African American Caregiver's Level of Knowledge About Alzheimer's Disease and Dementia and Its Relationship to Psychological Stress

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AFRICAN AMERICAN CAREGIVER’S LEVEL OF KNOWLEDGE
ABOUT ALZHEIMER’S DISEASE AND DEMENTIA AND
ITS RELATIONSHIP TO PSYCHOLOGICAL STRESS

By
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ABSTRACT

Caregivers of the elderly who suffer from AD and dementia have significantly high psychological stress. Alzheimer’s disease (AD) is a progressive degenerative disease that affects cognition, the ability to perform activities of daily living, and behavior. AD is the most common form of dementia, a group of disorders that impair mental functioning. Memory loss is one of the earliest symptoms of AD, along with a gradual decline of cognitive functions. Age is a key risk factor for AD in all racial and ethnic groups. Recent research has shown that the prevalence of AD in the African American community has graduated from a problem to an epidemic. Much of the burden of caring for patients with AD falls on family members, particularly spouses and adult children, predominantly female.

Because there is a lack of knowledge and awareness in the African American community about the disease, the progression of the disease, signs and symptoms, and resources available, many caregivers caring for individuals with AD and/or dementia suffer with physical illnesses and heightened levels of stress. This study examines the relationship between the level of knowledge and the level of psychological stress among African American primary caregivers of patients who have Alzheimer’s disease and/or dementia.

A sample size of 50 caregivers was obtained by convenience sampling. A cross-sectional design was employed in this study. Caregivers were asked to fill out a quiz and questionnaire regarding their knowledge and feelings about caring for a person with Alzheimer’s disease and/or dementia as well as some personal information about themselves.

Results of the study showed that increased knowledge about dementia was associated with higher levels of stress. Overall, there was a poor level of knowledge about dementia in African American caregivers. Caregiver stress was associated with relationship to the care recipient, showing that “others” were more stressed than spouses who took care of the elderly with dementia.

Caregivers’ lack of knowledge about the spiraling course of the disease may put them at risk for a multitude of psychological and physical health problems. Nurses can take an active role in educating the caregivers and public about the disease and providing access to available resources. Because African Americans demonstrated low levels of knowledge about dementia
in this study, efforts should focus on identifying the barriers to knowledge and their means of gaining information about dementia.
INTRODUCTION

Alzheimer’s disease (AD) is a progressive degenerative disease that affects cognition, the ability to perform activities of daily living, and behavior. AD is the most common form of dementia, a group of disorders that impair mental functioning. Memory loss is one of the earliest symptoms of AD, along with a gradual decline of cognitive functions. The progressive loss of cognitive function in AD is accompanied by pathologic changes in the brain known as plaques and neurofibrillary tangles. These pathologic changes in the brain are irreversible and nerve cells begin to shrink and die in several areas of the brain (Evans, 2002).

With increasing life expectancies and the increasing age of the population in the U.S., the number of people with AD will continue to rise. Age is a key risk factor for AD in all racial and ethnic groups. The number of African-Americans age 65 and over will more than double by 2030, from 2.7 million in 1995 to 6.9 million by 2030. Recent research has shown that the prevalence of AD in the African American community has graduated from a problem to an epidemic (Alzheimer’s Association, 2002). According to Laditka (2004), African Americans between the ages of 55 and 64 are three times more likely than Caucasians to develop early-onset Alzheimer’s. From ages 64 to 85, the AD rate in African Americans is twice as high as the rate in Caucasians. Today, it is estimated that more than 4.5 million Americans have AD. Worldwide, it is estimated that 18 million people have this disease. Unless something can be done to stem the rise, experts believe that as many as 13.2 million Americans will have the disease by the year 2050. AD usually begins after age 60 and risk increases with age. Younger people, in their 40s and 50s may get AD, but it is less common. The age group 85 years or older is one of the fastest growing segments of the population. It is also the group with the highest risk of AD (American, 2005).

People with AD live an average of 8 to 10 years after diagnoses, although some people may live as long as 20 years. The only way to accurately diagnose AD is to physically examine the brain of a probable Alzheimer’s sufferer after the patient has died (American, 2005). AD advances in stages: early, middle and late. AD progresses from mild forgetfulness to widespread loss of mental abilities. The development of symptoms
will differ from person to person and each stage will gradually progress over a period of years (Family, 2005).

Some of the most common symptoms seen in early stage are: trouble remembering recent events, conversation, the month or day of the week; tendency to lose things; poor judgment, withdrawal from social situations, and general apathy. Symptoms in the middle-stage are: difficult behaviors emerge; needing help with personal hygiene and getting dressed; increased difficulty in verbal expression and comprehension, loss of reading and writing abilities; and they may not recognize family and friends at times. Symptoms in the late stage are: inability to communicate; inability to recognize people, places and objects; loss of the ability to walk and smile; possible loss of ability to swallow; muscles may become contracted; incontinence; and spend majority of time sleeping (Alzheimer’s, 2001).

Persons with AD become dependent on others for every aspect of their care as the disease advances. Slightly more than half of AD patients receive care at home from family and friends. AD is often called a family disease, because the chronic stress of watching a loved one slowly decline affects everyone. Much of the burden of caring for patients with AD falls on family members, particularly spouses and adult children, predominantly female. Caregivers may spend 60 to 100 hours each week caring for their loved ones (Sadik, 2003). Caregiving can have deleterious mental health effects, as well as serious physical health consequences on caregivers. Studies have found that caregivers may have increased blood pressure, impaired immune systems, and may be at increased risk for cardiovascular disease among other health problems (Schulz, 1999). Many factors contribute to the stress caregivers experience and their changing health.

Statement of the Problem

There is a lack of research on the effects of dementia and AD in African Americans and major gaps in what is known about its effects on minority caregivers (McCann, Hebert, & Beckett, 2000). Research has suggested that African Americans are 14-100% more likely to have AD than Caucasians (Alzheimer’s Association, 2002). This poses a great concern in the African- American community because the number of African Americans over the age of 65 is expected to more than double by 2050. Upon the heels of this revelation comes the need to act now to ensure that African Americans are knowledgeable about the disease. The health care community must focus on
increasing access to information and care for both the patient and caregiver dealing with AD in the African American community. AD is sometimes referred to as a “silent” epidemic because it is so common and there is a lack of awareness and education about AD in the African American community. Many people don’t realize they have the disease, often dismissing the symptoms as just the signs of “old age”. Many African American caregivers mistake AD as a normal part of aging or confuse the disease with mental illness, something to be hidden away and never to be discussed outside of family. These misunderstandings and misperceptions about the disease, along with a mistrust of the medical system, often leads to a delay in seeking medical care earlier in the disease course. African Americans tend to be diagnosed at a later stage of AD, limiting the effectiveness of treatments that depend upon early intervention (Alzheimer’s Association, 2002). The consequences of this delay are that African American caregivers are not getting the information, support and assistance needed to effectively help them to prepare for and to meet the unique challenges presented in caring for someone with AD. This may put the African American caregiver at greater risk for physical and emotional problems associated with long-term care for a person with AD and/or dementia.

Caregivers of the elderly who suffers from AD and dementia have significantly high psychological stress. Caregiver stress has been well documented in the literature and reviews indicated prolonged consequences of poor physical and emotional health (Schulz & Beach, 1999). Symptoms of dementia were found to have a significant effect on caregivers’ level of stress (Dunkin & Anderson-Hanley, 1998). Gonzales-Salvador (1999) discovered that caregiver stress was found to increase with more advanced dementia. A number of individual factors have been related to stress. Specific factors which have been implicated in causing stress in caregivers include aspects of the patient’s illness, such as cognitive impairment, degree of difficulty with activities of daily living, presence of psychiatric symptoms, and problem behavior (Burns & Rabias, 2000).

Problem behavior has been reported to be the most stressful aspect of caregiving. Robinson, Adkinson & Weinrich (2001) suggested that caregivers experience higher level of stress because they have to more often cope with problem behaviors such as wandering, screaming, or destroying property. Other types of behaviors exhibited by the person with AD that caused the most stress in caregivers, particularly female caregivers, were depression behaviors and disruptive behaviors. Examples of depression behaviors
included: appearing sad and depressed, crying, making comments about hopelessness, death, being a burden, or threatening suicide. Examples of disruptive behaviors included: arguing, verbal aggression, and dangerous behavior to self or others. Caregiver reactions to depressive and disruptive behaviors may put them at risk for problems of declining physical and psychological health (Robinson et al., 2001).

Studies have also shown that the amount of time caregivers devote to caring for their family member or friend contribute to their stress (Sadik, 2003). Caregivers begin to feel that they have no control over their life anymore. They no longer have time for social activities or personal relationships. Caregivers who lack sufficient social support from family and friends are often put under heightened stress (Mittelman, 2001). Family conflicts, isolation, and loneliness further exacerbate the stress of caregiving.

**Significance of the Problem**

As the number of elderly persons suffering from AD and/or dementia continue to increase, the role of caregivers will continue to be important. Many African Americans are finding themselves taking on the role of caregiver to an older family member with the disease. Because there is a lack of knowledge and awareness in the African American community about the disease, the progression of the disease, signs and symptoms, and resources available, many caregivers caring for individuals with AD and/or dementia suffer with physical illnesses and heightened levels of stress. These problems suggest a need to raise awareness of AD as an increasingly important public health concern for African American caregivers.

Caregivers need to be well informed about the process of the disease and how to deal with the behavioral changes in order to provide the necessary care. Providing caregivers with education on the progression of the disease and what to expect during the different stages of the disease may help decrease their level of stress and help them cope with the situation. Mittelman (2001) found that providing caregivers with in-depth education, counseling and support had a major impact on the ability of caregivers to cope with behavioral problems, which in turn made it possible for the care recipient to stay at home longer instead of being institutionalized. Graham, Ballard & Sham (1997) found that caregivers who have a greater knowledge of dementia, when caring for a dependent with the disorder, experience significantly lower rates of depression than those caregivers who are less well informed.
Imparting knowledge to caregivers is an important task considering that more knowledgeable caregivers have lower rates of depression and more positive coping abilities. Caregivers who lack sufficient knowledge about AD and dementia often experience heightened levels of stress. Therefore, the purpose of this study is to determine if there’s a relationship between African-American caregivers level of knowledge about AD and dementia and the level of stress they experience.

**Research Question**

The research questions in this study are:

1. What is the relationship between the level of knowledge and the level of psychological stress among African American primary caregivers of patients who have Alzheimer’s disease and/or dementia?
2. Are there demographic variables that may be related to level of caregiver stress?

**Operational Definitions**

The terms defined in this study are:

1. Alzheimer’s disease: A neurological condition in which the nerve cells in the brain die. Alzheimer's disease is the most common form of dementia in older adults.
2. Dementia: A group of disorders that impairs mental functioning. Dementia symptoms include forgetfulness, problems with thinking, and difficulty performing daily activities.
3. Level of psychological stress: Biochemical response to feelings of being poorly in control and having the inability to cope with numerous difficult and challenging situations associated with caring for a person with AD and/or dementia on a routine bases as measured by the Zarit Burden Interview in this study.
4. African American primary caregiver: A person of African descent who provides the majority of care needed to maintain the physical or mental health of an older adult who suffers from dementia and/or Alzheimer’s disease. This individual may or may not live in the same residence with the individual and does not receive financial compensation for the care provided.
5. Level of knowledge: Knowledge the caregiver has on the subject of dementia and/or Alzheimer’s disease. General knowledge about the biomedical aspects of dementia and knowledge about caring for and coping with a person suffering from dementia as measured by the Dementia Quiz in this study.
6. Demographic Variables: Characteristics that describe the personal and social nature of the caregiver and care recipient as shown in the Demographic Questionnaire.

Assumptions
1. Caregivers will be honest about answering the questions.

Limitations
1. Generalizability of this study will be limited because of possible self-selection bias.
2. Selection of interested persons to participate in the study may make the sample bias.

Theoretical Framework

To better understand the processes of coping with stressful events, Lazarus and Folkman (1984) developed the Transactional Theory of Stress and Coping. The theory is composed of two parts: a primary appraisal and a secondary appraisal. Appraisals are influenced by an individual’s beliefs, values, goals and emotions, and the event is understood in terms of the personal significance it has for the individual (Stein, Folkman, Trabasso, & Richard, 1997). Primary appraisal refers to an evaluation of the situation with regard to its significance for the individual’s well-being. In this process the individual senses that something of importance is at stake in an encounter, for example, a loved one’s health or well-being. If the event is relevant to the person, the encounter is appraised as stressful. Secondary appraisal is an evaluation of the options and available resources for coping with the situation. When a transaction is appraised as stressful, coping is required. Lazarus and Folkman (1984) defines coping as “the person’s constantly changing cognitive demands and behavioral efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the resources of the person” (p. 141). Coping is thus an attempt to manage discomforting situations.

The theory outlines two types of coping: emotion-focused and problem-focused. Emotion-focused coping is directed at lessening emotional distress and a return to normal social and physiological functioning. Strategies used in this type of coping are avoidance, minimization, distancing, selective attention, and positive comparisons. Problem-focused coping is directed at defining the problem, generating alternative solutions, weighing the alternatives in terms of their costs and benefits, choosing among them, and acting. Cognitive processes can influence the outcome of stressful situations, and cognitive appraisal and coping are central to the theoretical perspective of this stress and coping theory (Lazarus and Folkman, 1984).
To better understand how knowledge plays a part in decreasing the level of stress caregivers’ experience, Betty Neuman (1989) developed the Neuman Systems Model. The model views the individual holistically from a system approach based on stress concepts and the individual’s reaction to stress. The whole system of the individual is comprised of five variables (physiological, psychological, socio-cultural, developmental, and spiritual) in interaction with the environment. The environment is considered all internal and external forces affecting the individual. The individual is the central core surrounded by concentric rings that represent three protective mechanisms, the normal line of defense, flexible line of defense, and lines of resistance.

The normal line of defense is the model’s outer solid circle. It represents the individual’s usual wellness state. It serves as a standard to assess deviations from the individual’s usual wellness. Factors which may influence the normal line of defense includes system variables and behaviors such as the individual’s usual coping patterns, lifestyle, and developmental factors as well as cultural considerations. The flexible line of defense is the model’s outer broken ring, which surrounds the normal line of defense. It is dynamic in nature and can be altered over a short period of time. It acts as a protective buffer to prevent stressors from invading the usual wellness state of the individual as represented by the normal line of defense. The lines of resistance protect the basic core structure and become activated when a stressor invades the normal line of defense. Variances in health or wellness are caused by the invasion of stressors through the normal line of defense (Neuman, 1989).

The Neuman system model looks at the impact of stressors on health and focus on achieving and maintaining client system stability through various levels of prevention. The model consists of three levels of prevention, primary, secondary and tertiary. For the purposes of this study, the focus will primarily be on primary prevention. Primary prevention occurs before the individual reacts to a stressor. It is used to protect the individual’s normal line of defense or usual wellness state by strengthening the flexible line of defense in the presence of stressors. Within this model, education will be used as the primary prevention method to attempt to strengthen the caregiver’s flexible line of defense by reducing his/her reaction to a stressor.

In primary prevention, African-American caregivers can strengthen their flexible line of defense by being knowledgeable about the progression of the disease, what to
expect during the different stages, and how to deal with difficult behavior. This knowledge may decrease the chances of experiencing heightened levels of stress. Being more knowledgeable about the disease can have a positive affect on the caregiver in terms of feeling more competent and confident in providing the care that is needed. Caregivers are more likely to have less expectation of the person’s abilities as the disease progress. Therefore, the needs for early intervention with education as a primary prevention is paramount in helping African American caregivers retain and/or maintain system stability.

In this study, the transactional theory of stress and coping along with Neuman system model will be used to determine if increased knowledge about AD and dementia has an affect on the level of stress caregivers’ experience.

Summary

AD and dementia pose challenges for both the person diagnosed with AD and the caregivers. Frequently, caring for an impaired elderly person can endanger the physical and mental health of caregivers. The role of the caregiver develops over time, with the early stages characterized by the caregiver taking over high-level functions, while becoming increasingly involved in self-care tasks, such as bathing and feeding. Caregivers struggle with great emotional and physical stress as they try to cope with the physical and mental changes in their loved ones. Many African American caregivers are not prepared for the many responsibilities that are associated with the disease, partly because they do not understand the course of the disease and what to expect during each stage as the disease progresses. Educating caregivers about the course of the disease will help them to understand the limitations of the elderly person with AD and/or dementia, which in turn may help lower their stress level. The transactional theory of stress and coping along with Neuman system model will be the theoretical framework for this study.
CHAPTER 2

REVIEW OF LITERATURE

This chapter presents selected literature as it relates to caregiver knowledge about Alzheimer’s disease and dementia and the level of stress they experience. Several studies show that caregivers experience heightened levels of stress when taking care of loved ones with Alzheimer’s disease and/or dementia. Some studies show that caregivers of Alzheimer and dementia patients lack knowledge about the disease itself and the downward course it will take as it advances.

Caregiver Knowledge and Stress

Ayalon (2004) evaluated ethnic group differences in knowledge of Alzheimer’s disease (AD) and to identify the role that level of education and level of acculturation play in ethnic group differences in knowledge of AD. There were a total of 193 participants in the study, 96 Anglo, 37 Latino, 30 Asian, and 30 African American. Participants had to be 55 years of age or older and to speak English or Spanish in order to participate in the study. All participants were given an AD quiz, which were read by trained research assistants in both English and Spanish. Variables measured were: knowledge of AD, which was assessed by 17 true-false questions; acculturation, which was defined as years living in the U.S. and years speaking English; education, derived from self-report; ethnicity; and other demographic information.

Results in the study showed significant differences in level of education with the Latino and the African American samples being less educated than the Anglo sample. No significant differences in level of education between the Anglo and the Asian samples. Significant ethnic group differences in knowledge of AD were found indicating that the Anglo sample was more knowledgeable about AD than the other ethnic groups. Level of education was partially responsible for higher levels of knowledge of AD among Anglo elderly relative to Latino elderly. In assessing level of acculturation, in the Asian sample, years of speaking English predicted knowledge of AD. For the Latino sample, neither years in the U.S. nor years of speaking English predicted knowledge of AD. This study suggest that many minority older adults remain ill-informed about the disease and that efforts should focus on identifying barriers to knowledge about AD and on identifying means of gaining information about AD (Ayalon, 2004).
Coen (1999) evaluated the impact of a dementia Carer Education Programme on caregiver quality of life, burden, and well-being. The Carer Education Programme consisted of eight weekly 2 hour education and support sessions covering general information on dementia and services available, management of everyday problems, Reality Orientation, communication techniques, coping with loss, management of stress, hospitalization, and legal issues. A total of 28 caregivers participated in the study and were interviewed by an experienced psychologist.

Patients were characterized in terms of cognitive status measured by the Mini Mental State Examination, behavioural status measured by the Dementia Behaviour Disturbance Scale, and functional status measured by Blessed-Roth Dementia Scale. Variables measured for caregivers included: quality of life, in which the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting was used; burden, in which Zarit Burden Interview was used; well-being, in which General Health Questionnaire was used; appraisal of informal social support, in which Vaux Social Support Appraisal Scale was used; and knowledge of dementia.

Results of the study showed there was a significant increase in knowledge about dementia, but no significant changes in quality of life, burden, or well-being. For some caregivers, as knowledge increased, there was evidence of poorer quality of life, increased burden, a poorer appraisal of social support, and increased patient behavior disturbance (Coen, 1999).

De Vugt (2004) agreed that specific caregiver strategies have an affect on the management and manifestation of behavioral problems. There were 99 informal caregivers of patients diagnosed with dementia who participated in the study. Patient measures in the study were behavioural problems, measured with the Neuropsychiatric Inventory and cognitive functioning, in which the Mini Mental Status Examination was used. Caregiver measures were caregiver competence, measured with the Short Sense of Competence Questionnaire and depressive symptoms, measured with the Montgomery-Asberg Depression Rating Scale. Caregivers were also given a semi-structured interview, which elicited information about the way caregivers manage the caregiving situation and how they deal with dementia-related problems. The semi-structured interviews were analyzed qualitatively to identify caregiver management strategies.
A total of three caregiver strategies were identified: nurturing, supporting and non-adapting. Nurturing indicated efforts to manage the patient by using a ‘parent-child approach’, in which the patient is taken by the hand and is no longer regarded as an equal. Supporting described efforts to manage the patient by adapting to the patient’s level of functioning and by stimulating his or her existing abilities. Non-adapting is characterized by a lack of understanding of the patient and of the situation. Caregivers primarily approached the patient with impatience, irritation or anger.

Results of the study showed there was a significant difference in caregiver functioning over time with the use of supporting strategy, as opposed to non-adapting strategy, which reported the lowest sense of competence over time. Caregivers who used non-adapting strategy reported higher levels of behavioral problems in patients than caregivers who used a supporting strategy (De Vugt, 2004).

Graham (1997) assessed whether a carer’s knowledge on the subject of dementia showed any correlation with physical and psychological morbidity and coping strategies. The participants in this study were primary caregivers of patients over the age of 65 who fulfilled the CAMDEX criteria for mild or moderate dementia. A total of 109 caregivers participated in the study. All caregivers were administered assessment schedules to assess: caregivers’ psychiatric health in which the Geriatric Mental State Schedule was used; caregivers’ physical health in which the Pennebaker Inventory of Limbic Languidness (PILL) was used; caregiver stress and caregiver coping strategies in which sections H, J and M of the Carer Stress Scale was used; and caregivers’ level of knowledge of dementia in which Dementia Knowledge Questionnaire was used. Psychiatric diagnosis for the caregiver was ascertained using the GMS-AGECAT program.

Findings in this study of caregivers’ level of knowledge as related to psychiatric morbidity showed that higher knowledge levels on the subject of dementia had significantly lower rates of depression (p= 0.023), but significantly higher rates of anxiety (p= 0.034). No positive or inverse correlation was found between caregivers’ knowledge and physical health. Also, there was no correlation found between caregivers’ knowledge levels and their feelings of ‘role captivity’.

The principle conclusion of this study shows that caregivers who have a higher level of knowledge of dementia experience significantly lower rates of depression than
those caregivers who are less well informed. Caregivers with higher levels of knowledge also have higher rates of anxiety, which may be the result of having too much information. Knowing the full extent of the disease and the course of decline it will follow may increase a caregivers’ anticipation of loss (Graham, 1997).

Hebert (2003) did a study to test the efficacy of a psychoeducative program in reducing caregivers’ reactions toward troublesome behaviors and indirectly reducing their burden, psychological distress, and anxiety, and improving their perception of social support and well-being. The study was a multicenter randomized controlled trial using assessments of participants before and after participation in the program. Participants in the study group received the experimental program and those assigned to the control group received the regular support group program. There were a total of 158 participants in the study, 79 in the study group and 79 in the control group. Inclusion criteria were: being the primary caregiver of a person with dementia for at least the previous 6 months; presenting a moderate or severe burden, which was scored on the Zarit Burden Scale; and caring for a person with dementia presenting as least one behavior problem per week.

Participants in the study group were given a group intervention that included fifteen 2-hour weekly sessions. The intervention was comprised of two components, cognitive appraisal and coping strategies. The participant first accurately appraises the specific stressful situation and identifies the type of stressor, based on its modifiable and nonmodifiable characteristics. The participant then chooses the appropriate coping strategy according to the type of stressor: problem-solving strategies when the stressor is modifiable or emotion-focus strategies when it is not or seeking social support.

Tools used to measure variables were: Revised Memory and Behavior Problem Checklist measured the frequency of behavioral and memory problems; Zarit Burden Interview which measured the subjective load experienced by the caregiver; Spielberger State-Trait Anxiety Inventory which measured anxiety; Inventory of Socially Supportive Behaviors which assessed four dimensions of support—informational, tangible, emotional, and integrative; and Ilfeld Psychiatric Symptoms Index which measured psychological distress.

Results of the study showed that study participants had a 14% decrease in their reactions to behavioral problems of care-receivers compared to a 5% decrease in the control group. The frequency of behavior problems also decreased (Hebert, 2003).
Marriott (2000) evaluated whether family intervention reduces the burden of care in caregivers of patients with Alzheimer’s disease (AD), as assessed by measures of psychological distress and depression and whether the intervention produces clinical benefits in the patients.

A prospective randomized controlled trial of family intervention was compared with two control groups with blind and independent assessment. A total of forty-two patient-caregiver dyads were included in the study, 14 being allocated to each group. Inclusion criteria were: patients had to satisfy DSM-III-R criteria for primary degenerative dementia of the Alzheimer type and the caregiver had to achieve psychiatric caseness with a score on the General Health Questionnaire of 5 or above, indicating significant psychological morbidity.

One of two control groups received an in-depth interview, the Camberwell Family Interview (CFI), and the other group received no interview. CFI covers specific areas such as household composition, psychiatric history, current problems and symptoms, and the quality of the relationship between patient and respondent. Family intervention consisted of three components: caregiver education, assessed by the Knowledge about Dementia Interview; stress management and coping skills training.

Caregiver assessment tools used were GHQ and Beck Depression Inventory, which assessed depression. Patient assessment tools used were Mini-Mental State Examination, which assessed cognitive function; Cornell Scale for Depression in Dementia, which assessed depressive symptoms in people suffering from dementia; MOUSEPAD, which assessed psychiatric symptoms and behavioural disturbances in dementia; and Clinical Dementia Rating, which assessed severity of dementia as mild, moderate, or severe. Results of study showed there were significant reductions (p=0.002) in distress and depression in the intervention group compared with control groups and there were reductions in behavioural disturbance at post-treatment (Marriott, 2000).

Morano (2002) developed and implemented a psychoeducational group model for Hispanic Alzheimer’s disease (AD) caregiver. The purpose for doing this study is there is limited intervention research in the literature that includes Hispanics. The focus of this study was to increase Hispanic caregivers’ knowledge of the progression and treatment of AD, to improve awareness of supportive services, to develop more effective coping skills, and to enhance caregivers’ ability to care for themselves.
A total of 20 caregivers were recruited from a local memory disorder clinic. Caregivers completed the Caregiver Knowledge Survey and a service utilization survey, which examined caregivers’ knowledge of the origin, treatment, prognosis, and management of AD. Caregivers were also questioned about their knowledge and use of community resources and support groups. A translation-back-translation methodology was used to ensure the accuracy of all measures. The Hispanic version of the instrument was used. Pre- and posttests were done to determine if participation in the program improved caregivers’ knowledge.

The proposed intervention was a 20-hr program that met on five consecutive mornings for 4 hours. Bilingual professionals from the Hispanic community were recruited to conduct sessions in their area of expertise. All sessions were conducted in Spanish. The program contents were devoted to providing factual information about AD and its progression; teaching caregivers how to recognize the antecedents of problematic behaviors and how to better manage these behaviors when they occurred; discussing the importance of structure for the person with AD and the type of activities that could be used in the home and AD services that provide caregiver assistance; and emotional consequences of being a caregiver.

Results of the program showed a significant increase (p< .05) in caregivers’ knowledge about AD, an increase in awareness of community-based services and a willingness to attend support groups. This study suggested a need for more intervention research with diverse ethnic groups. This study noted that majority of existing AD caregiving research has not included sufficient numbers of minority caregivers (Morano, 2002)

Proctor (2002) explored the relationship between caregivers’ existing knowledge of dementia and their reported levels of anxiety, depression and strain, and their preferred coping style. Participants of this study were caregivers of patients 65 years or older who was clinically diagnosed of having dementia and had a history of cognitive decline of at least six months. A total of 50 caregivers participated in the study. The type of research done was correlation.

The two types of coping style, monitoring and blunting, were explored to see whether differences in how caregivers respond to threat relevant information is correlated with levels of knowledge about dementia and reported psychological distress.
Individuals using monitoring coping style have been found to know more about the disease, but also to be more concerned about treatment side effects and risk. Individuals using blunting coping style avoid threat relevant information and thus blunt the psychological impact of the threatening information.

The use of questionnaires and patient symptom measures were administered to caregivers by the main researcher. The variables measured were socio-demographic information, patients’ clinical characteristics in which the Mini-Mental State Examination, Dementia Behavior Disturbance Scale, and Barthel Index of Activities of Daily Living were used. These tools assessed cognitive function, behavioral disturbance, and functional ability. Knowledge about dementia was determined by the Dementia Quiz; and coping style was assessed using the Miller Behavioral Style Scale. Caregiver strain, anxiety and depression were assessed using the modified version of the Machin Strain Scale and Hospital Anxiety and Depression Scale (HADS).

Results of the study showed an association between increased knowledge and higher levels of anxiety in which only biomedical knowledge was the predictor of anxiety for caregivers and the use of monitoring coping style. Blunting coping style was only correlated with knowledge of services. The duration of care was the strongest predictor of caregiver strain. There was no association between any of the independent variables and HAD depression (Proctor, 2002).

Ward (2003) did a study on the ways in which family members respond to the full range of behavioural and psychological symptoms. There were a total of 50 participants, who provided care to individuals with a diagnosis of dementia, which participated in the study. A skilled interviewer using the Manchester and Oxford University Scale for the Psychopathological Assessment of Dementia (MOUSEPAD) questioned caregivers. MOUSEPAD records the frequency, duration and severity of behavioural and psychological symptoms. In this study, psychological symptoms are categorized as delusions, hallucinations and misidentifications. Disturbed behaviours are categorized as excessive walking, disturbed sleep, physical aggression, verbal disruption, losing or hiding items and repeated questioning.

Caregivers were asked to describe their customary initial responses to each of the psychological and behavioural symptoms that occurred in the previous month and what they did if this first response proved unsuccessful. Caregiver responses were classified
using the eight-point typology developed by Dodds (1994) which included: reality orientation; diversion by means of activity and entertainment; sexual disinhibition; collusion with wrongly held beliefs; involving outsiders such as neighbors and police in monitoring wandering and conducting searches; avoidance of conflict through walking away; restricting movement; verbal and physical reprimands, and dispensing as-needed psychotropic medications. Three other categories were added by the researcher which were: providing guidance or reassurance; avoiding recognized symptom triggers; and other infrequent interventions.

Results showed that psychological and behavioural difficulties increased in line with dementia severity. Most symptoms were rated by caregivers as ‘no problem’ or a ‘mild problem’. Delusions, sexual disinhibition, physical aggression and verbal disruption presented the greatest difficulties to caregivers. The most common responses to psychological and behavioural symptoms were orientation, diversion, collusion, reassurance, and avoiding triggers. Involving outsiders, restricting movement, reprimands, medications, and other responses were used prominently for wandering. Verbal and physical reprimands, restriction of movement, and dispensing ‘as needed’ psychotropic medications were uncommon (Ward, 2003).

Werner (2001) examined family caregivers’ knowledge about Alzheimer’s disease (AD) and its correlates. A quantitative study was done using cross-sectional design with an intended audience of main informal caregivers of elderly persons suffering from AD. A total of 220 caregivers participated in the study that was recruited from large memory clinics across Israel. The participants were asked 17 questions derived from a modified version of the Alzheimer’s Disease Knowledge Test with culturally related items adapted to the Israeli population. The questions focused on knowledge about the prevalence, temporal process, causes and symptoms of the disease, the availability and effectiveness of drug treatment, and the availability and financing of services.

Knowledge about AD was the dependent variable. Independent variables included caregivers’ socio-demographic characteristics, such as, age, gender, level of education and income; the patients’ clinical characteristics, such as, cognitive functioning which was assessed by the Mini Mental State Examination; and characteristics of the caregiving situation, such as, duration of caregiving and relationship to the patient.
Results of the study displayed poor levels of knowledge overall. Lack of knowledge was especially seen for the items assessing the prevalence, causes and symptoms of the disease. The most important vulnerability factors associated with poor knowledge were low education and being a spouse (Werner, 2001).

Conceptual Framework

The Neuman Systems Model developed by Betty Neuman (Neuman, 1989) is a comprehensive framework that focuses on a total approach to client care. It is a model that is relevant for use by all health care disciplines. The Neuman Systems Model views the client, which is known as the caregiver in this study, as an interacting open and dynamic system in total interface with both the internal and external environment. Within the client system five variables exists. These variables consist of the psychological, physiological, sociocultural, developmental, and the spiritual. The model is based upon the client’s relationship to stress. The client is a system capable of input and output of extra-, intra-, and interpersonal factors from the environment. The client interacts with the environment by adjusting to it or adjusting the environment to itself, resulting in varying degrees of harmony, stability, or balance.

Neuman’s approach views the client as containing a central core, surrounded by a series of concentric rings. Neuman describes this central core as consisting of “basic survival factors common to the species, such as variables contained within it, innate or genetic features, and strengths and weaknesses of the system parts” (Neuman1989, p. 27). The three concentric rings function as protective mechanisms for the client system integrity and contain similar protective elements related to the five variables mentioned earlier. The three concentric rings are known as the lines of resistance, normal line of defense, and flexible line of defense.

Surrounding this basic central core are the lines of resistance. These lines are activated when environmental stressors invade the client system. The normal line of defense as described by Neuman “represents what the client has become, the state to which the client has evolved over time, or the usual wellness level” (Neuman1989, p. 30). It is used as a standard to determine any deviance from the usual wellness state. Factors that may influence the normal line of defense include life-style factors, system variables, coping patterns, developmental and spiritual influences, and cultural considerations. The
normal line of defense is considered dynamic in terms of its ability to become and remain stabilized as the client system deal with life stresses over time. The flexible line of defense surrounds the normal line of defense. It acts as a protective buffer system for the client’s normal or stable state. Neuman states, “it ideally prevents stressor invasions of the client system, keeping the system from stressor reactions, or symptomatology (Neuman1989, p. 28). The flexible line of defense is dynamic in nature and can be rapidly altered over a short period of time. Neuman describes it as having an accordionlike function as “it expands away from the normal defense line, greater protection is provided; as it draws closer, less protection is available” (Neuman1989, p. 28). Single or multiple stressors have the ability to reduce the effectiveness of this flexible line of defense. The client presents with symptoms of instability or illness once the lines of defense have been penetrated.

Neuman defines the environment as “all internal and external factors or influences surrounding the identified client or client system” (Neuman1989, p. 31). At any given time, the client may influence or be influenced by environmental forces either positively or negatively. The environment is classified as being internal, external, or created. The internal environment as described by Neuman “consists of all forces or interactive influences internal to or contained solely within the boundaries of the defined client/client system” (Neuman1989, p. 31). The external environment is made up of all external forces or influences existing outside of the defined client/client system. The created environment is an open system exchanging energy with both the internal and external environment. The created-environment represents the client’s mobilization of all system variables. Neuman states the created-environment “supersedes or goes beyond the internal and external environments, encompassing both” (Neuman1989, p. 32).

Neuman views health as being on a continuum from wellness to illness. “Health for the client is equated with optimal system stability, that is, the best possible wellness state at any given time” (Neuman1989, p. 37). The wellness-illness continuum implies that energy flow is continuous between the client and the environment. Neuman and Fawcett (2002, p. 24) states that client movement is towards wellness when more energy is being generated than used; when more energy is required than is being generated, movement is toward illness and possible death.
Keeping the client system stable is viewed by Neuman as the major concern for nursing. This is achieved through assessment of actual or potential effects of environmental stressors and assisting the caregiver with any adjustments required to maintain an optimal wellness level. Nursing actions are initiated to achieve and maintain client system stability through the use of various levels of prevention. Primary prevention as intervention occurs when the degree of risk is known but a reaction has not yet occurred. It is used to protect the client’s usual wellness state by strengthening the flexible line of defense. The goal is to promote client wellness by stress prevention and reduction of risk factors. Secondary prevention as intervention is used when there has been penetration of the client’s normal line of defense and a reaction has occurred. It is geared toward wellness attainment. The goal is to provide appropriate treatment of symptoms in an effort to conserve energy and obtain client stability. Tertiary prevention as intervention is used for maintenance of system stability following treatment. The goal is to maintain optimal wellness and support existing strengths within the client system.

Sources of stress are perceived as environmental stressors that directly impact on the mental and physical health of an individual, and also elicit coping responses. Helping the client to cope with a stressful event by reducing stressor input and increasing client resistance is paramount to maintaining client stability. This study will also employ a transactional model of stress and coping developed by Richard Lazarus and Susan Folkman (1984) to use as a framework for evaluating the processes of coping with stressful events in caregivers. Within this model stressful experiences are construed as person-environment transactions. Lazarus defines stress as “a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus and Folkman1984, p.21).

The way in which the caregiver appraises the caregiving situation influences the coping efforts put forth by him/her. According the Lazarus and Folkman’s model of stress and coping, individuals faced with a stressor make two appraisals, referred to as the primary and secondary appraisal. Primary appraisal involves assessing the situation by determining the extent to which the situation is threatening, controllable, or predictable. Secondary appraisal involves the individual’s assessment of his/or her ability to cope. Once the caregiver has appraised the situation, he or she then determines which coping strategies to employ in order to cope with the situation. Within this model, coping
is defined as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus and Folkman 1984, p. 141). Coping involves a constant process of trying out different ways of dealing with a situation, in order to feel better or to improve the situation. Caregivers facing a stressful situation/ or event may use a combination of coping strategies to deal with various stressors. According to Lazarus and Folkman (1984), an individual chooses from one of two types of coping strategies to deal with situation-specific demands. These two coping strategies are known as problem-focused and emotion-focused coping.

Problem-focused coping strategies are those whose aim is to improve a stressful situation by taking direct action. Examples of this include confronting the problem, seeking information, and seeking social support. These types of strategies are often used when the situation is seen as controllable. Emotion-focused coping strategies are those whose aim is to reduce one’s emotional response to a stressful situation. Examples of this include avoidance, wishful thinking, and regression. These strategies are often used when the situation is seen as uncontrollable or unchangeable.

The many stressors encountered by caregivers may require them to use a wide array of coping strategies and techniques. Some caregivers cope less well because they simply do not know how to use more effective coping strategies. Others simply choose an ineffective strategy for a specific situation. Coping strategies may be seen as adaptive or maladaptive. According to Lazarus and Folkman (1984) problem-focused coping strategies may be adaptational and effective if they facilitate interpersonal communication, secure social support, provide relevant information, increase feelings of personal control, and contribute to positive feelings. On the other hand, emotion-focused coping strategies may be maladaptive and ineffective if they facilitate feelings of guilt, contribute to withdrawal and avoidance behaviors, reduce emotional ventilation, and facilitate negative feelings. Coping strategies vary depending upon the type of situation and the individual person's habits and resources. The effectiveness of a coping strategy depends on the extent to which it is appropriate to the situation (Lazarus and Folkman 1984, p. 185). The use of a coping strategy may be effective in one situation, but totally ineffective in another.
Lazarus and Folkman's theory predicts that the relationship between the appraisal of stressors and outcomes is mediated by coping strategies. The ultimate effect of coping strategies may lead to a change in the caregiver’s interpretation of their relationship with the environment, which can lead to new appraisals. Caregivers who see their roles as meaningful can cope better in the caregiving role than those who define it in negative terms. Caregivers who experience more stress in their caregiver roles often feel stuck in a situation and powerless to change their circumstances, either because they do not know how to cope or because they use ineffective coping strategies. In order for caregivers to cope effectively in their roles, they must be able to balance the demands of caregiving with the resources available to them and the use of effective coping strategies. Effective coping can be beneficial to health, resulting in increased well-being.

Summary

The literature review revealed that many factors play a part in caregivers’ knowledge and its relationship to the level of stress they experience, such as socio-economic status, socio-demographic characteristics, the patient’s clinical characteristics, and caregiver’s relationship to the patient. Some studies revealed that there were significant reductions in stress and depression in caregivers who participated in intervention groups coupled with education on how to deal with behavioral problems, which is one of the main problems of the disease. Other studies show that caregivers who have a higher level of knowledge of the illness experience lower rates of depression, but higher rates of anxiety, which may be the result of too much information, the type of information given and the way it was presented. Another reason that may contribute to higher rates of anxiety in caregivers is that anxious caregivers seek more knowledge of the illness. Some studies showed there was a lack of knowledge about AD in some minority caregivers and that majority of AD research involves Caucasian participants. Even though literature shows that AD is more prevalent among African Americans compared to Caucasians, African-Americans have traditionally been under-represented in Alzheimer's research. More research is needed to understand the impact of AD and/or dementia on African American caregivers and the level of stress they may experience when taking care of someone with this debilitating disease.
Neuman Systems Model is a comprehensive framework that focuses on a total approach to client care. The model is based upon the client’s relationship to stress. Helping the client to cope with a stressful event by reducing stressor input and increasing client resistance is paramount to maintaining client stability.

Transactional Model of Stress and Coping is used as a framework for evaluating the processes of coping with stressful events in caregivers. The way in which the caregiver appraises the caregiving situation influences the coping efforts put forth by him/her. The many stressors encountered by caregivers may require them to use a wide array of coping strategies and techniques. The ultimate effect of coping strategies may lead to a change in the caregiver’s interpretation of their relationship with the environment, which can lead to new appraisals.
CHAPTER 3
RESEARCH METHODOLOGY

Methodology

This chapter presents the methods and procedures employed to address the research question, and plan for the actual collection of data. The implementation of the study’s design, sampling plan, instruments, procedures to follow, and data analysis will be discussed. Also, ways to protect human subjects will be discussed.

Research Questions

The research questions in this study are:
1. What is the relationship between the level of knowledge and level of stress among African American caregivers of patients who have Alzheimer’s disease and dementia?
2. Are there demographic variables that may be related to level of caregiver stress?

Design

In this study a cross-sectional survey was used to examine the relationship between knowledge and stress. The design determined whether there was no relationship between knowledge and stress or whether knowledge about Alzheimer’s disease and dementia increased or decreased the level of stress caregivers’ experience.

Setting

The settings for this study were various sites including senior citizen centers, adult day care centers and support groups in the North Florida counties.

Population and Sample

The sample for this study consisted of African-American primary caregivers, both male and female, of an elderly person with a diagnosis of Alzheimer’s disease and /or dementia as reported by the caregiver. Inclusion criteria: patient had to present with at least one behavior problem, reported by the caregiver, per week; and the caregiver must be the one who provided the majority of care needed. The population was limited to caregivers between the ages of 30-80 years. Additionally, the population was restricted to English-speaking caregivers. A sample size of 50 was obtained by convenience sampling.
Instruments

This study utilized the Zarit Burden Interview (ZBI), which assessed burden in caregivers. The tool was developed by Steve Zarit (1985) and consists of 22 questions. The possible score on the ZBI range from 0 to 110; a higher score indicated greater caregiver stress. The ZBI included factors most frequently mentioned by caregivers as problem areas such as caregiver’s health, psychological well-being, finances, social life, and the relationships between the caregiver and the patient with dementia. The ZBI was the instrument most consistently used in dementia caregiver research (Bedard et al., 2000). The ZBI has proven to have excellent internal consistency (alpha= 0.83 and 0.89) (Zarit et al., 1987).

A revised version of the Dementia Quiz (DQ) was also used to examine caregiver’s knowledge of the biomedical aspects, and how to care for a person with dementia. The tool was developed by Chris Gilleard and Fiona Groom and consists of 16 questions. The quiz was broken down into 2 sub-scales, measuring bio-medical knowledge and coping knowledge. The quiz was compared with a version of Dieckmann, Zarit, Zarit & Gatz’s (1988) Alzheimer’s Disease Knowledge Test (ADK), another test assessing knowledge about dementia. An examination of the internal reliability of both tests showed alpha coefficients ranged from .71 for the ADK and .88 for the DQ (Gilleard and Groom, 1994). The DQ is used as a means of assessing caregiver’s knowledge about one of the most disabling conditions affecting older people.

Socio-demographic information was gathered which included: age, gender, relationship to patient, living arrangements, length of time in the caring role, and employment status. The demographic questionnaire was developed by the researcher. Permission from the authors who developed the instruments was obtained before using the instruments in this study.

Procedure

Upon permission from the directors of the various centers to solicit volunteers to participate in the study and with approval from the thesis committee, the researcher applied for approval from the Institutional Review Board (IRB) at Florida State University. Once approved by the IRB, the researcher placed flyers in the family room of the centers to inform interested caregivers about the study and to seek volunteers. The researcher was also on site to recruit caregivers face-to-face. The information on the
flyer consisted of the title of the study, the reason the study was being done, eligibility criteria, and the researcher’s name and phone number so that interested volunteers can call. Email address was also given if there were any additional questions the participants may have.

Participants interested in the study were given the options of completing the questionnaires there on-site or mailing them back. Participants requesting to participate by mail were given a packet that included a cover letter describing the nature of the study, informed consent form, demographic questionnaire, burden interview questionnaire, and a survey on caregiver knowledge, along with a self addressed stamped envelope. Informed consent was implied if questionnaires were completed and returned to the researcher.

Participants were told that participation in this study was on a voluntary base and that no monetary gain will be offered. Participants were informed of the risk and benefits of the study and they have the right to withdraw from the study without penalty. The participants were informed that all information given will be kept confidential. No identifiers were recorded on the forms. The participants were also informed that all materials and forms will be kept in a locked safe at the researcher’s home. After completion of the research study the data will be kept for two years and then shredded. Participants were also given contact information to call the thesis Chair or member of the IRB if they had any concerns or questions.

**Protection of Human Subjects**

In this study the Nuremberg Code and the fundamental ethical principles were used to guide the ethical standards of research. The researcher strived to eliminate all harm and discomfort from the participant; assured the participants freedom from exploitation; informed participants of the right to decide voluntarily whether to participate in the study without coercion; inform participants of the right to know the nature of the study and their right to refuse participation; and ensured right to fair treatment and that privacy was maintained throughout the study.

**Data Analysis**

Data analysis in this study consisted of bivariate descriptive statistics, Pearson’s correlations, one-way ANOVA and cross-tabulation. This analysis tested the relationship between caregiver level of knowledge and caregiver level of stress simultaneously.
These statistics are normally used to establish that a relationship exists between two variables. Cross-tabulation determines the number of cases occurring when the two variables are considered simultaneously. The dependent variable was caregiver stress and independent variables were socio-demographic characteristics and caregiver knowledge.

Summary

In this chapter, the methodology was discussed. A cross-section design was chosen for this study. The physical location and conditions in which data collection took place was discussed. A plan specifying the method, sample size, and procedures for recruiting subjects was discussed, along with protecting human rights. Also bivariate descriptive statistics and cross-tabulation was used to organize and synthesize research data. The data was analyzed by using the Statistical Package for Social Sciences (SPSS), a software statistical package.
Sample Description (caregivers and care recipients)

Of the 50 caregivers who participated in this study, 42 (84%) were women and 8 (16%) were men. The mean age of the caregivers was 55.0 years (SD=11.5 years) with a minimum age of 30 years and a maximum age of 80 years. Twenty-three (46%) of the caregivers were married, 10 (20%) were single, 12 (24%) were divorced or separated, and 5 (10%) were widowed. Eleven (22%) of the caregivers had other caregiving responsibilities outside of taking care of the elderly person with dementia and 39 (78%) of the caregivers had no other caregiving responsibilities. Twenty-two (44%) of the caregivers received no assistance from family members in caring for the elderly relative and 28 (56%) did receive assistance. The average incomes for the caregivers were $20,000-$29,000. Most caregivers rated their health status as good or fair. A summary of the demographic information on the caregivers who took part in the study is presented in Table 1.

More than half of the care recipients were over the age of 75. The mean age of the care recipient was 76.3 years (SD=9.3) with a minimum age of 50 years and a maximum age of 94 years. Thirty-six (72%) of the care recipients were women, and 14 (28%) were men. See Table 2 for other descriptive information on the care recipient.

Table 3 presents characteristics of the caregiving situation. Thirty four (68%) of the care recipients stayed in the same household as the caregiver. Eighteen (36%) of the caregivers were daughters. Thirty two (64%) had been caregivers for 1-5 years. For more information on the caregiving situation, see Table 3.
Table 1

Caregivers’ Demographic Characteristics

<table>
<thead>
<tr>
<th>Educational Level</th>
<th>N</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some High School</td>
<td>7</td>
<td>14.0%</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>15</td>
<td>30.0%</td>
</tr>
<tr>
<td>Vocational/Technical School</td>
<td>13</td>
<td>26.0%</td>
</tr>
<tr>
<td>Associate Degree</td>
<td>4</td>
<td>8.0%</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>7</td>
<td>14.0%</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>4</td>
<td>8.0%</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>N</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Time</td>
<td>23</td>
<td>46.0%</td>
</tr>
<tr>
<td>Part Time</td>
<td>5</td>
<td>10.0%</td>
</tr>
<tr>
<td>Not Employed</td>
<td>3</td>
<td>6.0%</td>
</tr>
<tr>
<td>Retired</td>
<td>19</td>
<td>38.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Yearly Household Income</th>
<th>N</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$10,000</td>
<td>1</td>
<td>2.0%</td>
</tr>
<tr>
<td>$10,000 - $19,999</td>
<td>8</td>
<td>16.0%</td>
</tr>
<tr>
<td>$20,000 - $29,999</td>
<td>16</td>
<td>32.0%</td>
</tr>
<tr>
<td>$30,000 - $39,999</td>
<td>15</td>
<td>30.0%</td>
</tr>
<tr>
<td>$40,000 - $49,999</td>
<td>4</td>
<td>8.0%</td>
</tr>
<tr>
<td>&gt;$50,000</td>
<td>6</td>
<td>12.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health Status of Caregiver</th>
<th>N</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>8</td>
<td>16.0%</td>
</tr>
<tr>
<td>Good</td>
<td>28</td>
<td>56.0%</td>
</tr>
<tr>
<td>Fair</td>
<td>12</td>
<td>24.0%</td>
</tr>
<tr>
<td>Poor</td>
<td>2</td>
<td>4.0%</td>
</tr>
</tbody>
</table>
Table 2

Care Recipients’ Demographic Characteristics

<table>
<thead>
<tr>
<th>Race of Care Recipient</th>
<th>N</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>47</td>
<td>94.0%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>2</td>
<td>4.0%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender of Care Recipient</th>
<th>N</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>36</td>
<td>72.0%</td>
</tr>
<tr>
<td>Male</td>
<td>14</td>
<td>28.0%</td>
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</table>

<table>
<thead>
<tr>
<th>Health Status of Care Recipient</th>
<th>N</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>1</td>
<td>2.0%</td>
</tr>
<tr>
<td>Good</td>
<td>7</td>
<td>14.0%</td>
</tr>
<tr>
<td>Fair</td>
<td>23</td>
<td>46.0%</td>
</tr>
<tr>
<td>Poor</td>
<td>19</td>
<td>38.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary Medical Problem</th>
<th>N</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular disease</td>
<td>23</td>
<td>46.0%</td>
</tr>
<tr>
<td>Respiratory disease</td>
<td>2</td>
<td>4.0%</td>
</tr>
<tr>
<td>Gastrointestinal disease</td>
<td>2</td>
<td>4.0%</td>
</tr>
<tr>
<td>Urological disease</td>
<td>1</td>
<td>2.0%</td>
</tr>
<tr>
<td>Endocrine disorder</td>
<td>7</td>
<td>14.0%</td>
</tr>
<tr>
<td>Neurological disorder</td>
<td>6</td>
<td>12.0%</td>
</tr>
<tr>
<td>Psychiatric disease</td>
<td>1</td>
<td>2.0%</td>
</tr>
<tr>
<td>No other medical problems</td>
<td>8</td>
<td>16.0%</td>
</tr>
<tr>
<td>Living Arrangements of Care Recipient</td>
<td>N</td>
<td>% of Participants</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>-----</td>
<td>-------------------</td>
</tr>
<tr>
<td>Lives in same household as caregiver</td>
<td>34</td>
<td>68.0%</td>
</tr>
<tr>
<td>Live alone</td>
<td>14</td>
<td>28.0%</td>
</tr>
<tr>
<td>Lives in assisted care facility</td>
<td>1</td>
<td>2.0%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Length of Time as Caregiver</th>
<th></th>
<th></th>
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<tbody>
<tr>
<td>&lt;1 year</td>
<td>6</td>
<td>12.0%</td>
</tr>
<tr>
<td>1-5 years</td>
<td>32</td>
<td>64.0%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>9</td>
<td>18.0%</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>3</td>
<td>6.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relationship to Care Recipient</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>8</td>
<td>16.0%</td>
</tr>
<tr>
<td>Son</td>
<td>3</td>
<td>6.0%</td>
</tr>
<tr>
<td>Daughter</td>
<td>18</td>
<td>36.0%</td>
</tr>
<tr>
<td>Friend</td>
<td>5</td>
<td>10.0%</td>
</tr>
<tr>
<td>Other</td>
<td>16</td>
<td>32.0%</td>
</tr>
</tbody>
</table>
Instruments used to measure variables

Two primary scales were used to measure variables within this study. Caregivers experience of psychological stress was the dependent variable and was assessed using the Burden Interview scale. The primary independent variable was knowledge about dementia that was assessed using the Dementia Quiz. The Dementia Quiz was also broken down into two sub-scales, assessing biomedical knowledge and coping knowledge. Other independent variables included the caregivers and care recipients socio-demographic characteristics and characteristics of the caregiving situation. For descriptive statistics on the two primary scales see Table 4.

Table 4

Means, Standard Deviations, Ranges, Minimums and Maximums for Primary Scales

<table>
<thead>
<tr>
<th>Scale Name</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Stress</td>
<td>55.8</td>
<td>15.4</td>
<td>64.00</td>
<td>24.0</td>
<td>88.0</td>
</tr>
<tr>
<td>Dementia Knowledge</td>
<td>46.2</td>
<td>15.9</td>
<td>57.00</td>
<td>18.0</td>
<td>75.0</td>
</tr>
<tr>
<td>Biomedical</td>
<td>36.3</td>
<td>16.3</td>
<td>57.00</td>
<td>14.0</td>
<td>71.0</td>
</tr>
<tr>
<td>Coping</td>
<td>53.2</td>
<td>21.8</td>
<td>77.00</td>
<td>22.0</td>
<td>99.0</td>
</tr>
</tbody>
</table>

Relationship between Dementia Knowledge and Caregiver Stress

To examine the overall relationship between dementia knowledge and caregiver stress, Pearson correlations were calculated between the two variables. A significant positive correlation between dementia knowledge and caregiver stress was observed ($r = 0.300$, $p = .034$), indicating that higher levels of knowledge about dementia was associated with higher levels of caregiver stress. Pearson correlations were also performed between the knowledge scores on the two sub-scales of the Dementia Quiz and caregiver stress. There was a positive association between coping knowledge ($r = 0.393$, $p = .005$) and caregiver stress, but not biomedical knowledge. These finding indicated that increased knowledge about caring for and coping with a person with dementia was associated with increased caregiver stress. See Table 5 for correlations between dementia knowledge, sub-scales, and caregiver stress.
Table 5

Correlation between Dementia Knowledge, Sub-scales, and Caregiver Stress

<table>
<thead>
<tr>
<th>Dementia Knowledge</th>
<th>Correlation with Caregiver Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>.300*</td>
</tr>
<tr>
<td>Biomedical knowledge</td>
<td>.009</td>
</tr>
<tr>
<td>Coping knowledge</td>
<td>.393*</td>
</tr>
</tbody>
</table>

* A significant correlation exists

**Caregivers Level of Knowledge about Alzheimer’s Disease/ Dementia**

Overall caregivers displayed poor levels of knowledge about Alzheimer’s disease and dementia. As many as 47 caregivers’ (94%) failed the Dementia Quiz with a score of 68 or lower. Lack of knowledge was especially noticeable for the items assessing the biomedical aspects of dementia. Low levels of knowledge were found to be associated with age. Pearson correlations were calculated between dementia knowledge and caregiver age and an inverse relationship was observed ($r = -.392$, $p = .005$), indicating that older caregivers were less knowledgeable about dementia.

**Relationship between Independent Variables, Dementia Knowledge, and Caregiver Stress**

To determine if certain demographic variables were significantly related to dementia knowledge and caregiver stress, a One-Way ANOVA was performed between the two measures and selected socio-demographic characteristics of caregivers, care recipients, and the caregiving situation. A significant difference was found between relationships to care recipient on the level of caregiver stress, $F (4, 45) = 3.56$, $p = .013$. Tukey Post Hoc tests were done to see exactly which pairs of groups were significantly different. The tests showed that there were significant differences between spouse and others. Findings indicated that others reported significantly more caregiver stress than spouses. No significant difference was found between relationship to care recipient and dementia knowledge.

A significant difference was found between educational levels on the level of dementia knowledge, $F (5,44) = 6.10$, $p = .001$. Tukey tests showed that there were significant differences between some high school and Bachelor’s degree, some high
school and Master’s degree, high school graduate and Master’s degree, vocational school and Master’s degree, and Associate degree and Master’s degree. Findings indicated that caregivers with a Master’s degree were more knowledgeable on the subject of dementia. No significant difference was found between educational levels and caregiver stress.

A significant difference was found between employment status on the level of dementia knowledge $F(3,46) = 3.24, p = .030$. Tukey tests showed that there were significant differences between full-time and retired caregivers. Findings indicated that caregivers who worked full-time were more knowledgeable on the subject of dementia than ones who were retired. No significant difference was found between employment status and caregiver stress. There were no significant associations found between caregiver health status, duration of caregiving, living situation, and income on the level of dementia knowledge and caregiver stress. See Table 6 for means and standard deviations on select variables mentioned above when comparing groups to dementia knowledge and caregiver stress using ANOVA. See Table 7 for degrees of freedom, mean square, F-test, and P-value.

Table 6

Means and Standard Deviations for Multiple Comparisons

<table>
<thead>
<tr>
<th>Dementia Knowledge</th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational Level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>7</td>
<td>32.7</td>
<td>10.1</td>
</tr>
<tr>
<td>High school graduate</td>
<td>15</td>
<td>41.2</td>
<td>14.6</td>
</tr>
<tr>
<td>Voc/technical school</td>
<td>13</td>
<td>46.3</td>
<td>13.7</td>
</tr>
<tr>
<td>Associate’s degree</td>
<td>4</td>
<td>43.2</td>
<td>13.4</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>7</td>
<td>57.4</td>
<td>12.3</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>4</td>
<td>71.5</td>
<td>4.0</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>23</td>
<td>52.8</td>
<td>15.3</td>
</tr>
<tr>
<td>Retired</td>
<td>19</td>
<td>40.3</td>
<td>15.9</td>
</tr>
<tr>
<td>Burden Interview</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship to care recipient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>8</td>
<td>48.0</td>
<td>19.4</td>
</tr>
<tr>
<td>Other</td>
<td>16</td>
<td>66.3</td>
<td>12.1</td>
</tr>
</tbody>
</table>
Table 7

Degrees of freedom, Mean Squares, F-tests, and P-values for ANOVA

<table>
<thead>
<tr>
<th>Burden Interview</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to Care Recipient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>4</td>
<td>700.756</td>
<td>3.568</td>
<td>.013*</td>
</tr>
<tr>
<td>Within Groups</td>
<td>45</td>
<td>196.422</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living Situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>3</td>
<td>274.785</td>
<td>1.168</td>
<td>.332</td>
</tr>
<tr>
<td>Within Groups</td>
<td>46</td>
<td>235.167</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of Caregiving</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>3</td>
<td>232.988</td>
<td>.979</td>
<td>.411</td>
</tr>
<tr>
<td>Within Groups</td>
<td>46</td>
<td>237.893</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Health Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>3</td>
<td>247.263</td>
<td>1.043</td>
<td>.382</td>
</tr>
<tr>
<td>Within Groups</td>
<td>46</td>
<td>236.962</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of Services Utilized</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>3</td>
<td>627.359</td>
<td>2.957</td>
<td>.042*</td>
</tr>
<tr>
<td>Within Groups</td>
<td>46</td>
<td>212.173</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church Members Support Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>1</td>
<td>912.173</td>
<td>4.081</td>
<td>.049*</td>
</tr>
<tr>
<td>Within Groups</td>
<td>48</td>
<td>223.538</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Dementia Quiz                           |     |             |      |      |
| Educational Level                       |     |             |      |      |
| Between Groups                           | 5   | 1023.197    | 6.108| .001*|
| Within Groups                            | 44  | 167.514     |      |      |
| Total                                    | 49  |             |      |      |
| Employment Status                       |     |             |      |      |
| Between Groups                           | 3   | 726.285     | 3.241| .030*|
| Within Groups                            | 46  | 224.081     |      |      |
| Total                                    | 49  |             |      |      |

*A significant relationship exist
Relationship between Utilization of Services and Caregiver Stress

To determine if the numbers of services used were significantly related to caregiver stress, a One-Way ANOVA was performed between the two groups. A significant difference was found between the numbers of support services utilized on the level of caregiver stress, F(3,46) = 2.95, p = .042. Tukey tests showed a difference in mean score on the Burden Interview, among those who used no services (M = 47.4, SD = 19.7) and those who used two services (M = 64.1, SD = 8.3). Findings indicate that caregivers who used two services had a significantly higher mean burden than caregivers who used no services.

To determine if utilization of individual services were significantly related to caregiver stress, a One-Way ANOVA was performed for each service utilized. A significant difference was found between utilization of church members as a source of support and those not using church members F (1,48) = 4.08, p = .049. Caregivers using church members as a source of support reported a higher mean burden (M = 61.3, SD = 12.7) than caregivers not using church members (M = 52.5, SD = 16.1). No other significant differences were found between the other support services and caregiver stress. See Table 8 for the number of caregivers who did and did not utilize select services, along with the means and standard deviations related to caregiver stress.

Table 8

Means and Standard Deviations for Types of Services Utilized and Caregiver Stress

<table>
<thead>
<tr>
<th>Support Services</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Health Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=11)</td>
<td>60.1</td>
<td>13.4</td>
</tr>
<tr>
<td>No (n=39)</td>
<td>54.6</td>
<td>15.8</td>
</tr>
<tr>
<td>Respite Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=6)</td>
<td>54.6</td>
<td>12.6</td>
</tr>
<tr>
<td>No (n=44)</td>
<td>56.0</td>
<td>15.8</td>
</tr>
<tr>
<td>Adult Day Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=6)</td>
<td>61.3</td>
<td>20.6</td>
</tr>
<tr>
<td>No (n=44)</td>
<td>55.1</td>
<td>14.7</td>
</tr>
</tbody>
</table>
Table 8 continued

<table>
<thead>
<tr>
<th>Support Services</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=6)</td>
<td>56.1</td>
<td>14.6</td>
</tr>
<tr>
<td>No (n=44)</td>
<td>55.8</td>
<td>15.6</td>
</tr>
<tr>
<td>Church Members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=19)</td>
<td>61.3</td>
<td>12.7</td>
</tr>
<tr>
<td>No (n=31)</td>
<td>52.5</td>
<td>16.1</td>
</tr>
<tr>
<td>Friends/Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=34)</td>
<td>57.1</td>
<td>13.1</td>
</tr>
<tr>
<td>No (n=16)</td>
<td>53.1</td>
<td>19.6</td>
</tr>
</tbody>
</table>

Relationships Between Crosstabulated Variables

To determine what support services were used the most by specific caregivers’ within each select group, cross tabulation was performed between relationship to care recipient and utilization of support services. There were no significant statistical relationships found between the cross tabulated variables. Chi-Square tests were not significant in each category because there were insufficient numbers of observation and expected counts were too low.

Even though the relationships between the cross tabulated variables were not significant, the data told which caregiver used the greatest amount of services within specific groups. Out of the 34 caregivers who used family/other as a source of support, n= 13 (38%) were daughters and 13 (38%) were other. Out of the 19 caregivers who used church members as a support system, n= 10 (52%) were “other”. Out of all the support services, caregivers utilized church members and friends/others the most.

Other cross tabulations that were not statistically significant, but warrant mentioning were the relationships between length of time as caregiver and caregiver health status. Data showed that majority of the respondents, n= 32 (64%) have been caregivers for 1 to 5 years. Out of those 32 caregivers, 18 rate their overall health as good. Only 2 (100%) caregivers rated their health as poor and the length of time caregiving was 6 to 10 years. Most of the caregivers, n= 28 (56%) rated their overall health as good, followed by 12 (24%) who rated their overall health as fair. There were
only 3 (6%) respondents who were caregivers for more than 10 years and rated their health as either fair or good.

Summary

In summary, a significant positive correlation was found between dementia knowledge and caregiver stress. A significant difference was also found between spouses and others on the level of caregiver stress. A significant difference was found between the numbers of support services utilized on the level of caregiver stress. Finally, out of all the support services, caregivers’ utilized informal support services the most.
CHAPTER 5

DISCUSSION

Discussion

This study set out to explore the relationship between African American caregivers’ level of knowledge about Alzheimer’s disease and dementia and its relationship to psychological stress. Additionally, this study sought to determine if there were demographic variables that may be related to level of caregiver stress. The results showed that caregivers’ who were more knowledgeable about dementia also experienced a higher level of caregiver stress. This finding supported the results reported by Graham, Ballard, and Sham (1997). These researchers found that caregivers with higher knowledge levels on the subject of dementia had significantly higher rates of anxiety and lower rates of depression. In the present study, increased caregiver stress was associated with knowledge on how to cope with and care for a person with dementia. This can possibly be due to caregivers feeling inadequate when it comes to providing the care required to a person with dementia. This finding was the opposite of findings reported by Proctor, Martin, and Hewison (2002). Their research showed that caregivers who demonstrated more knowledge on the biomedical aspects of dementia experienced higher levels of anxiety. A reason for this as stated in the study is that increased awareness of biomedical aspects of dementia may heighten caregivers’ anticipation of loss.

Results of this study also showed that caregivers displayed a poor level of knowledge on the subject of dementia. Out of the fifty caregivers, only three passed with a grade of 75 or higher. Examination of relationship to care recipient showed that “others” scored higher on the Dementia Quiz, followed by daughters. Low levels of knowledge about dementia were also found to be associated with age. A possible explanation for this finding is lack of access to relevant, up-to-date information. Many elderly persons only have television and radio as their main source for information. Also, caregivers’ with higher educational levels were found to be more knowledgeable on the subject of dementia. These findings were consistent with results reported by Werner (2001), stating that caregivers with at least 12 years of education and higher had especially higher levels of knowledge on the subject of AD. Retired caregivers were found to have lower levels of knowledge compared to caregivers’ who worked full-time.
A possible explanation for this finding is caregivers who work full-time may feel overwhelmed with the responsibilities of maintaining employment and providing care to a person who requires a lot of time, therefore, caregivers seek more information to help deal with the stress of caregiving.

Consistent with other studies, majority of the caregivers in this study were females and daughters to the care recipient. Previous studies have shown that daughters experienced higher stress, followed by spouses. This study showed that “others” experienced higher levels of stress compared to spouses when taking care of the person with dementia. Finding in this study was not consistent with the findings of Gilhooly (1984) regarding relationship to the care recipient and the level of stress experienced. This researcher found that the more removed the caregiver is from the patient in terms of blood relationship and role, the better the caregiver’s psychological health. There were no significant relationships found between caregiver health status, length of time as a caregiver, living situation, income, and caregiver stress. Also, there were no significant relationships were found between other caregiver responsibilities, gender of care recipient, additional medical problems, and caregiver stress. The relationship to care recipient was the strongest predictor of caregiver stress.

This study also showed that majority of the caregivers used friends/other as a source of support, followed by church members. Findings in this study showed that caregivers who utilized church members as a source of support reported increased stress. One possible explanation for this finding is that overly stressed and burdened caregivers seek spiritual support. This finding supported the research of Cox and Monk (1996). They reported that rather than alleviating stress and protecting caregivers, social support can contribute to a sense of burden or strain. Ten of the caregivers did not use any support services and very few of them used formal support services. This may be due to the lack of awareness about the availability of services. Another explanation for this finding is caregivers did not feel they needed assistance from services at the time because of a low level of stress and adequate support from family and friends. The non-use of formal support services may also be due to lack of finances, especially for retired caregivers. Some of the caregivers in this study verbalized their willingness to use services but were unable to do so because of cost.
As this study has shown, many African American caregivers seek support from family members, friends, and the church. Cultural norms may also be a possible explanation for the lack of formal support service usage by African American caregivers. In African American families, caregiving is seen as a traditional family value. There are strong expectations and a sense of obligation that family members will take care of their own elderly relatives with dementia, which may prevent seeking support outside of the family network. The caregiving role is shared within a family network and assumed by multiple members of the family and extended family, even though previous research has shown that majority of caregivers are daughters.

The descriptive findings in this study demonstrated that the majority of respondents have been caregivers for 1 to 5 years. Most of the caregivers rated their overall health as good. Over half of the care recipients lived in the same household as the caregiver.

Limitations of the Study

The size of the sample in this study was small. The use of a sample of convenience did not allow generalization. This research study was not able to determine a causal relationship between two variables because the use of cross-sectional design would not allow it.

Implications for Nursing

As the population age, the prevalence of Alzheimer’s disease and dementia will increase. Many family members will be taking on the role of caregiver. In light of these projections, the effect of caregiving on families is an important societal issue and requires efforts to understand and support family caregivers. Nurses are in an ideal position to ease the stress of caregiving. Assessment of the caregiving situation can lead to positive outcomes for the caregiver and care recipient. As many studies have shown, there is a lack of awareness in the community regarding Alzheimer’s disease and dementia. Caregivers’ lack of knowledge about the spiraling course of the disease may put them at risk for a multitude of psychological and physical health problems. Nurses can take an active role in educating the caregivers and public about the disease and providing access to available resources. Education may facilitate early detection of dementia and assist caregivers in getting a diagnosis and initiating early treatment.
Nursing Education

This study suggests that more cultural awareness needs to be incorporated into the preparation of nurses. Nursing students need to develop an understanding of the large array of needs in the person with Alzheimer’s disease and dementia and the effect these needs have on the caregiver. Being able to understand these needs may lead to identifying demands and challenges that may create caregiver stress. Providing nurses with the education they need to help caregivers cope with difficult situations and to find available resources is paramount to reducing caregiver stress. Nurses being more knowledgeable about how Alzheimer’s disease affects the African American community can help them to provide more culturally congruent care. Working towards increasing awareness and education about Alzheimer’s disease in the African American community, nurses should focus on exploring the potentially significant roles that religious institutions could play in providing outreach and support to this ethnic group. The church is central to the African American community and is typically perceived as a trusted, healing resource that offers a sense of belonging and support (McRae, Carey, and Anderson, 1998). Partnering with religious institutions may help nurses and other health professionals reach this underrepresented population to provide educational interventions that can reduce the stress and burden often associated with caregiving.

Advance Practice Nurse

Addressing caregiver stress is a very important aspect in the treatment of Alzheimer’s disease. Therefore, it is important for nurse practitioners to have an understanding of complex factors associated with caregiver stress in African Americans. Nurse practitioners must understand that culture plays a big part in African American caregivers’ perceptions about Alzheimer’s disease. Providing culturally sensitive care has the potential to increase caregivers’ usage of formal support services, which in turn, can prevent some of the negative consequences of long-term caregiving. For optimal wellness for both the patient and caregiver, nurse practitioners also need to be aware of the significance in using pharmacological and psychosocial interventions in improving management of Alzheimer’s disease and dementia.
Implications for Future Research

There is an urgent need for research focused on the identification of ethnic minority elderly with dementia in primary care settings. Many African Americans are diagnosed with AD in the later stage where treatment is limited. It would also be helpful if research were focused on expanding the knowledge about the warning signs of AD. Because African Americans demonstrated low levels of knowledge about dementia in this study, efforts should focus on identifying the barriers to knowledge and their means of gaining information about dementia. More research need to be done that looks at patient and caregiver issues in African Americans. Also, future research should focus on the role of community resources for African American caregivers and examine why the formal health care system is low on the list of social support systems for minorities. In addition research needs to determine African American caregivers’ expectations of and barriers to using services.

Discussion of Theoretical Framework

Caregivers experience significantly high levels of stress when caring for someone with dementia. Some of the stress experienced by caregivers resulted from lack of knowledge about the prevalence, signs and symptoms, progression of the disease, and effective ways of coping with behavioral problems. According to Neuman Systems Model, which focuses on an individual’s relationship to stress and the impact it has on the person’s health, stressors are capable of having either a positive or negative effect on caregivers. For caregivers who are frequently faced with stressors, this focus is particularly relevant. A stressor is any environmental force which can potentially affect the stability of the client system. Stressors are identified as intrapersonal, interpersonal, or extrapersonal that has the potential for disrupting system stability. Such stressors may invade the normal line of defense, or the client's usual health state, unless warded off by a concept referred to as the flexible line of defense. Once the normal line of defense has been invaded, a stress response occurs. Within the caregiver’s environment, intrapersonal stressors that have been found to increase caregiver stress included the caregiver’s health, relationship to care recipient, role conflict/stress, and the existence of any problematic behavior from the care recipient. The lack of family support, along with lack of knowledge on the subject of dementia was examples of interpersonal stressors. Extrapersonal stressors included financial concerns and legal issues.
Understanding the effects of stressors on caregivers can assist the nurse in achieving and maintaining their usual state of wellness through various levels of prevention. In this study, educational intervention was used as the primary prevention method to protect the caregiver’s normal line of defense by strengthening the flexible line of defense. Educating African American caregivers on the subject of Alzheimer’s disease and dementia can help reduce the level of stress they may experience when taking care of some one with the disease. Previous research has found that educating caregivers about dementia can give them a sense of control over their situation and improve their coping abilities (McFarland & Sanders, 1999). This in turn may delay the institutionalization of the care recipient longer. Graham (1997) found that more knowledgeable caregivers felt more competent and confident as caregivers and were more likely to have reduced expectations’ of their dependants’ abilities.

Providing caregivers with the resources and education they need in the early stages of the disease can act as a buffer to reduce the caregivers’ reaction to a stressor. At this point primary prevention is being used to maintain system stability. Research has shown that African American caregivers rarely seek help in the early stages of the disease, partly because of lack of knowledge. Usually African American caregivers enter the health care system at a point where initiation of services is needed to help deal with the crisis they find themselves in. This intervention would be known as secondary prevention. Attendance of support groups by the caregivers following a reaction to a stressor was seen as tertiary prevention to help return caregivers to their usual wellness state.

Working towards maintaining an optimal level of wellness, caregivers need to learn how to use strategies which allow them to successfully manage a stressful situation. The negative influence of stress on health is thought to be buffered by effective coping. The way in which African American caregivers appraise the caregiving situation determines whether or not they experience caregiver stress. According to the Transactional Theory of Stress and Coping, a proper appraisal of the stressful situation is essential to effective coping. Caregivers may appraise the caregiving situation as either changeable or unchangeable, which in turn determines the type of coping style to be used. Problem behaviors of the care recipient were reported to be associated with high levels of caregiver stress (Gonzalez, 1999). Problem-focused coping is most often used when the
stressor is appraised as changeable. An example of this is when the care recipient exhibits problem behaviors such as agitation or aggression. Emotion-focused coping is used to manage a situation that is felt to be unchangeable. An example of this is when the care recipient cannot remember a loved one’s name anymore or when she no longer can communicate effectively.

According to Lazarus and Folkman (1984) relationships between stressors and caregiver stress are influenced by such factors as the caregiver’s gender, health, age, and relationship to the care recipient; care recipient’s behavior problems; and the caregiver’s appraisal of the caregiving situation as stressful or satisfying. Caregivers who find meaning in their roles are less likely to experience high levels of stress. Several studies in the literature suggested that African Americans appraise aspects of caregiving as less stressful than Whites, and that they derive more benefit and meaning from the experience (Gonzales, 1997; Knight and McCallum, 1998). With the use of effective coping strategies, along with a reliable and stable support system, African American caregivers can maintain their well-being while dealing the numerous daily sources of stress associated with caring for an elderly relative with dementia.
APPENDIX A
Informed consent to participant

I freely and voluntarily, and without any force or coercion, consent to be a participant in the research project titled “African American Caregiver’s Level of Knowledge about Alzheimer’s Disease and Dementia and its Relationship to Psychological Stress”.

I understand this study is being conducted by Shynequria McNealy, RN, as part of the thesis requirement for a Master’s Degree in Nursing at Florida State University. This research study will be completed under the direction and supervision of Dr. Sandra Faria, DSN, a Professor in the School of Nursing.

I understand the purpose of this study is to determine if there’s a relationship between African American caregivers level of knowledge about Alzheimer’s disease and dementia and the level of stress they experience when providing care to persons with the disease. I understand that if I participate in the study I will be asked to fill out a quiz and questionnaire regarding my knowledge and feelings about caring for a person with Alzheimer’s disease and/or dementia as well as some personal information about myself. This will take between 15 and 20 minutes.

I understand that my participation in this study is voluntary, and I may stop at any time. All of my responses will be anonymous. My name will not appear on any of the results. All information obtained during the course of this study will remain confidential, to the extent allowed by law. No payment will be offered for participation in this study. The results of this study will be sent to you upon request.

I understand there is the possibility of a minimal level of risk involved if I agree to participate in this study. I may experience some anxiety while answering some of the questions. I may contact Mrs. McNealy who will be available to talk with me.

I understand there also may be benefits in participating in this study. I will be providing healthcare professionals with valuable information which may be useful in formulating strategies to help decrease the level of stress caregivers may experience.

I understand that I may contact Shynequria McNealy at (850) 875-3350 or Dr. Sandra Faria at Florida State University (850) 644-1111 for answers to any questions I have concerning the research study or my participation in it at any time.
In the event I have questions about my rights as a participant in this research study, or if I feel I have been placed at risk, I can contact the Chair of the Human Subjects Committee Institutional Review Board, through the office of the Vice President for Research at (850) 644-8633.

I have had all my questions answered about this study and about this consent form. My completion of the questionnaire will be taken as my consent to participate in this research study.
APPENDIX B
Demographic Information

The following group of questions asks about you, the caregiver and your household situation. Please circle the answer that best describes your situation or fill in the blank.

1. Age: ______
2. Gender:
   a. Male
   b. Female
3. Marital Status:
   a. Single
   b. Married
   c. Divorced/Separated
   d. Widowed
4. Educational level:
   a. Some high school
   b. High school graduate
   c. Vocational/Technical School
   d. Associate degree
   e. Bachelor’s degree
   f. Master’s degree
   g. Doctoral degree
5. Employment Status:
   a. Full-time
   b. Part-time
   c. Not Employed
   d. Retired
   Occupation______________
6. Yearly household income:
   a. Less than $10,000
   b. $10,000-19,999
   c. $20,000-29,999
   d. $30,000-39,999
   e. $40,000-49,999
   f. more than $50,000

7. How would you rate your overall health:
   a. Excellent
   b. Good
   c. Fair
   d. Poor

8. Relationship to care recipient:
   a. Spouse
   b. Son
   c. Daughter
   d. Friend
   e. Other (specify)______

9. Length of time as caregiver: ________

10. Are there any other family members that assist you in caring for the individual
    a. yes
    b. no

11. Do you have other caregiver responsibilities for anyone else
    a. yes   Who__________
    b. no

12. How many other people live in your house________
The next group of questions asks about the elderly family member that you are caring for. Please circle to answer that best describe your situation or fill in the blank.

1. Age: _____

2. Gender:
   a. Male
   b. Female

3. Race:
   a. Caucasian
   b. African-American
   c. Hispanic
   d. Native American
   e. Asian
   f. Other__

4. Physical Health:
   a. Excellent
   b. Good
   c. Fair
   d. Poor

5. Living arrangements:
   a. Live in same household as caregiver
   b. Lives alone
   c. Lives in Assisted Care Facility
   d. Other_______

6. List other medical problem(s) below

   ______________________________
   ______________________________
   ______________________________
Identify all the services or sources of support that you and the care recipient are currently receiving.

Please circle all that apply
   a. Home health care
   b. Respite care
   c. Adult day care
   d. Support groups
   e. Church members
   f. Friends/ community
   g. Other (specify)___________________________
The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

1 Never          2 Rarely         3 Sometimes     4 Quite Frequently  5 Nearly Always

2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?

1 Never          2 Rarely         3 Sometimes     4 Quite Frequently  5 Nearly Always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

1 Never          2 Rarely         3 Sometimes     4 Quite Frequently  5 Nearly Always

4. Do you feel embarrassed over your relative’s behavior?

1 Never          2 Rarely         3 Sometimes     4 Quite Frequently  5 Nearly Always

5. Do you feel angry when you are around your relative?

1 Never          2 Rarely         3 Sometimes     4 Quite Frequently  5 Nearly Always
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

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7. Are you afraid what the future holds for your relative?

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8. Do you feel your relative is dependent upon you?

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9. Do you feel strained when you are around your relative?

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10. Do you feel your health has suffered because of your involvement with your relative?

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11. Do you feel that you don’t have as much privacy as you would like, because of your relative?

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12. Do you feel that your social life has suffered because you are caring for your relative?


13. Do you feel uncomfortable about having friends over, because of your relative?


14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?


15. Do you feel that you don’t have enough money to care for your relative, in addition to the rest of your expenses?


16. Do you feel that you will be unable to take care of your relative much longer?


17. Do you feel you have lost control of your life since your relative’s illness?

18. Do you wish you could just leave the care of your relative to someone else?

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19. Do you feel uncertain about what to do about your relative?

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20. Do you feel you should be doing more for your relative?

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21. Do you feel you could do a better job in caring for your relative?

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22. Overall, how burdened do you feel in caring for your relative?

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APPENDIX D

Dementia Quiz

The following questions ask about what your medical knowledge and understanding of dementia is. Please circle the answer you think is correct.

1. Alzheimer’s disease is caused by:
   a. a series of little strokes that destroy small areas of brain cells
   b. several heart attacks
   c. increased levels of aluminum in drinking water
   d. excessive alcohol intake
   e. don’t know

2. How many people over 80 develop dementia:
   a. five in a hundred
   b. 20 in a hundred
   c. 10 in a hundred
   d. 10 in a 1000
   e. don’t know

3. In its early stages dementia can be recognized by:
   a. an inability to recognize familiar faces
   b. inappropriate behavior like going out in one’s nightclothes
   c. headaches and nausea
   d. forgetfulness and confusion
   e. don’t know

4. Your chances of developing dementia are greater if:
   a. you are of above-average intelligence
   b. you have blood circulation or blood pressure problems
   c. your parents or grandparents suffered from Parkinson’s disease
   d. you are a woman
   e. don’t know

5. People who have never smoked or never drunk alcohol are:
   a. more likely to develop Alzheimer’s disease
   b. less likely to develop Alzheimer’s disease
   c. neither more nor less likely to develop Alzheimer’s disease
   d. less likely to become senile
   e. don’t know

6. The most common symptom in cases of dementia is:
   a. poor memory
   b. dizziness
   c. trembling
   d. headache
   e. don’t know
7. Some forms of dementia are caused by:
   a. infections
   b. environmental pollution
   c. aging of the brain
   d. brain tumors
   e. don’t know

The next group of questions asks about how you would handle the different situations that caregivers sometimes find themselves in. Please circle the answer that best describes what you would do in the given situation.

8. If your elderly confused relative begins to wander you would:
   a. not let them out of your sight so you always know where they are
   b. install unfamiliar locks on street doors so they won’t be able to get out
   c. keep them in one room most of the time and only let them out with supervision
   d. ask the doctor to prescribe sedatives
   e. don’t know

9. If your elderly relative suffers from a poor memory you can help by:
   a. constantly repeating things to them until they sink in
   b. provide them with memory aids such as diaries, notes and calendars
   c. ignore their constant questions
   d. tell them it’s not important
   e. don’t know

10. If you disagree with your elderly confused relative and you know you are right, you would:
    a. argue with them till your point sinks in
    b. avoid confrontation by seeking something to distract them
    c. make your point and if (s)he doesn’t agree go back to it later on
    d. point out that they do not understand because of their brain failure
    e. don’t know

11. If you find you are embarrassed by your elderly confused relative when you go out in public you would:
    a. simply leave your relative at home when you go out
    b. find excuses not to visit others and stay home
    c. explain to your friends and neighbors what is the matter
    d. treat the matter as if nothing happened
    e. don’t know
12. If your elderly confused relative follows you about all over the house you would:
   a. encourage them to stay in just the one room
   b. always tell them where you are going and what you are going there for
   c. ignore them completely
   d. lock yourself in the toilet or bathroom to give yourself a break
   e. don’t know

13. If your elderly confused relative becomes alert and agitated at night, the first thing to do is:
   a. ask your general practitioner to prescribe some sleeping tablets for them
   b. put a night light in the bedroom
   c. make sure (s)he has plenty of exercise during the day
   d. organize a break for yourself and get someone in to ‘take over’ once a week
   e. don’t know

14. If your elderly confused relative refuses to take a bath you would:
   a. be firm and insist that they need to have a bath regularly
   b. let the matter pass and try later on
   c. tell them not to be silly and trust you as you know best
   d. sponge them down in the bed the next morning
   e. don’t know

15. If your elderly confused relative starts to hallucinate (sees or hears things that are not there) you would:
   a. tell them clearly there is nothing there
   b. comfort their feelings without denying or acknowledging the hallucinations
   c. pretend you too can see or hear them and tell them that there is nothing to worry about
   d. ask your general practitioner for some pills
   e. don’t know

16. Once an elderly person receives a diagnosis of dementia you would:
   a. take over as many tasks as possible to alleviate any added mental stress
   b. discuss with your doctor about placing the person in a home as soon as possible
   c. encourage the person to be as independent as possible
   d. carry on as usual and make sure the sufferer is unaware that anything has changed
   e. don’t know
APPENDIX E

Human Subjects Research Approval Letter

OFFICE OF THE VICE PRESIDENT FOR RESEARCH
HUMAN SUBJECTS COMMITTEE
TALLAHASSEE, FLORIDA 32306-2742
(850) 644-8673; FAX (850) 644-4392

APPROVAL MEMORANDUM

Date: 7/12/2006

To:
SHYNEQUIRIA WILLIAMS-MCNEALY
105 NORTH 9TH STREET, APT. 6
QUINCY, FL 32351

Dept.: NURSING

From: THOMAS L. JACOBSON, CHAIR

Re: USE OF HUMAN SUBJECTS IN RESEARCH
African American Caregiver's Level of Knowledge About Alzheimer's Disease and Dementia and Its Relationship to Psychological Stress

The forms that you submitted to this office in regard to the use of human subjects in the proposal referenced above have been reviewed by the Secretary, the Chair, and two members of the Human Subjects Committee. Your project is determined to be Exempt per 45 CFR § 46.101(b) 2 and has been approved by an accelerated review process.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals, which may be required.

If the project has not been completed by 7/10/2007 you must request renewed approval for continuation of the project.

You are advised that any change in protocol in this project must be approved by resubmission of the project to the Committee for approval. Also, the principal investigator must promptly report, in writing, any unexpected problems causing risks to research subjects or others.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols of such investigations as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Protection from Research Risks. The Assurance Number is IRB00000446.

Cc: SANDRA FABIA
HSC No. 2006.0514
REFERENCES


Alzheimer’s Disease Education and Referral Center. (2001). Progress report on Alzheimer’s disease: Taking the next steps. Alzheimer’s Disease Education and Referral Center (NIH Publication No. 00-4859), Silver Spring, MD.


Proctor, R., Martin, C., Hewison, J. (2002). When a little knowledge is a dangerous thing…a study of carers’ knowledge about dementia, preferred coping style and psychological distress. *International Journal of Geriatric Psychiatry* 17, 113-1139.


BIOGRAPHICAL SKETCH

Shynequria D. Williams-McNealy is a Family Nurse Practitioner. She graduated with a Bachelor of Science in Nursing, cum laude, from Florida Agricultural & Mechanical University in December 1999. A Master of Science degree was awarded from Florida State University in December 2006.

Mrs. McNealy work experience includes travel nursing in Florida for two years. She also worked in the areas of Endoscopy and Special Procedures. She is passionate about providing quality healthcare to underserved, rural areas.