an aspect of access and utilization of services most affected by culture and the interaction between patient and provider performance. Trust needed to be developed between the
provider and patient in order to gain access to services. In order to gain access and utilize services, indigenous networks for education and outreach must be formulated. Utilization of churches, temples, lay leaders and non-professional advocates can be utilized to increase access to medication and services for African Americans with Alzheimer’s disease.

Caregiver Stressors

Some five million Americans care for loved ones with Alzheimer’s disease at home, in nursing homes or assisted living facilities. Many caregivers feel isolated from family, friends and their communities. Stress levels of caregivers rise as Alzheimer’s disease symptoms grow and become more severe. Social support is needed to help bear not only the financial burden, but the psychological and social aspects of those diagnosed with Alzheimer’s disease. Improving social support and reducing family conflict to help the caregiver withstand the hardships of care giving requires a multitude of social support systems. To help society and other family members understand the primary caregiver’s needs and how to best become helpful may postpone the institutionalization of patients diagnosed with Alzheimer’s disease (Fisher Center, 2006).

Caregivers who lack sufficient or appropriate social support are often put under heightened stress. Family conflicts, isolation, loneliness further exacerbate the stress of the caregiver. While social support may not affect primary stress caused by Alzheimer’s disease, it can change the caregivers’ response to the illness. Feeling supported by social/community services and family can improve the psychological response to stress and boost the caregivers sense of well being. Caregivers can benefit from formal support by community services such as in home respite or day care programs for the patient, and
support groups in conjunction with the informal support of family and friends (Alzheimer’s Caregivers Fact Sheet, 2007).

More than 80% of Alzheimer’s caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression. The National Family Caregiver Alliance terms caregiver depression as “...one of today’s all-to-silent health crises”. The alliance estimates that care giving spouses the ages of 66 to 96 who are experiencing mental or emotional strain have a 63% higher risk of dying than people the same age who are not caregivers (Abel,2003).

Caregivers often experience feelings of guilt, believing they are not doing enough to help. Spouses and adult children feel grief and loss except for being sudden, it spreads over years. Alzheimer’s is a progressively worsening disease, but the rate of progression from mild to advanced stages can vary from three to 20 years. As the disease progresses, the loss of brain function itself will cause death unless the patient has one or more other serious illnesses (Health Link Fact Sheet, 2003).

Financial strain from the disease process brings about problems that can also add to stress and depression. Caregivers will often give up paying jobs for the unpaid job of caring for the family member with Alzheimer’s disease. Additional responsibilities are thrust upon them such as over seeing medication régime, taking on power of attorney along with living wills and advance directives that specify whether terminal patients should undergo extreme measures to keep them alive. In the book “The 36 Hour Day, Mace and Rabins made the first reference to caregiver stressors:

As the patient’s illness progresses and the person changes, you may experience the loss of a companion and a relationship that was important to you. You may grieve the way she use to be. We usually think of grief
as an emotional experience that follows death. However, grief is a natural emotional response to loss and so it is a normal experience for people who love a person with a chronic illness (p. 209).

Caregiver’s of individuals with Alzheimer’s disease are at an increased risk of mental and physical problems as a result of the strain that accompanies this role. Despite clear indications that caregiver grief and feelings of loss are normal, researchers did not begin to address the idea until late 1980’s and mid 1990’s. Two of the earliest researchers on this topic were Wasow and Coons. They indicated that the grief of caregivers of individuals with Alzheimer’s disease often remained undetected by society. Not recognized as normative behavior, grief and loss were combined with feelings of stigma which was often associated with the disease (Wasow & Coons, 1987).

In 1999, Boss coined the term “ambiguous loss” to define grief that has no clear starting point and no clear ending point. This type of grief experienced by Alzheimer’s disease caregivers is ambiguous because the care recipient is still physically present, but cognitively not the same person. Boss argued that the depression commonly noted in caregivers of individuals with Alzheimer’s disease probably has more to do with the ambiguity of their loss than their heavy work load. The feeling of being out of control commonly associated with ambiguous losses can lead to increase family conflict; problematic communication patterns an obsession with the day to day activities of caring for the patient (Boss, 1999).

There is also grief at different stages of the disease. The profound feelings of grief expressed following the diagnosis of Alzheimer’s disease. Grief becomes stronger when the patient no longer recognizes the caregiver which often occurs in the middle
stages of the disease progression. Other researchers suggest that the final stage and the
death of the patient bring about the strongest display of grief. There are multiple losses
for the caregiver, the loss of the previous relationship, social interaction an support,
health status, resolution of pass issues, activities, previously established social roles,
intimacy and control (Sanders & Adams, 2005).

In another study, grief and depression was examined. A racially diverse sample
of caregivers was drawn from an urban setting on the east coast of the United States.
Results indicated not only that a significant proportion of caregivers experienced high
levels of grief that may place them at risk of other difficulties, but also that grief was a
significant predictor of increased depressive symptoms (Sanders & Adams, 2005).

Another study investigated the predictors of caregiver burden and depression.
The participants were 613 individuals with dementia, living in either the community or
an institution, and their informal caregivers. Structural equation models representing
four alternative pathways from care giving stressors (e.g., functional limitations,
disturbing behaviors, patients' residence, and assistance given to caregiver) to caregiver
burden and depression was compared. The data provided the best fit to a model whereby
the effects on the caregivers well being are mediated by appraisals of burden. A higher
frequency of disturbing behavior, caring for a community-dwelling patient, and low
informal support were related to higher burden, which in turn led to more depressive
symptomatology. Caregivers of patients exhibiting more disturbing behaviors and
functional limitation received less help from family and friends, whereas those whose care
recipients resided in an institution received more informal support (Clyburn, et al., 2000).
Sleath, et al., examined the relationship between race and psychotropic drug use (antidepressants, anti-anxiety, sedative/hypnotics agents) in informal caregivers with symptoms of depression who provided care for elderly relatives with dementia. Whether racial differences in medication use relate to racial differences on predisposing, enabling, and need factors associated with use of these agents was also examined. There were 2,932 African American and white caregivers of elderly male veterans diagnosed with probable Alzheimer’s disease or vascular dementia. Depressive symptoms were measured using a modified version of the Center for Epidemiological Studies Depressive Scale. Antidepressant, anti-anxiety, and sedative/hypnotic agents were indexed using the Veterans Affairs’ medication classification system. Of caregivers with depressive symptoms, 19% used anti-depressants, 23% anti-anxiety agents, and 2% sedative hypnotics. African American caregivers with depressive symptoms were significantly less likely than whites with depressive symptoms to use antidepressants’ and anti-anxiety medications. This study concludes that 81% of caregivers had depressive symptoms and were not taking medication and that African American caregivers were less likely than whites to take antidepressants (Sleath, et al., 2005).

Theoretical Framework

The theoretical framework for this study was based on Systems Theory; a means by which some resolutions to the myriad of problems facing our society and the family may be beneficial. Systems Theory is an approach to human behavior. There are two substantive assumptions in defining Systems Theory: 1) The state or condition of a system, at any one point in time is a function of the interaction between it and the
environment in which it operates; and 2) Change and conflict are always evident in a system (Longres, 1990).

Two basic components of Systems Theory are elements and processes. Elements are measurable things that can be linked together. They are called objects, event, patterns, or structures. Processes change elements from one form to another. They are also called activities, relations, or functions. The family system and the organizations needed to serve the myriad of problems facing the Alzheimer client, caregiver and society are part of complex social systems meeting the needs and the events that take place in the progression of Alzheimer disease (Pavard & Dugdale, 2004).

When utilizing Systems Theory for this dissertation the family is a smaller system with the involvement of multiple other larger systems of service. The communications between all systems must be open for services to meet the needs of the Alzheimer’s client and caregiver. Systems are most productive when conflict arises and alternatives are established. When the diagnosis of Alzheimer’s disease is established communication between all systems of services are needed. If systems are not in place to meet the needs of the client and caregiver then communication is developed between systems until a resolution can take place. The family as well as the larger systems must address the needs of the Alzheimer’s epidemic among African American. These needs are met by larger systems such as Federal and sate funding for respite care, prescriptions, nursing homes, in home health care and assisted living (Gurman & Kniskern, 1979).

The impact of Alzheimer disease on the family and society are astronomical. African Americans are being diagnosed disproportionately higher than any other ethnicity. Integration of available resources and available services must be tapped into.
Systems theory will serve as an intervention, enabling social workers to advocate on the grounds of empirical research in the area of social dynamics; as opposed to multiple studies whose focus is on the physiological aspects (Bruton, 2007).

A secondary theoretical approach was incorporated into this paper. Behavior Cognitive Theory (BCT) is based on the concept that there is a reciprocal interaction between what we think, how we feel, and how we behave. This theory serves as an intervention for the caregiver. In BCT the problems are specified (i.e. aging, dementia, inability of the client to care for self, housing medications, access to health care, lack of participation in research etc). The challenge at hand is identified as the focus of change, which may be collectively or one situation at a time. The behaviors or attitudes that may be changed, altered or suppressed are identified by the caregiver the Alzheimer's client and society. The system that is most likely to assist with the solutions of the problem is identified and ways are established with the help of social organizations to meet those needs (Cooper & Leer, 2005).

The caregiver is then requested to obtain knowledge regarding available resources to assist in the care, both psychologically, emotionally and financially of the client. The caregiver may also began to set goals as specified in CBT secondary to the progressive nature of the disease and the need for hospice, respite care and possibly the need for placement issues associated with the final stage. The client may not be able to remain in the home and the caregiver may be requested to do homework to practice future skills that may be needed in order to identify future services needed as the disease process continues (Corcoran, 2006).
CHAPTER III

METHODOLOGY

Chapter III presents the methods and procedures that were used in conducting the study. The following are described: research design; description of the site; sample and population; instrumentation; treatment of data; and limitations of the study.

Research Design

A descriptive and explanatory research design was employed in this study. The study was designed to ascertain data in order to describe and explain the higher diagnosis of Alzheimer’s disease in the African American population.

The descriptive and explanatory research design allowed for the descriptive analysis of the demographic characteristics of the respondents. Also, this research design facilitated the explanation of the statistical relationship between diagnosis of Alzheimer’s disease among African Americans and their socio-economic status, participation in research, caregiver knowledge and support systems, access to health care and medication and caregiver stressors for family members with the diagnosis of Alzheimer’s.

Description of the Site

The research study was conducted in Atlanta Georgia. Atlanta is the largest urban metropolitan city in the state of Georgia. The surveys were administered at Sadie G.
Mayes Nursing Home, Staff Builders Home Health Care and Ashton Hall Assisted Living Facilities. The assisted living facilities were selected due to the selection of both male and female clients and involvement in patients care. Caregivers that were not present during the session were interviewed by phone.

Sample Population

The target population for the research was composed of primary caregivers for patients diagnosed with Alzheimer’s disease. One hundred (100) respondents were selected utilizing non-probability convenience sampling from among the participants at the selected sites for the study.

Instrumentation

The research study employed a survey questionnaire entitled Alzheimer’s Awareness. The survey questionnaire consisted of 6 sections with a total of 30 questions. The questions were answered by the caregiver or family member of the client. The first section solicited demographic information about the characteristics of the patient or relative of the respondent.

Section I consisted of three questions numbers 1-3 as independent variables of the study. The questions in Section I were related to gender, age and ethnicity.

Sections II of the survey consisted of three questions numbers 4-6, and were independent variables to determine socio-economic status. The questions in Section II were income, occupation and educational level. Section I and II provided information for the presentation of a demographic profile on the respondents of the research study as well as serving as independent variables.
Section III of the survey consisted of four (4) questions numbered 7-10. The four (4) questions were related to research participation in Alzheimer’s disease studies. Items were responded to on a four point continuum Likert Scale. The scale was as follows: 1 = Disagree; 2 = Somewhat Disagree; 3 = Agree; 4 = Strongly Agree.

Section IV consisted of eight (8) questions numbers 11-18 related to caregiver knowledge using a “yes” “no” response. Participants’ answered questions related to their knowledge of Alzheimer’s disease and these responses served as independent variables.

Section V consisted of five (5) questions numbers 20-24 and were related to access to health care and medications. A “yes” “no” response was measured and questions served as independent variables. Two questions are open ended with suggested responses.

Section VI (6) the six questions numbers 25-30 using a four point Likert scale to measure stressors related to care giving of an Alzheimer’s disease patient. The scale was as follows: 1 = Disagree; 2 = Somewhat Agree 3 = Agree; 4 = Strongly Agree.

Treatment of Data

Statistical treatment of the data employed descriptive statistics, which include measures of central tendency, frequency distribution, and cross tabulation. The test statistics for the study were phi and chi square.

Frequency distribution was used to analyze each of the variables of the study in order to summarize the basic measurements. A frequency distribution of independent variables was used to develop a demographic profile and to gain insights about the respondents of the study.
Cross tabulation were utilized to demonstrate the statistical relationship between independent variables and the dependent variable. Cross tabulations were conducted between high and low socio-economic status and the diagnosis of Alzheimer’s disease, the lack of distrust and participation in research, institutionalization and knowledge of Alzheimer’s disease process, association between access to medication and diagnosis and the association of diagnosis of depression and the care of Alzheimer’s relative in the African American population.

Two test statistics will be employed. The first test was Phi (0) which is a symmetric measure of association that is used to demonstrate the strength of relationship between two or more variables (Bromstead & Knoke, 1995). The following are the valuables associated with phi (O):

- .00 to .24 “no relationship”
- .25 to .49 “weak relationship”
- .50 to .74 “moderate relationship”
- .75 to 1.00 “strong relationship”

The second test statistics employed in the research study was chi square. Chi Square was used to test whether there was statistical significance at the .05 level of probability among variables in the study.

**Limitations of the Study**

There were two basic limitations to the study. The first limitation was the inability of the caregiver to have a broad knowledge of the patient’s socio-economic status and access to health care history prior to the onset of memory loss. The second
limitation was the lack of sites made available for this study secondary to confidentiality of many facilities to allow an outside practitioner to gain access to caregivers of patients with Alzheimer’s disease due to confidentiality (i.e., HIPAA Guidelines).
CHAPTER IV

PRESENTATION OF FINDINGS

The purpose of this chapter was to present the findings of the study in order to describe and explain the social barriers leading to the disproportionately higher incidence of Alzheimer’s disease in the African American population. This chapter presents the findings of the study. The findings are organized into two sections: demographic data and research questions and hypotheses.

Demographic Data

This section provides a profile of the study respondents. Descriptive statistics were used to analyze the following: gender, age group, and ethnicity.

A target population for the research was composed of caregivers of patients with Alzheimer’s disease living or deceased. Ninety caregivers were selected utilizing convenience sampling from among participants of the selected sites.

As indicated in Table 1, the typical respondent of the study was African American, a female and seventy-one years or older.
Table 1

Demographic Profile of Study Respondents

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>29</td>
<td>32.2</td>
</tr>
<tr>
<td>Female</td>
<td>61</td>
<td>67.8</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-70</td>
<td>10</td>
<td>11.1</td>
</tr>
<tr>
<td>71-80</td>
<td>28</td>
<td>31.1</td>
</tr>
<tr>
<td>81-Up</td>
<td>26</td>
<td>28.9</td>
</tr>
<tr>
<td>Deceased</td>
<td>26</td>
<td>28.9</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>69</td>
<td>76.6</td>
</tr>
<tr>
<td>White</td>
<td>11</td>
<td>12.2</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6</td>
<td>6.7</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>4.4</td>
</tr>
</tbody>
</table>
Research Questions and Hypotheses

There were five research questions and five null hypotheses in the study. This section provides an analysis of the research questions and testing of the null hypotheses.

Research Question 1: Is there a relationship between socio-economic status and the diagnosis of Alzheimer’s disease?

Hypothesis 1: There is no statistically significant relationship between low socio-economic status in the African American population and the diagnosis of Alzheimer’s disease.

Socio-economic Status of Alzheimer’s Patients

Numerous studies have documented the importance of socio-economic status (SES) to a variety of health outcomes. The National Committee on Vital Statistics and other federally-sponsored health conferences has recommended regular collection of SES data and for the use of SES variables in studies of differential health outcomes (Daly, et al., 2000).

In the study socio-economic status was defined as the patients’ occupation, education and income level. Table 2 is a frequency distribution of nine (9) occupations reported by the caregiver of the patients’ last employment status prior to the Alzheimer’s patients’ retirement.

As shown in Table 2, the greatest percentile of Alzheimer’s patients were in the lower occupational category of Helper-Laborer, 33.3% with an executive percentage of 6.4%.
Table 2

Occupation of Alzheimer’s Respondents

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive</td>
<td>5</td>
<td>5.6</td>
</tr>
<tr>
<td>Professional</td>
<td>17</td>
<td>18.9</td>
</tr>
<tr>
<td>Technical</td>
<td>3</td>
<td>3.3</td>
</tr>
<tr>
<td>Service Organization</td>
<td>6</td>
<td>6.7</td>
</tr>
<tr>
<td>Machinist</td>
<td>3</td>
<td>3.3</td>
</tr>
<tr>
<td>Service Occupation</td>
<td>11</td>
<td>12.2</td>
</tr>
<tr>
<td>Helper-Laborer</td>
<td>26</td>
<td>28.9</td>
</tr>
<tr>
<td>Transportation</td>
<td>2</td>
<td>2.2</td>
</tr>
<tr>
<td>Clerical</td>
<td>5</td>
<td>5.6</td>
</tr>
</tbody>
</table>

Another measure of socio-economic status was the educational level of the Alzheimer’s survey respondent of their relative diagnosed with Alzheimer’s disease. Studies show that fewer years of formal schooling, lower income and lower occupational status each predicted risk of incident of Alzheimer’s. The risk of Alzheimer’s disease decreased approximately 17% for each year of education (Evans 2007). Table 3 is a frequency distribution of the level of education of each respondent.
Table 3

Educational Level of Respondents

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>13</td>
<td>14.4</td>
</tr>
<tr>
<td>Some High School</td>
<td>19</td>
<td>21.1</td>
</tr>
<tr>
<td>Vocational</td>
<td>9</td>
<td>10.0</td>
</tr>
<tr>
<td>Some College</td>
<td>10</td>
<td>11.1</td>
</tr>
<tr>
<td>College Graduate</td>
<td>17</td>
<td>18.9</td>
</tr>
<tr>
<td>Graduate School</td>
<td>2</td>
<td>2.2</td>
</tr>
<tr>
<td>Masters</td>
<td>2</td>
<td>2.2</td>
</tr>
<tr>
<td>Doctoral Degree</td>
<td>1</td>
<td>1.1</td>
</tr>
</tbody>
</table>

As displayed in Table 3 the greatest educational level of respondents was between “Some High School” (35.5%) and “College Graduates” (18.9%) with Elementary in third place at fourteen percent (14.4%).

Income has been more widely used as a measure of SES in the United States than anywhere else. Studies in the U.S. and the United Kingdom found that indicators of wealth, independent of the more traditional indicators is more valuable as a SES variable. The income reflects the value of human wealth or capital (Daly, et al, 2000).
Table 4

The Income of Respondents Diagnosed with Alzheimer’s Disease

<table>
<thead>
<tr>
<th>Income</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Under 30,000</td>
<td>30</td>
<td>34.9%</td>
<td>30</td>
</tr>
<tr>
<td>30,001-40,000</td>
<td>20</td>
<td>23.3%</td>
<td>6</td>
</tr>
</tbody>
</table>

O = .251 df = 1 p = .02

As indicated in Table 4 the income of respondents taking medications and have a diagnosis of Alzheimer’s disease with income under 30,000 was 69.8% and those with incomes over 30,001 and taking medications was 30.2%.

The statistical measurement phi (O) was employed to test for strength of association between income and Alzheimer’s diagnosis. As indicated there was a weak relationship (O = .251) between income and diagnosis of Alzheimer’s disease. When the chi-square statistical test for significance was applied, the null hypothesis was not rejected (p = .0200 indicating that there was a statically significant relationship between the two variables at the .05 level of probability.

Research Question 2: Is there a relationship between African American participation in research and lack of trust in the medical/research field?
Hypothesis 2: There is no evidence of a relationship between African American participants in research and lack of trust in the medical/research field.

Participation in Research

Trust is an important element of communication and many ethnic elders lack trust in health care professionals as well as the American health system. As the older population becomes more ethnically diverse, health professionals will need to become more knowledgeable about the cultural backgrounds of their clients to obtain subjects to participate in Alzheimer's research (Washington, 2006).

Table 5 is a cross tabulation of participation in research and the lack of trust in the medical/research field of those diagnosed with Alzheimer's disease. As indicated in Table 5 a large majority of respondents, 65.9%, agree that research risk is not shared equally by all while 34.1% agree that risk for research is shared equally.

Table 5
Risk for Research not Shared Equally

<table>
<thead>
<tr>
<th>Income</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Disagree</td>
<td>2</td>
<td>2.4%</td>
<td>27</td>
</tr>
<tr>
<td>Agree</td>
<td>3</td>
<td>3.5%</td>
<td>53</td>
</tr>
</tbody>
</table>

O=.031 df=1 p=.775
As indicated in Table 5, the statistical measurement phi ($\phi$) was employed to test for the strength of association between risk shared in medical/research fields by all ethnicities. As indicated there was a weak relationship ($O = .031$) between the two variables. When the chi-square statistical test for significance was applied, the null hypothesis was rejected ($p = .775$) indicating that there was a statistically significant relationship between the two variables at the .05 level of probability.

Research Question 3: Is there a relationship between institutionalization of the client with Alzheimer’s disease and caregiver knowledge and support?

Hypothesis 3: There is no relationship between institutionalization of the client with Alzheimer’s disease and the caregiver knowledge and support.

With the current aging of U.S. population, the number of those with Alzheimer’s disease is rapidly increasing, along with the financial impact of the disease on society. Research is expanding both to prevent or delay the disease and to assist the caregiver in maintaining the patient in the home. More than 75% of those diagnosed with Alzheimer’s disease are cared for in the home (Stanton, 2001).

Table 6 is a crosstabulation of the institutionalization by Alzheimer’s patients. It shows the association between institutionalization of Alzheimer’s patients and support of other family members in the care of the patient and maintain the patient in the home.
As indicated in Table 6, 13.6% of patients diagnosed with Alzheimer’s disease resided in and assisted living facility or nursing home and 56.8% remained in the home with support from family members.

As shown in Table 6, the statistical measurement phi ($\phi$) was employed to test for strength of association between residence and support of family members in the care of the Alzheimer’s patient. As indicated there was no relationship ($\phi = .084$) between the two variables. When the chi-square statistical test for significance was applied, the null hypothesis was not rejected ($p=.431$) indicating that there was a statistically significant relationship between the two variables at the .05 level of probability.

In Table 7 is a crosstabulation of knowledge by available community resources. It shows the association of the Alzheimer’s caregiver’s knowledge and the patient’s place of residence (i.e., institutionalization versus in-home care).
As indicated in Table 7, 41.4% of caregivers are aware of community resources of those patients who remain in the home and 58.6% are not aware of available community resources of those patients who remain in the home.

As shown in Table 7, the statistical measurement phi ($\phi$) was employed to test for the strength of association between ability to remain in the home and institutionalization of the patient by the caregiver. As indicated there was no relationship ($\phi = .064$) between the two variables. When the chi-square statistical test for significance was applied, the null hypothesis was not rejected ($p = .549$) indicating that there was a statistical significant relationship between the two variables at the .05 level of probability.

Research Question 4: Is there a relationship between diagnosis of Alzheimer’s disease in the African American population and the access to health care and medication?
Hypothesis 4: There is no statistically significant relationship between the diagnosis of Alzheimer's disease in the African American population and the access to health care and medication.

Early identification of Alzheimer’s disease provides opportunities to initiate treatment that may slow a patient's disease progression until the family member can connect and access health care providers and supportive services. The factors that may improve access to services for people with dementia are measured.

Table 8 is a crosstabulation of access to healthcare by medication. It shows the association of the diagnosis of Alzheimer’s disease by compliance of the patient in relationship to access to medication and services.

As indicated in Table 8, of the caregiver respondents' only 38.8% were given handouts at the time of diagnosis. The majority (61.2%) indicated that they were not given any additional information after the diagnosis of Alzheimer’s disease or assistance with medication or access to other health care services.

As shown in Table 8, the statistical measurement phi (\(\phi\)) was employed to test for the strength of association between diagnosis and access to other healthcare services. As indicated, there was a weak relationship (\(\phi=.266\)) between the two variables. When the chi-square statistical test for significance was applied, the null hypothesis was rejected (\(p=.014\)) indicating that there was no statistically significant relationship between the two variables at the .05 level of probability.
Table 8

Access to Health Care/Medication

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Yes</th>
<th>%</th>
<th>No</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Handouts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11</td>
<td>12.9%</td>
<td>22</td>
<td>25.9%</td>
<td>33</td>
<td>38.8%</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>7.1%</td>
<td>46</td>
<td>54.1%</td>
<td>52</td>
<td>61.2%</td>
</tr>
</tbody>
</table>

O=0.266 df=1 p=0.014

Research Question 5: Is there a significant relationship between caregiver stressors and caring for an Alzheimer’s relative?

Hypothesis 5: There is no statistically significant relationship between caregiver stressors and caring for Alzheimer’s disease relative.

Some five million Americans care for loved ones with Alzheimer’s disease at home, in nursing homes or assisted living facilities. Stress levels of caregivers rise as Alzheimer’s disease grows and become more severe. Improvement in social support and reducing family conflict to help the caregiver withstand the hardships of care giving requires a multitude of support (Fisher Center, 2006).

Table 9 is a crosstabulation of caregiver stressors. It shows the association of caring for a relative with Alzheimer’s disease and lack of personal time as evidenced by producing a strain on the caregiver. As indicated in Table 9, 47.1% respondents disagree
with stress involved in caring for the relative with Alzheimer’s disease and 52.9% agree with associated stress in the care of the relative with Alzheimer’s disease.

In table 9 the statistical measurement phi (\(\phi\)) was employed to test for the strength of association between caregiver stress by caring for the Alzheimer’s patient. As indicated, there was no relationship (\(\phi=.219\)) between the two variables. When the chi-square statistical test for significance was applied, the null hypothesis was rejected (\(p=.043\)) indicating that there was no statistically significant relationship between the two variables at the .05 level of probability.

Table 9

<table>
<thead>
<tr>
<th>Stress</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Disagree</td>
<td>29</td>
<td>34.1%</td>
<td>11</td>
</tr>
<tr>
<td>Agree</td>
<td>23</td>
<td>27.1%</td>
<td>23</td>
</tr>
</tbody>
</table>

\(\phi=.219\)  \(\text{df}=1\)  \(p=.043\)
CHAPTER V
CONCLUSIONS AND RECOMMENDATIONS

The research study was designed to answer five questions concerning social aspects related to the higher incidence of Alzheimer's diagnosis in the African American population. Those aspects were socio-economic status, lack of trust and participation in research, knowledge and support in relationship to institutionalization, access to healthcare/medication upon diagnosis and the relationship of stress among caregivers of Alzheimer's patients.

The conclusions and recommendations of the research findings are presented in this chapter. Recommendations are proposed for future discussions for policy makers, social workers, practitioners, the medical field, administrators and schools of social work. Each research question is presented in order to summarize the significant findings of interest.

Research Question 1: Is there a relationship between socio-economic status and the diagnosis of Alzheimer's disease?

In order to determine if there was a relationship to diagnosis of Alzheimer's disease by socio-economic status three variables were analyzed, occupation, education and income of the Alzheimer's patient.
Of the 90 respondents surveyed for the nine (9) occupations given: executive, professional, technical, service organization, machinist, service occupation, helper/laborer, transportation, and clerical. The largest number of respondents (26) was helper/laborers (28.9%). The smallest percentage of respondents at 5.6% were executives and clerical workers (See Table 2).

The educational level of the respondents was highest, 21.1% for “Some High School” and the lowest percentage (1.1%) was at the Doctoral Level” (See Table 2).

The income level of the respondents was highest (69.8%) for incomes under $30,000 per year and 30.2% had incomes over $30,001 per year (See Table 4).

The statistical measurement phi (O) was employed to test for strength of association between income and diagnosis of Alzheimer’s disease. As indicated there was a weak relationship (O=.251) between the variables. When the chi-square statistical test for significance was applied, the null hypotheses was not rejected (p=.02) indicating that there was a statistically significant relationship between the two variables at the .05 level of probability (See Table 4).

Research Question 2: Is there a relationship between African American participation in research and lack of trust in the medical/research field?

Sixty-five point nine percent (65.9%) of the respondents agreed that research risk is not shared equally by all while 34.1% agreed research is shared equally (See Table 5).

The statistical measurement phi (O) was employed to test for the strength of association between risk of research being shared equally by all ethnicities. As indicated, there was a weak relationship (O=.031) between the two variables. When the chi-square
statistical test for significance was applied the null hypotheses was rejected (p=.775) indicating that there was a statistically significant relationship between the two variables at the .05 level of probability (See Table 5).

Research Question 3: Is there a relationship between institutionalization of the client with Alzheimer’s disease and caregiver knowledge and support?

Seventy point five percent (70.5%) of respondents reported that patients with Alzheimer’s disease remained in the household with the support of family members as opposed to the 29.5% who reported that patients resided in nursing homes or assisted living facilities when family support was present.

The statistical measurement phi (\(\phi\)) was employed to test the strength of association between support and institutionalization. As indicated, there was no relationship (\(\phi=.084\)) between the two variables. When the chi-square statistical test for significance was applied the null hypotheses was not rejected (p=.431) indicating that there was a statistically significant relationship between the two variables at the .05 level of probability (See Table 6).

As indicated in Table 7, 41.4% respondents had knowledge of community resources by association to institutionalization and 58.6% were unaware of resources. The statistical measurement phi (\(\phi\)) was employed to test the strength of association community resource knowledge by institutionalization of the relative. As indicated there was no relationship (\(\phi=.064\)) between the two variables. When the chi-square statistical test for significance was applied, the null hypotheses was not rejected (p=.54) indicating
there was a statistical significant relationship between the two variables at the .05 level of probability (See Table 7).


The majority of respondents, 61.2% were never given handouts or additional information related to compliance or healthcare by obtaining medications. Only 38.8% were given handouts and other information related to access to health care (See Table 8).

The statistical measurement phi (0) was employed to test for the strength of association between the access to healthcare and medications and compliance. As indicated, there was a weak relationship (0=.266) between the two variables. When the chi-square statistical test for significance was applied, the null hypotheses was rejected (p=.014) indicating that there was no statically significant relationship between the two variables at the .05 level of probability (See Table 8).

Research Question 5: Is there a significant relationship between caregiver stressors and caring for an Alzheimer’s relative?

Respondents reported 47.1% that stress was not involved in caring for a relative with Alzheimer’s disease while 52.9% agree that there was stress involved in caring for the relative with Alzheimer’s disease (See Table 9).

The statistical measurement phi (0) was employed to test for the strength of association between stressors involved in caring for the relative with Alzheimer’s
disease. As indicated there was no relationship \((O=0.219)\) between the two variables. When the chi-square statistical test for significance was applied, the null hypotheses was rejected \((p=0.043)\) indicating that there was no statistically significant relationship between the two variables at the .05 level of probability.

Recommendations

Studies inclusive of African Americans in Alzheimer’s research are frequently limited by the lack of access to research and utilization of services. The decision to include ethnicities with this growing population is paramount in decreasing the incidence in this costly and growing disease.

As a result of the findings of this study, the researcher is recommending the following:

1. Research should continue and increase the number of African Americans in research to increase both internal and external validity of future research projects (i.e. becoming more culturally sensitive in recruitment efforts).

2. Social workers should engage in research to assist and advise policy makers in patterns of utilization by the African American population.

3. Programs should be developed to deal specifically with research findings associated with availability, accessibility, acceptability and financial restraints to gaining access to services provided for the treatment of Alzheimer’s disease.

4. Schools of Social Work must begin to incorporate studies for the aged, as they explore the dynamics of the catastrophic results of overlooking the number three (3) disease of the elderly, Alzheimer’s disease.
5. The Social Work Leadership Institute (SWLI) must support policies that cultivate leaders to assist with public policies. SWLI must recruit and retain qualified social workers in the area of gerontology to effect changes in access to health care and services, participation in research by minorities and assist the caregiver with community resources.

6. Social work textbooks for aging content must be developed for students for our aging society.
APPENDIX A

Letter to Sadie G. Mayes Nursing Home

November 14, 2007

Charles Robinson, Jr. CEO
Sadie G. Mayes
1870 Anderson Avenue
Atlanta Georgia 30314

Dear Sir:

I am a graduate student in the Ph.D. Program at the Whitney M. Young, Jr., School of Social Work at Clark Atlanta University. I am presently writing my doctoral dissertation on the disproportionately higher incidence of Alzheimer’s disease in the African American population. I had spoken with Ms. Brooks, in your Human Resource Department who referred me to your office to obtain permission for this endeavor.

I am presently a nursing supervisor in the substance abuse arena in the Ann Arbor Michigan area; however my research population will be in the metropolitan Atlanta area encompassing Assisted Living facilities and Home Health Care Organization.

I would appreciate an appointment to discuss this potential research with you. I am sending you a proposed Survey Questionnaire for your information. I have also sent a copy of my correspondence to Ms. Jocelyn Brantley your Social Worker for her review as well. I will be in touch via phone to confirm a date to speak with you.

Edna Andrews-Benson, Ph.D. Candidate
Clark-Atlanta University

cc: Richard Lyle, Chair
APPENDIX B

Letter to Staff Builders Home Health Care

November 14, 2007

Jean Bishop, RN, BSN, Case Manager
Staff Builders Home Health Care
9040 Roswell Rd.
Atlanta, Georgia 30350

Dear Madame:

I am a graduate student in the Ph.D. Program at the Whitney M. Young, Jr., School of Social Work at Clark Atlanta University. I am presently writing my doctoral dissertation on the disproportionately higher incidence of Alzheimer’s disease in the African American population.

I am presently a nursing supervisor in the substance abuse arena in the Ann Arbor Michigan area; however my research population will be in the metropolitan Atlanta area encompassing Assisted Living facilities and Nursing Homes.

I would appreciate an appointment to discuss this potential research with you. I am sending you a proposed Survey Questionnaire for your information. I will be in touch via phone to confirm a date to speak with you.

Edna Andrews-Benson, Ph.D. Candidate
Clark-Atlanta University

cc: Richard Lyle, Chair
APPENDIX C

Letter to Ashton Hall Assisted Living Facility

November 14, 2007

Ashton Hall Assisted Living facility
1155 Lawrenceville Hwy.
Lawrenceville, Georgia 30044

Dear Madame:

I am a graduate student in the Ph.D. Program at the Whitney M. Young, Jr. School of Social Work at Clark Atlanta University. I am presently writing my doctoral dissertation on the disproportionately higher incidence of Alzheimer’s disease in the African American population.

I am presently a nursing supervisor in the substance abuse arena in the Ann Arbor Michigan area; however my research population will be in the metropolitan Atlanta area encompassing Assisted Living facilities and Nursing Homes.

I would appreciate an appointment to discuss this potential research with you. I am sending you a proposed Survey Questionnaire for your information. I will be in touch via phone to confirm a date to speak with you.

Edna Andrews-Benson, Ph.D. Candidate
Clark-Atlanta University

cc: Richard Lyle, Chair
APPENDIX D

Survey Questionnaire

Alzheimer’s Caregiver Questionnaire

Dear Caregiver:

I am a student in the Ph.D. Program at the Whitney M. Young, Jr., School of Social Work at Clark Atlanta University. I invite you to participate in a questionnaire related to Alzheimer’s disease. The questionnaire will take between 5-10 minutes to complete. The purpose of the study is to learn more about the diagnosis of Alzheimer’s disease in the African American population. The findings will be used in an analysis for my dissertation. I would appreciate your cooperation. To maintain confidentiality please do not place your name on the questionnaire answer sheet. Again thank you for your time and cooperation.

Edna Andrews-Rose

If your family member is deceased please answer on the status prior to death.

Section I Demographic Information
Place an (X) next to the appropriate item. Choose only one answer for each question,

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My family member is:</td>
<td></td>
</tr>
<tr>
<td>1) Male</td>
<td>2) Female</td>
</tr>
<tr>
<td>2. My family members age is:</td>
<td></td>
</tr>
<tr>
<td>1) 60-70</td>
<td>2) 71-80</td>
</tr>
<tr>
<td>3. Racial category of my family member is:</td>
<td></td>
</tr>
<tr>
<td>1) Black</td>
<td>2) White</td>
</tr>
</tbody>
</table>

Section II Socioeconomic Status:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4. My family member s’ yearly income is/was:</td>
<td></td>
</tr>
<tr>
<td>1) under 10,000</td>
<td>2) $10,001-20,000</td>
</tr>
<tr>
<td>3) 20,001-30,000</td>
<td>4) 30,001-40,000</td>
</tr>
<tr>
<td>5. My family members’ occupation prior to retirement:</td>
<td></td>
</tr>
<tr>
<td>1) Executive</td>
<td>2) Professional</td>
</tr>
<tr>
<td>5) Machinist</td>
<td>6) Service Occupation</td>
</tr>
<tr>
<td>9) Clerical</td>
<td></td>
</tr>
<tr>
<td>6. My family members’ educational level is:</td>
<td></td>
</tr>
<tr>
<td>1) Elementary</td>
<td>2) Some High School</td>
</tr>
<tr>
<td>4) Vocational School</td>
<td>5) Some College</td>
</tr>
<tr>
<td>7) Graduate School</td>
<td>8) Masters</td>
</tr>
</tbody>
</table>
APPENDIX D (continued)

Section III: Participation in Research

The following statements are designed to get your opinion on several variables associated with Alzheimer’s disease. Write the appropriate number (1 thru 4) in the blank space in front of each statement on the questionnaire. Please respond to all questions.

1=Strongly Disagree  2=Disagree  3=Agree  4=Strongly Agree

7. Risk for research is shared by all.
8. Risk for research is not shared equally by all.
9. Minorities bear much of the risk of research.
10. I am aware of research related to Alzheimer’s disease.

Section IV: Caregiver Knowledge

Respond to the following questions by checking either Yes or No regarding you or your family member.

Yes  No

11. Have you ever been asked to participate in research for Alzheimer’s disease?
12. Would you be willing, if asked, to allow you or your family member to participate in Alzheimer’s research?
13. Are you aware of the Tuskegee research study on Syphilis?
14. Are you aware of the three stages of Alzheimer’s disease?
15. Are you aware of any community resources to assist with the needs of your family member?
16. Were you given handouts or written material at the time of the diagnosis of Alzheimer’s?
17. Are there any other family members who help with the care of your family member?
18. Does your family member presently reside in a nursing home or assisted living facility?
19. If yes to the above question, how long did the family member reside with you prior to placement?
   _ 1-3 years  _ 4-6 years  _ 7-9 years  _ 10 years or greater

Section V: Access to Health care

Yes  No

20. Does your family member presently take medications for Alzheimer’s?
21. Were you asked if medication cost was a barrier to compliance?
22. Have you ever received samples of medications used in the treatment of Alzheimer’s?
23. If you answered “Yes” to # 20 who pays for the medication?
   _ (1) Medicaid  _ (2) Out of pocket  _ (3) By Nursing home/assisted living facility
24. What medications does your family member presently take for Alzheimer’s condition?
   _ (1) Exelon  _ (2) Aricept  _ (3) Remeron  _ (4) Namenda  _ (5) Cognex  _ (6) other
   _ (7) None
Section VI: Caregiver Stressors
For the following questions right the appropriate response (1 thru 4) in the blank space in front of the statement or question. Please respond to all questions.

1= Strongly Disagree   2= Disagree   3= Agree   4= Strongly Agree

25. Do you feel because of the time you spent with your relative, you did not have enough time for yourself?
26. Do you feel strained when around your relative?
27. Do you feel that your health has suffered because of your involvement with your relative?
28. Do you feel that you will be unable to care for your relative very much longer?
29. Do you feel uncertain about what to do for your relative?
30. Do you feel embarrassed by your relatives’ behavior at times?

Once again I thank you for your participating in this research endeavor.
APPENDIX E

SPSS Program Analysis

TITLE 'ALZHEIMER CAREGIVER QUESTIONNAIRE'.
SUBTITLE 'Edna Andrews Rose - CAU PhD Program'.

DATA LIST FIXED/
  ID       1-3
  GENDER   4
  AGEGRP   5
  ETHNIC   6
  INCOME   7
  OCCUPAT  8
  EDUCA    9
  RISKYES  10
  RISKNO   11
  MINORITY 12
  RESEARCH 13
  KNOW1    14
  KNOW2    15
  KNOW3    16
  KNOW4    17
  KNOW5    18
  KNOW6    19
  KNOW7    20
  KNOW8    21
  KNOW9    22
  ACCESS1  23
  ACCESS2  24
  ACCESS3  25
  ACCESS4  26
  ACCESS5  27
  STRESS1  28
  STRESS2  29
  STRESS3  30
  STRESS4  31
  STRESS5  32
  STRESS6  33.

VARIABLE LABELS
  ID        'Case Number'
  GENDER    'Q1 Gender of my family member'
  AGEGRP    'Q2 Age of my family members'
  ETHNIC    'Q3 Racial category of my family member'
  INCOME    'Q4 Income of my family member'
APPENDIX E (continued)

OCCUPAT 'Q5 Occupation prior to retirement of my family member'
EDUCA 'Q6 Highest educational level of my family member'
RISKYES 'Q7 Risk for research is shared by all'
RISKNO 'Q8 Risk for research is not shared equally by all'
MINORITY 'Q9 Minorities bear much of the risk of research'
RESEARCH 'Q10 I am aware of research related to Alzheimer disease'
KNOW1 'Q11 Have you ever been asked to participate in research for Alzheimer disease'
KNOW2 'Q12 Would you allow a family member to participate in Alzheimer research'
KNOW3 'Q13 Are you aware of the Tuskegee research study on Syphilis'
KNOW4 'Q14 Are you aware of the three stages of Alzheimer disease'
KNOW5 'Q15 Are you aware community resources to assist with the needs of a family member'
KNOW6 'Q16 Were you given written handouts at the time of the diagnosis of Alzheimer'
KNOW7 'Q17 Are there any other family members who help with the care of your family member'
KNOW8 'Q18 Does your family member presently reside in a nursing home or assisted living facility'
KNOW9 'Q19 How long did the family member reside with you prior to placement'
ACCESS1 'Q20 Does a family member presently take medications for Alzheimer disease'
ACCESS2 'Q21 Were you asked if medication cost was a barrier to compliance'
ACCESS3 'Q22 Have you ever received samples of medication used in the treatment of Alzheimer'
ACCESS4 'Q23 Who pays for the medication'
ACCESS5 'Q24 What medications do your family member presently take for Alzheimer'
STRESS1 'Q25 Because of the time you spend with relatives you do not have enough time for yourself'
STRESS2 'Q26 Do you feel strained when aroung your relatives'
STRESS3 'Q27 Do you feel that your health has suffered because of your involvement with relatives'
STRESS4 'Q28 Do you feel that you will be unable to care for your relative very much longer'
STRESS5 'Q29 Do you feel uncertain about what to do for your relative'
STRESS6 'Q30 Do you feel embarrassed by your relatives behavior at times'.
APPENDIX E (continued)

VALUE LABELS

GENDER
1 'Male'
2 'Female'

AGEGRP
1 '60-70'
2 '71-80'
3 '81 up'
4 'Deceased'

ETHNIC
1 'Black'
2 'White'
3 'Hispanic'
4 'Other'

INCOME
1 'Under $10,000'
2 '$10,001 - 20,000'
3 '$20,001 - 30,000'
4 '$30,001 - 40,000'
5 'Over $40,000'

OCCUPAT
1 'Executive'
2 'Professional'
3 'Technical'
4 'Service Organization'
5 'Mechinist'
6 'Service Occupation'
7 'Helper-Laborer'
8 'Transportation'
9 'Clerical'

EDUCA
1 'Elementary'
2 'Some High School'
3 'High School Grad'
4 'Vocational School'
5 'Some College'
6 'College Grad'
7 'Graduate School'
8 'Masters Degree'
9 'Doctoral Degree'

RISKYES
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'

RISKNO
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'
MINORITY
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'

RESEARCH
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'

KNOW1
1 'Yes'
2 'No'

KNOW2
1 'Yes'
2 'No'

KNOW3
1 'Yes'
2 'No'

KNOW4
1 'Yes'
2 'No'

KNOW5
1 'Yes'
2 'No'

KNOW6
1 'Yes'
2 'No'

KNOW7
1 'Yes'
2 'No'

KNOW8
1 'Yes'
2 'No'

KNOW9
1 'Yes'
2 'No'

ACCESS1
1 'Yes'
2 'No'

ACCESS2
1 'Yes'
2 'No'

ACCESS3
1 'Yes'
2 'No'

ACCESS4
1 'Yes'
2 'No'

ACCESS5
1 'Yes'
2 'No'
APPENDIX E (continued)

STRESS1
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'/

STRESS2
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'/

STRESS3
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'/

STRESS4
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'/

STRESS5
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'/

STRESS6
1 'Strongly Disagree'
2 'Disagree'
3 'Agree'
4 'Strongly Agree'/.

MISSING VALUES
GENDER AGEGRP ETHNIC INCOME OCCUPAT EDUCA RISKYES
RISKNO MINORITY RESEARCH KNOW1 KNOW2 KNOW3 KNOW4
KNOW5 KNOW6 KNOW7 KNOW8 KNOW9 ACCESS1 ACCESS2 ACCESS3 ACCESS4 ACCESS5
STRESS1 STRESS2 STRESS3 STRESS4 STRESS5
STRESS 6 (0).

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0111215264344211211212121232233
012221324132222112012230233232

BegiN DATA
APPENDIX E (continued)

END DATA.

RECODE INCOME (1 THRU 3.99=3) (4 THRU 5.99=4).
RECODE RISKYES RISKNO MINORITY RESEARCH (1 THRU 2.99=2) (3 THRU 4.99=3).
RECODE STRESS1 STRESS2 STRESS3 STRESS4 STRESS5 STRESS 6 (1 THRU 2.99=2) (3 THRU 4.99=3).
STRESS6 (0).

FREQUENCIES /VARIABLES GENDER AGEGRP ETHNIC INCOME OCCUPAT EDUCA
RISKYES RISKNO MINORITY RESEARCH KNOW1 KNOW2 KNOW3 KNOW4
KNOW5 KNOW6 KNOW7 KNOW8 KNOW9 ACCESS1 ACCESS2 ACCESS3
ACCESS4 ACCESS5 STRESS1 STRESS2 STRESS3 STRESS4 STRESS5
STRESS6
/STATISTICS =.
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