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# A Study about Older African American Spousal Caregivers of Persons with Alzheimer's Disease

Lillian D. Parker

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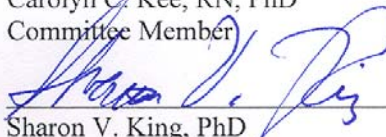
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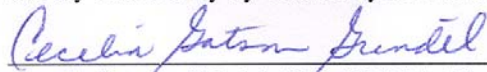


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## ABSTRACT

### A STUDY ABOUT OLDER AFRICAN AMERICAN SPOUSAL CAREGIVERS OF PERSONS WITH ALZHEIMER'S DISEASE

by

LILLIAN D. PARKER

The purpose of this descriptive correlational study was threefold: (a) to assess the relationships between boundary ambiguity, spirituality, marital relationship quality, and caregiver strain and depression among older African American spousal caregivers of persons with Alzheimer's Disease (AD); (b) to identify which variables are the best predictors of caregiver strain; and (c) to identify which variables are the best predictors of depression. The sample consisted of 25 female and 15 male spouses, who were ages 60 to 87. The data were analyzed using descriptive statistics, Pearson correlation coefficients, and multiple regression. Marital relationship quality was correlated with the two dependent variables, caregiver strain and depression. In hierarchical multiple regression, a model containing gender, years since spouse's diagnosis with AD and marital relationship quality predicted 40% of the variance in caregiver strain. Marital relationship quality was the only significant predictor for depression. The model containing marital relationship quality predicted 22% of the variance in depression. Additional findings were that participants scored high on the spirituality measure, that years since diagnosis of AD was negatively correlated with boundary ambiguity, spirituality, and caregiver strain, that there was a significant decrease in the quality of the marital relationship since the spouse became a caregiver, and that almost half had no help with caregiving. There was limited support for the proposed conceptual model, therefore,

a revised model was proposed. Based on the study results, in dealing with spouses who are providing caregiving to AD patients, nurses need to assess the quality of the marital relationship, and to recognize that the longer the spouse is a caregiver the greater the strain and depression, and that community resources need to be mobilized to assist the spouse with caregiving. A depression screen and marital assessment may provide cues regarding psychosocial needs of spousal caregivers.



A STUDY ABOUT OLDER AFRICAN AMERICAN SPOUSAL CAREGIVERS  
OF PERSONS WITH ALZHEIMER'S DISEASE

by

LILLIAN D. PARKER

A DISSERTATION

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Degree of Doctor of Philosophy in Nursing in the Byrdine F. Lewis School of Nursing  
in the College of Health and Human Sciences  
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Atlanta, Georgia

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Last but not least, this study is dedicated to my late grandmother, my mother, and others with Alzheimer's disease, related dementias and their family caregivers. Your strength and courage have taught me the power of faith and love.

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## LIST OF ABBREVIATIONS

AA	African American(s)
AD	Alzheimer's Disease
BAS	Boundary Ambiguity Scale
CESDS	Center for Epidemiological Studies Depression Scale
CSQ	Caregiver Strain Questionnaire
IRB	Institutional Review Board
MSS	Marital Satisfaction Subscale
PCSQ	Parent Caregiver Strain Questionnaire
SPS	Spiritual Perspective Scale
SPSS	Statistical Package for the Social Sciences

## CHAPTER I

### INTRODUCTION

Alzheimer's Disease (AD) is a serious debilitating illness that affects more than four million people and their family caregivers. Providing care for persons with this illness can involve performing activities of daily living, preparing meals, providing 24-hour supervision, attending to medical needs, and dealing with agitated behavior (Adams, 1996; Irwin & Acton, 1997). Caring for a dependent family member can be exhausting and make the caregiver susceptible to stress related illness (Irwin & Acton, 1997; Winslow, 1997). The impact of caregiver strain on older caregivers can have severe consequences.

The spouse is frequently the primary caregiver for persons with AD residing in the community setting. Over 62% of older spousal caregivers provide care for their mates within the home environment (National Alliance for Caregiving & American Association for Retired Persons (NAC & AARP, 2004). Elderly spousal caregivers (between the ages of 66 and 96) who experience mental or emotional strain have a 63% higher risk of dying than non-caregivers (Schulz & Beach, 1999). Boundary ambiguity, the marital relationship, and spirituality are major factors in the occurrence of strain for spousal caregivers. Few studies in the literature have investigated the influence of the aforementioned variables and the occurrence of strain and depression among older African American (AA) spousal caregivers.

Alzheimer's disease affects caregivers of all ethnic origins, yet little is known about the experience of caregiving among older AA spouses. Currently, African Americans comprise the third largest minority group in the United States (U.S. Census, 2005). Caregiving for persons age 50 and older occurs more often among individuals in this ethnic group. AA caregivers of persons with AD spend an average of 20.5 hours per week engaged in caregiving for person's age 65 and over. Caregiving career lasts approximately five years after diagnosis of AD (National Alliance for Caregiving & AARP, 2004). Caregiving statistics clearly reflect that older African Americans provide care for dependent family members. Information pertaining to variables that impact caregiving and strain are limited for this population.

Discrepancies exist in the literature regarding ethnicity and caregiving. A review of several studies concluded that non-white caregivers in comparison to white caregivers were less likely to be a spouse, and were less likely to experience strain and depression (Connell & Gibson, 1997). Life satisfaction decreased over time for white caregivers in comparison to blacks, and black caregivers responded more favorably to treatment for depression (Roth, Haley, Owen, Clay, & Goode, 2001). In contrast, Yin, Zhou, and Bashford (2002) reported findings from six studies that suggested a lack of differences in depression among black and white caregivers when other factors were controlled. One study found black caregivers adapted better and reported less deterioration when compared to white caregivers (Roth et al., 2001).

Spirituality appears to be a significant coping factor for older African Americans (Taylor, Chatters, & Levin, 2004). Spirituality was cited as a positive coping resource for black caregivers in comparison to whites (Picot, Debanne, Namazi, & Wykle, 1997).

However, Chang, Noonan, & Tennstedt (1998) did not find a direct relationship between caregiver strain and spirituality. No studies address marital relationship quality and caregiver strain among AA spousal caregivers. A study that examines relationships between boundary ambiguity, spirituality, and marital relationship quality will expand the knowledge of variables that influence caregiving for older spouses.

#### Statement of the Problem

The demands of caregiving render the older spouse susceptible to adverse health consequences. The older AA spouse is a primary caregiver for a mate with AD. The literature is somewhat limited in studies that explore specific variables that impact caregiving for older AA spouses. An exploration of the relationships between boundary ambiguity, spirituality, marital relationship quality, and caregiver strain and depression will enhance knowledge and understanding of variables that may impact coping for older AA spousal caregivers.

#### Significance to Nursing

Family members who care for persons with AD within the home environment perform a valuable service. The total annual national cost of AD care is well over \$100 billion dollars (Alzheimer's Association, 2005). Due to a decline in mortality rates, the number of persons living with chronic illnesses including AD is expected to increase to 148 million by the year 2030 (Hoffman, Rice, & Sung, 1996). It is projected that nearly one half of all people greater than 85 will have either AD or other dementias.

As the population ages, the number of caregivers and their needs will grow significantly. Care of persons with AD can adversely affect the health of caregivers, especially older spouses. The older spousal caregiver is susceptible to emotional and

physical strain that can have a deleterious effect on health (Lichtenstein & Gatz, 1998; Rosseau, 2000) as well as create an increased risk of death (Yates & Stetz, 1999).

Spousal caregivers (between the ages of 66 and 96) who experience mental or emotional strain have a 63% higher risk of dying than non-caregivers (Schulz & Beach, 1999).

Nurses can be instrumental in early detection and prevention of adverse consequences related to caregiving. Referring the spousal caregiver for emotional support and physical assessment can facilitate detection and appropriate interventions for mental and physical health consequences of caregiving.

### Theoretical Framework

Ambiguous loss (Boss, 1991; 1999) a mid-range descriptive theory from a symbolic interaction perspective provides one of the concepts used in the framework for the current study. The theory of ambiguous loss concerns incomplete or unclear losses, the uncertainty of knowing whether a loved one is absent, or present, dead or alive. Caregivers affected by ambiguous loss experience unresolved grief and are at risk for developing stress related symptoms of anxiety, depression, somatic illness and family dysfunction (Boss, 1999).

According to Boss (1999) there are two types of ambiguous losses. The first occurs when a loved one is perceived as physically absent but psychologically present. In this type of loss an individual is missing and it's unclear whether they're dead or alive. Two extreme examples of situations in which loss of this nature occurs include when soldiers are missing in action and in the case of kidnapped children. A less extreme example is the situation in families where a child or parent is viewed as absent or

missing, such as when a child runs away from home or when a spouse divorces a mate after twenty years of marriage.

The second type of ambiguous loss occurs in situations in which people are perceived as psychologically absent while being physically present. This type of loss occurs when loved ones have serious and chronic illnesses that effect cognition and memory, such as Alzheimer's disease, substance addictions or cerebral infarcts. A less extreme example can occur in an everyday situation such as, when a spouse is pre-occupied with work and ignores family members.

Ambiguous loss can result in unresolved grief and a lack of clarity about who is in the family or present in a relationship. Ambivalence concerning roles and identity occurs with people experiencing this type of loss (Boss, 1999). The uncertainty about family identity and boundaries creates strain among family members.

Ambiguous loss stems from family stress theory and the concept of boundary ambiguity (Boss & Greenberg, 1984). According to family theory (Boss, 1980) stress occurs in families whenever something is added to or subtracted from the family system resulting in boundary change and ambiguity. Some families recover from change and become stronger; others can't cope and experience increase in dysfunction. The ambiguous loss experienced by caregivers involves a lack of clarity concerning perceptions of who is in and who is out of the family system. The ambiguity is a source of stress. Concepts pertaining to the theory of ambiguous loss include boundary ambiguity, physical absence with psychological presence, physical presence with psychological absence, and culture. Though culture is included as a concept in Boss's theory of ambiguous loss, it has been explored in studies pertaining to primarily



Caucasian females located in different geographical areas (Boss, 1999). Boundary ambiguity is one of the concepts in the framework for this study.

Boundary ambiguity is a family stress construct that describes how families respond to both normal and unexpected losses over time (Boss, 1977; Boss, 1991; Boss & Greenberg, 1984). In terms of an ambiguous loss, boundary ambiguity exists when families are unaware of who is in or out of the family system. The family may perceive a physically absent member as psychologically present or a physically present member as psychologically absent. These perceptions create ambiguous family boundaries. The lack of clarity regarding perceived family structure, as in the case of ambiguous loss or separation, impedes the family's ability to reorganize, blocks restructuring, and creates a sense of limbo (Boss, 1991). Family members experience stress from the lack of clarity in the family system. Boundary ambiguity also develops in situations where families deny anxiety provoking events or when a diagnosis threatens the family system (Boss, 1991).

Boundary ambiguity for caregivers exists in response to change due to a loss in previously defined family functioning (Boss, 1991). The older spousal caregiver can experience alterations in roles due to functional losses experienced by a spouse in the latter stages of AD. The marital relationship is altered as a result of changes in communication patterns, and roles. Household responsibilities previously belonging to the ill spouse may have to be assumed by the caregiver. Patterns involving social activities and the handling of finances may become altered as well.

Another concept in the framework is spirituality. Spirituality appears to be a more important coping resource for AA caregivers than for other ethnic groups (Picot,

1995; Taylor, et al., 2004). Spirituality provides comfort during times of stress (Stolley & Koenig, 1997). Spiritual beliefs and practices are positive coping resources employed by older African Americans when confronted with major life challenges such as loss and grief due to illness (Picot et al., 1997). Spirituality may enhance the older caregiving spouse's ability to cope with the stress of caring for a mate with AD.

A third concept in the framework is marital relationship quality. The quality of the marital relationship between the caregiver and the care recipient appears to be a factor in stress, coping and outcomes associated with spousal caregiving (Lawrence, Tennstedt, & Assmann, 1998). Spousal caregivers who have positive perceptions of the marital relationship may view the demands of caregiving as favorable and a means of fulfilling needs. Caregivers with negative feelings about the quality of the marital relationship may view caregiving activities as a source of strain, and an unwanted demand. Negative perceptions of the quality of the marital relationship may impact the caregiver's ability to accept the existing ambiguity in the spousal relationship. The spouse with AD (dependent on the severity and characteristics of the illness) may not be able to maintain previously established roles and responsibilities. The losses due to change in functional abilities may adversely impact the spousal caregiver when the marital relationship is perceived negatively. Spousal caregivers with negative perceptions of the marital relationship may be more susceptible to the adverse consequences of caregiving such as depression.

Depression, the fourth concept in the framework, has been identified as a loss related emotional response or symptom resulting from caregiving efforts (Bergman-Evans, 1994; Buckwalter et al., 1999; Given, Given, Stommel, & Azzouz, 1999; Katz,

1996; Mui, 1992; Wright, Clipp, & George, 1993; Wright, Hickey, Buckwalter, Hendrix, & Kelechi, 1999; Young & Kahana, 1995). Symptoms of depression include appetite or sleep disruption, low energy, low self-esteem, hopelessness and sadness (Burgess, 1998). Spousal caregivers who have difficulty coping with loss due to change in the marital relationship and ambiguous boundaries are susceptible to a decline in both physical and mental health. Depression is often a consequence of caregiver strain.

In summary, boundary ambiguity, spirituality and marital relationship quality are variables that impact caregiver strain and depression among AA spousal caregivers of persons with AD. These concepts were used to generate a model for AA spousal caregivers (see Figure 1).

In the model, boundary ambiguity, spirituality and marital relationship quality are influential factors that affect the strain and depression experienced by AA spousal caregivers. Boundary ambiguity can be a source of strain for caregivers when the spouse who may have been the decision maker, head of the household as well as a caring, thoughtful mate, becomes incapacitated due to AA. Life for the caregiving spouse changes and can produce symptoms of depression.

Spirituality is an important resource for coping with the challenges and strain associated with caring for a mate with a chronic illness (Reed, 1986). Older AA spousal caregivers can engage in activities such as prayer, attending and participating in church organizations and read the bible as a means of coping with the strain created from boundary ambiguity.

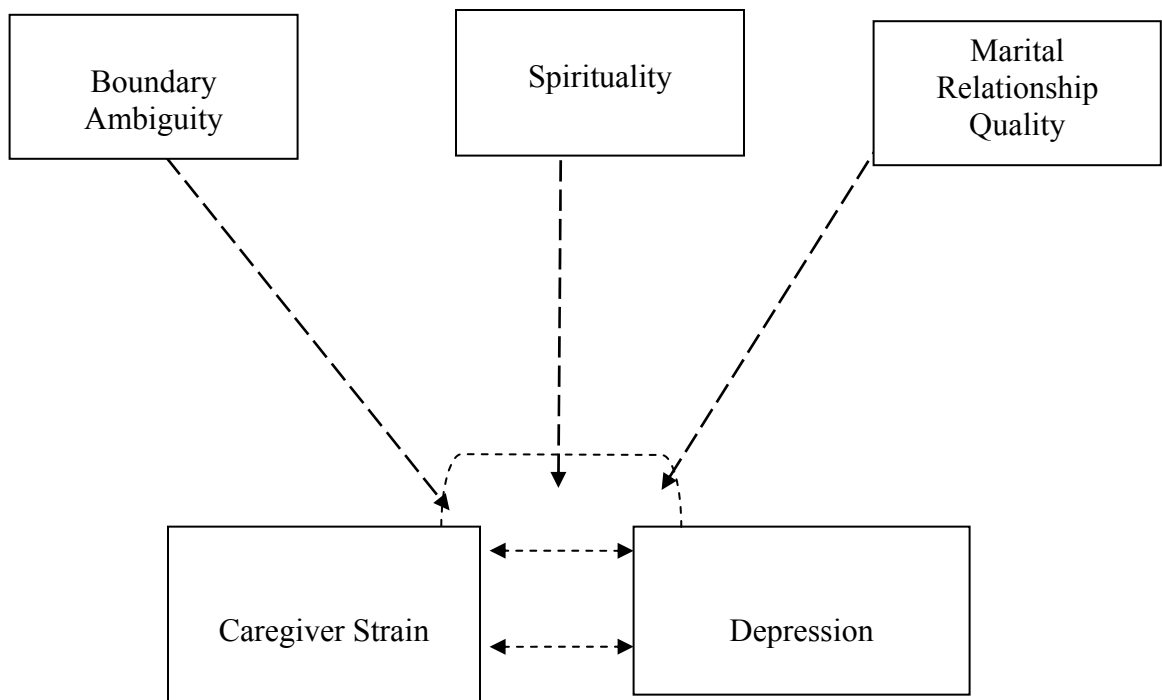
The quality of the marital relationship may suffer when the spouse is primary caregiver for a mate with AD. The marital relationship is impacted when a spouse

becomes ill. The spousal caregiver may experience boundary ambiguity as a result of changes that occur within the family functioning when caring for a mate with AD.

Boundary ambiguity, spirituality and marital relationship quality are influential factors in the experience of strain and depression for older AA spousal caregivers.

A study that explores the relationships among these variables and caregiver strain and depression will enhance the ability to understand the African American older spousal caregiver so that supportive healthcare strategies can be developed.

*Figure 1.* Proposed Model of AA Spousal Caregiving



#### Purpose of the Study

The purpose of this study is to explore the relationships between boundary ambiguity, spirituality, marital relationship quality, and caregiver strain and depression among older AA spousal caregivers of persons with AD.

### Research Questions

1. What are the relationships between boundary ambiguity, spirituality, and marital relationship quality and caregiver strain and depression among older African American spousal caregivers of persons with AD?
2. Which variables are the best predictors of caregiver strain (boundary ambiguity, spirituality, and marital relationship quality)?
3. Which variables are the best predictors of depression (boundary ambiguity, spirituality and marital relationship quality)?

### Concepts Defined

Caregiver strain is the physical, financial and emotional symptoms of stress experienced as a result of caring for an ill family member.

Boundary ambiguity is a state of uncertain perceptions regarding whether family members are in or out of the family system and who is performing what roles and tasks within the family due to a member being physically present and psychologically absent as in the case of AD. The person with AD although physically present is emotionally unavailable to caregivers and other family members.

Spirituality is the extent to which a person holds certain religious beliefs, and engages in religious interactions with others and with God.

Marital Relationship Quality is defined as how much the marital relationship is affectively valued and includes having: (a) feelings of emotional closeness, (b) positive sentiment towards the spouse, and (c) similarities in values and beliefs).

Depression is feelings of sadness, loss and low mood related to changes occurring as a result of caring for a partner with AD.

## Summary

The literature suggests differences exist in caregiving and coping behaviors among African American caregivers in comparison to caregivers of other racial groups (Dilworth-Anderson, Williams, & Gibson, 2002; Picot et al., 1995; 1997; Rose-Rego, Strauss, & Smith, 1998). Spirituality is a coping resource for older AA and may benefit the AA spousal caregiver. The marital relationship is seriously impacted when a spouse becomes ill with AD. Previously identified roles and responsibilities change and often are perceived as a source of stress for the family caregiver. Clearly, established patterns and behaviors are altered as a result of ambiguous boundaries within the marital relationship.

Boundary ambiguity and marital relationship quality can influence the occurrence of strain for older spousal caregivers of persons with AD. Multiple losses, the lack of clarity concerning family identity, roles and relationships can be a major source of strain for the older spousal caregiver. Depression is often a consequence of caregiver strain for AD caregivers. Spirituality may be a mitigating factor in the experience of strain for caregivers. Knowledge gleaned from this study will facilitate the development of appropriate, culturally specific healthcare strategies that can decrease the likelihood of adverse health consequences for the caregiver and facilitate the care of the spouse with AD.

## CHAPTER II

### REVIEW OF THE LITERATURE

Caring for persons with AD entails performing activities of daily living, preparing meals, providing 24-hour supervision, attending to medical needs, and dealing with agitated behavior (Adams, 1996; Irwin & Acton, 1997). According to Winslow (1997) caregivers often have stress-related physical and emotional health problems as a result of the strain experienced when caring for a dependent family member. Symptoms of caregiver burden or strain include depression, insomnia, decreased socialization, physical exhaustion, physical illness, and anxiety (Robinson & Austin, 1998). The following section addresses research pertaining to caregiver strain among AA caregivers. Caregiver strain and the variables of race, spousal caregivers, marital relationship quality, boundary ambiguity, spirituality, gender, and depression are discussed in this section.

#### Caregiver Strain and Race

Young and Kahana (1995) found race was not a significant factor in caregiver burden nor in depression when all context variables were controlled. Mui (1992) reported black daughters experienced less role strain due to caregiving efforts than their Caucasian counterparts. Wood and Parham (1990) found no significant difference in perceptions of caregiver burden in terms of race but suggested that further study with a large ethnically diverse sample would be beneficial.

Picot (1995) examined the relationship between confrontive, emotive and palliative coping by AA female caregivers of persons with dementia or confusion. Study results suggested that perceptions of cost, rewards, and social support quality were more important than caregiver demands. These findings were consistent with other studies that suggest AA caregivers use fewer problem-solving, information-seeking and confrontive coping strategies in caregiving and more prayer and faith in God.

Wood and Parham (1990) investigated differences in patterns of coping with caregiver strain among families of varying ethnic and cultural backgrounds. Results revealed no significant differences in the experience of burden according to race. These findings contradict those of Fredman, Paly, and Lazur (1995) which indicated that black caregivers participated in more caregiving activities than white caregivers but reported less burden. Blacks also reported receiving more support from family, friends and their ministers than whites did. Yin et al. (2002) conducted an intervention study that investigated whether group or individual programs positively impacted caregiver burden. Study results indicated that treatment was more effective for non-white caregivers.

A two-year longitudinal study employed latent models to compare change across time for AA and white caregivers (Roth et al., 2001). Study findings were that life satisfaction decreased over time for white caregivers. AA caregivers showed better adaptation and less deterioration when compared to white caregivers. The findings in this study also supported the hypothesis that AA caregivers were less vulnerable to the adverse psychological consequences of caregiving. Rose-Rego et al. (1998) noted that African Americans appraised caregiving more positively than Caucasians.



A review of studies on racial, ethnic, and cultural differences in dementia caregiving (Connell & Gibson, 1997) reported several consistent findings pertaining to African Americans and caregiving. The studies found that: (a) African American caregivers were less likely to be a spouse, (b) reported less burden, (c) reported less depression, and (d) had stronger feelings about filial support than white caregivers. Some studies did not find racial differences in caregiver stress nor depression. Connell and Gibson also noted that studies included in their review often failed to examine within group differences as well as the impact of race, ethnicity and culture on common constructs pertaining to caregiving. A meta-analysis of intervention studies concerning caregiver strain (Yin et al., 2002) noted that treatments aimed at reducing caregiver burden appear to be more effective for non-white family caregivers than white caregivers.

Dilworth-Anderson et al. (2002) summarized the following findings in a twenty-year review of studies on caregiving that addressed race, ethnicity and culture. African American caregivers were more likely to be the sole care provider when compared to white caregivers when confounding variables were controlled. African American caregivers also expressed a greater need or desire for formal support services when compared to white caregivers. Depression and burden were the two main areas reviewed in the negative affects domain. Studies comparing AA caregivers and white caregivers on measures of depression had conflicting results. Six studies reported no difference in depression between the two groups when other factors were controlled. Four studies found white caregivers to be more depressed than AA caregivers. Factors thought to contribute to differences in study findings included small AA samples, the use of different measurement tools, and diverse sampling techniques. Similar findings existed

for studies measuring burden. Five studies found that white caregivers reported more burden than African Americans. Four studies found no differences in measures of burden between the two groups. Several disadvantages cited in the review include the fact that few within group comparisons occurred, and there was an inadequate number of AA subjects to establish a desirable effect size. The influence of and ethnicity as it pertains to caregiving needs further exploration.

Contradictions exist when comparing caregivers according to race and strain, however, differences in terms of coping response and behavior are reported consistently. Instrumentation and inadequate sample size were thought to contribute to differences in study findings. These findings do not address the problem regarding the fact that older adult caregivers are extremely vulnerable to strain with implications for a decreased lifespan for the spousal caregiver. The elderly spousal caregivers (between the ages of 66 and 96) who experience mental or emotional strain were found to have a 63% higher risk of dying than non-caregivers (Schulz & Beach, 1999).

#### Spousal Caregivers and Strain

This section discusses the literature related to older spousal caregivers and strain. Findings indicate the spouse is frequently primary caregiver for persons with AD residing in the community setting. Over 62% of older spousal caregivers provide care for their mates within the home environment (National Alliance for Caregiving & AARP, 2004). Ory, Hoffman, Yee, Tennstedt and Schulz (1999) concur with these findings and note that caregivers of persons with dementia spend more time providing constant care than non-dementia caregivers. Grant et al. (2002) examined the psychological, physical, and physiological effects of placement and death of a spouse with AD in a longitudinal study

of AD caregivers. An objective of this study was to identify the medical and psychological correlates of two transitions during the caregiving career: placement of the AD relative and the death of a relative with AD. Medical, psychological symptoms, and blood pressure measures of caregivers were assessed during this longitudinal study. Findings indicated that the caregiver group had higher ratings of depression than non-caregiver control subjects. Caregivers who placed their spouse out of the home had a decline in depressive symptoms and serious medical problems. Systolic blood pressure measurements were higher for the caregiver group at rest when compared to non-caregiving control subjects. The authors infer that death and out of home placement of spouses with AD, are accompanied in the long term by health benefits to the caregiver.

Providing care for a spouse with AD prompts alterations in roles due to the mates decline in functioning. Altered roles were a source of strain for caregiving spouses. Mui (1992) examined spouse role strain from a role theory perspective. Study results indicated a high prevalence of role strain for both husband and wife caregivers.

Farran, Miller, Kaufman, and Davis (1997) investigated spousal caregiver role strain pertaining to the relationships between race, finding meaning, and outcomes of caregiver depression. Variables examined in this study included the experience of physical health distress in response to behavioral problems and the number of tasks involved in assisting with activities of daily living (baths, feeding, and toileting) for spouses with AD. Study findings indicated that the best predictors of depression and role strain for spouses were being white, behavior problems of the care recipient, task distress, and providing assistance with personal acts.

Almberg, Grafstrom, and Windbald (1997) described a longitudinal study that examined the relationship between caregiver burden and burnout among family caregivers of demented elderly persons in this study. The sample consisted of 46 family caregivers. The study involved a comparison between two groups of dementia caregivers in an effort to compare the experiences of burden and burnout related to physical and emotional strain.

The study results indicated that caregivers who initially had poor health, a limited social life and lacked a positive outlook on the caregiving situation were more vulnerable to burnout. Older women caring for their husbands, and daughters caring for parents were most likely to experience high levels of burden and burnout. Group and individual interventions were effective in reducing perceptions of burden for this population.

#### Caregiver Strain and Depression

Alzheimer's Disease spousal caregivers experienced more depression when compared to caregiving spouses of persons with strokes according to Wright et al. (1999). A study comparing spousal caregivers of persons with AD and non-caregiving spouses on measures of well-being, life satisfaction and physical health indicated that measures of overall health were higher, and less depression existed among spouses who were non-caregivers when compared to spousal caregivers.

A four year longitudinal, intervention study to evaluate a community based psycho-educational program which taught caregivers to manage behavioral problems in persons with AD and other dementias was conducted by Buckwalter et al. (1999). A major aim of the study was to evaluate the impact of an intervention, the Progressively Lowered Stress Threshold Model (PLST), on caregiver affective responses, especially

depression. The sample consisted of 245 caregivers divided into experimental and control groups. Findings on the two measures of depression varied. Scores on one depression scale indicated caregivers in the experimental group were significantly less depressed in comparison to caregivers in the control group at six months. However, there was no significant difference between groups at 12 months. Scores on the second measure, the Geriatric Depression Rating Scale indicated that the experimental group was less depressed than the control group at both six and twelve months. The PLST model was concluded to have a positive impact on caregiver depression.

Wright et al. (1999) conducted a time series study which explored the emotional and physical health of AD and stroke caregivers. The sample consisted of 84 spouses who were primary caregivers of persons with a stroke or AD. The subjects were placed into three groups: caregivers of persons with strokes, AD caregivers, and a community control group. Variables operationalized in the study included depression, physical health, and background characteristics. Data collection involved face to face interviews in the homes of couples, with measures at baseline, six months, and a phone interview at one year.

Findings indicated no significant differences between groups in terms of the demographic data. Baseline measurement and scores for depression at times two and three were higher for both AD and Stroke caregivers than the community controls. No significant differences were found on the physical health measures. The mean depression scores between AD and Stroke caregivers were significantly different. AD caregivers revealed a steady increase in depression scores over time, where as depression in stroke caregivers declined after baseline measures. No correlation was found between cognitive

impairment and functional decline for AD caregivers in comparison to stroke caregivers. This study found that depression exists among caregivers in the early stages of AD and that AD caregivers reported more symptoms of depression than caregivers of persons with stroke.

Hepburn, Tornatore, Center, and Oswald (2001) conducted an intervention study that involved training caregivers for the caregiving role. The study evaluated training that focused on restructuring caregiver beliefs and examining the relationships between beliefs, burden, depression and other variables. A sample consisting of 117 relatives of persons with dementia were randomly assigned to treatment and control groups. The results in this study revealed no significant differences between groups at baseline according to measures on the Beliefs About Caregiving Scale (BACS). At five months, scores for the treatment group were higher in nurturing, and lower reaction to care receiver behavior problems. The treatment group also had lower scores on measures of depression and burden. Grief intensity was related to negative health consequences. Findings in this study suggested that depression and caregivers perception of the caregiving role can be positively impacted through an intervention which alters beliefs about caregiving.

Bergman-Evans (1994) examined differences in depression and physical health characteristics among spousal caregivers of persons with AD living at home or in a nursing home. A non-probability sample of 36 wives and 11 husbands in a home caregiver group and 29 wives and 18 husbands in a nursing home group completed measures of depression, physical health status and health characteristics.

Findings in this study included both groups being similar on measured levels of depression. There were no significant differences in depression and perceptions of physical health. Depression among home caregivers was significantly related to self-assessed health and the inability to work. Only seven caregivers in the nursing home group identified depression as a disease condition, suggesting an inability to recognize depressive symptoms. This study supported the fact that depression exists in both caregivers of persons with AD residing at home as well as in nursing homes, though symptoms may go unrecognized.

#### Gender and Caregiving

Pinquart and Sorensen (2006) conducted a meta analysis on gender differences in caregiver health, stressors and social resources by integrating the results from 229 studies. Findings indicated that women reported higher levels of care recipient behavioral problems, more hours providing care, higher levels of burden and depression, and, lower levels of physical health and subjective well-being than male caregivers. There were no significant gender differences for other stressors such as, formal support use, and the availability and use of informal supports.

A meta-analysis examining differences between caregivers and non-caregivers in psychological and physical health was also implemented by Pinquart & Sorensen (2003). Findings from 84 articles were integrated and revealed that women provide more personal and instrumental care than men. Female caregivers are also more likely to report impaired well-being, negative feelings and less effective coping than male caregivers.

A review by Dilworth-Anderson et al. (2002) summarized findings from 59 articles and indicated that there is a need for more studies that examine the effects of

gender among caregivers. The authors noted that few studies in the review described gender differences in caregiving.

Hooker, Manoogion, Monahan, Frazier, and Shifren (2000) examined gender differences in reported patterns of stress, depression, anxiety and coping among AD caregivers in comparison to caregivers of spouses with Parkinson's disease. Findings indicated that there were no significant differences in gender regarding depression for the sample as a whole. There were significant within group differences. AD wife caregivers reported greater levels of depression, stress and anxiety when compared to their male counterparts. There were no significant gender effects for spousal caregivers of persons with Parkinson's.

Ory et al. (1999) reported findings from a national survey of 1500 dementia and non dementia caregivers. Survey results indicated that women caregivers of persons with dementia reported higher levels of emotional and physical strain in comparison to other caregivers. Female dementia caregivers reported more symptoms of physical health problems than males when compared to non-dementia caregivers.

Robinson and Austin (1998) compared perceptions of health and social support between wives caring for husbands with AD and other mental illnesses and their supportive others. Findings indicated that caregiving wives perceived their health as fair to poor in contrast with the perceptions of supportive others of the same age. They were also more depressed and perceived themselves as having less help than their supportive others.



Mui (1992) investigated role strain, role demand and role conflict among black and white caregivers of dependent parents. Study results indicated that white female caregivers had higher role strain scores than AA female caregivers.

In summary, there is an indication that gender differences exist among caregivers of persons with AD. Female caregivers reported more symptoms of strain, depression and difficulty dealing with behavioral problems. Research pertaining to caregiving and males is somewhat limited and needs further exploration.

#### Marital Relationship Quality and Caregiver Strain

Caregiver health outcomes and the marital relationship was investigated by Beach, Schulz, Yee, and Jackson (2000) in a caregiver health effects study. Findings included the fact that higher quality marital relationship had positive correlations with health related outcomes. Caregivers with higher quality marital relationships reported fewer health risk behaviors and fewer anxiety symptoms at wave one of the longitudinal study. The sample in this study was from a community-based population of subjects participating in a cardiovascular health study.

Williamson and Shaffer (2001) investigated the extent to which pre-morbid, communal relationships determine whether caregivers perceive their current relationships as rewarding and whether relationship perception influenced the ability to predict caregiver depression and potentially harmful behavior. Findings suggested that caregivers who experienced more relationship rewards and had communal relationships before illness evaluated past and current relationships as more rewarding. These caregivers were less depressed and less frequently engaged in potentially harmful

behaviors. Current relationship rewards were thought to mediate the impact of dementia on caregiver depression.

Uchino, Kiecolt-Glaser, Cacioppo (1999) investigated linkages between AD caregiver's construal of a pre-illness relationship and cardiovascular response. Findings indicated that caregivers who had a more positive construal of affection for the pre Alzheimer's patient, had lower basal diastolic blood pressure and lesser heart rate reactions to psychological stressors of an experimental nature. Twenty of the 30 subjects in this study were spousal caregivers.

In summary, the literature suggests that quality of marital relationship can have physical as well as psychological effects on spousal caregivers of persons with AD. There is an indication that a positive pre-illness relationship favorably affects a caregiver's perception of strain and decreases symptoms of depression and harmful behavior. Few studies in the literature have investigated the influence of a pre-illness relationship quality on the current functioning of AD spousal caregivers among various ethnic groups.

#### Boundary Ambiguity

Boss (1977) investigated 47 families of servicemen believed to be missing in action (MIA) in a five year longitudinal study. The concepts of psychological father presence was operationalized with the Psychological Father Presence (PFP) instrument developed by the author. Findings in this study included a significant covariance between PFP and family functioning. The PFP instrument was supported as a valid measure of the construct psychological father presence. Boss et al. conducted a study which operationalized boundary ambiguity as PFP. The study supported the existence of high and low boundary ambiguity.

Boss, Caron, Horbal, and Mortimer (1990) in a study of 70 dementia patients and their caregivers examined two perceptual variables, boundary ambiguity, and perceptual mastery. Boundary ambiguity was operationalized with the PFP. Findings suggested significant correlations exist between caregiver depression, boundary ambiguity and mastery orientation. No direct relationship existed between level of disability and the number of reported depressive symptoms for caregivers.

Boundary ambiguity was examined in a study exploring the relationship between caregiver depression and behavioral problems in patients with AD (Caron, Boss, & Mortimer, 1999). The authors hypothesized that a causal link exists between caregiver behavior and patient behaviors and attitudes. Findings indicated that caregivers distancing themselves from the patients predicted and increased frequency of behavior problems such as activity disturbances, paranoia and anxiety. The increase in behavior problems led to an increase in closeout or withdrawal behaviors by the caregiver.

In summary, there is an indication that the spouse and other family members can be adversely impacted when caring for a member with AD. Boundary ambiguity results from the unclear loss in which a mate is physically present but mentally absent. The family caregiver experiences a change in roles and perceptions. These changes can be a source of strain that impacts a spouses physical and emotional health as well the family system. There are limited studies that explore boundary ambiguity and caregiving. Studies that have examined this variable among AA caregivers could not be found.

#### Spirituality and Caregiver Strain

Taylor et al. (2004) cited numerous studies that support the idea that spirituality in terms of religiosity is an important coping resource for older AA's. There is an indication

that religious practices such as, attending church and engaging in other religious activities such as prayer, has a beneficial influence on physical health for African Americans. No information pertaining to AA spousal caregivers was gleaned from studies summarized in this source.

Spirituality (Stuckey, 2001) is a belief or practice that connects an individual with sacred and meaningful entities beyond self. It involves creating and sustaining a personal relationship with a supreme being according to one's personal views (Stuckey, 2001). Meditation and prayer are two common practices utilized in expressing spirituality.

A study on aging and health revealed that 74% of caregivers surveyed stated that prayer was the most common method of coping with strain (Shirey & Summer, 1997). Religion or spirituality was a means of providing comfort during times of stress for caregivers and prayer took place more often among African Americans than among their white counterparts (Stolley & Koenig, 1997).

Theis, Biordi, Coeling, Nalepka, and Miller (2003) conducted a qualitative study to explore how caregivers and care receivers utilize respite as a form of self-care as well as how they coped with giving and receiving care. A total of 60 caregiver and care-receiver dyads were interviewed. Data synthesis revealed that spirituality was the most prevalent response for caregivers when asked how they coped with caregiving. An equal number of African American and Caucasian caregivers view spirituality as a means of coping with caregiving.

A study examining linkages between systems of support for caregivers of older African Americans indicated the church was an important support resource. Findings were that 20% of the 187 caregivers sampled utilized church support (Williams &

Dilworth-Anderson, 2002). Caregivers were more likely to use church support when activities of daily living limitations increased. Caregivers who utilized the church as a support source were three times more likely to use formal support resources.

Stuckey (2001) conducted a qualitative study on religion and spirituality among AD caregivers. Data collection entailed tape recorded interviews with ten respondents. Data transcription and analysis revealed the following themes concerning spirituality: (a) attributes of God and faith, (b) prayer as an important coping strategy, and (c) reliance on spiritual beliefs and practices.

Chang et al. (1998) investigated spirituality, caregivers and coping. This study involved exploring the extent to which caregivers reported via telephone interviews how religious/spiritual beliefs helped them in the caregiving experience. Study findings were that caregivers who utilized spiritual or religious beliefs to cope with caregiver stress were more likely to have a good quality relationship with the care recipient. No support existed for the model concerning a direct association between stressors and religious or spiritual coping.

Religiosity as a mediator of perceived caregiver rewards was examined among a sample consisting of black and white community dwelling caregivers (Picot et al., 1997). The results of this study indicated religiosity variables had a mediating effect. A significant relationship existed between situational variables, demographic variables and religiosity. Black caregivers perceived more rewards from caregiving than their white counterparts did.

Kirby, Coleman, and Daly (2004) examined the impact of frailty, spiritual beliefs and gender on the psychological well being of frail older adults. Findings indicated that

spiritual beliefs had a direct positive effect on psychological well-being. Gender was not a significant factor in overall spiritual well being. Frailty in older adults had a significant direct negative effect on psychological well being.

In summary, the literature supports the fact that spirituality is an influential variable in the caregiving experience. There are apparent differences in perceptions of religion as an important variable according to race. Support exists concerning spirituality as an important variable in coping for older African American caregivers. Ideas concerning spirituality as a coping resource for AD caregivers need further exploration.

#### Summary

The relationships between spirituality, marital relationship quality, boundary ambiguity, depression, and caregiver strain among African American older spousal caregivers has not been explored, but is clearly warranted. Evidence suggests the existence of cultural and gender differences in strain and coping behaviors among caregivers. As the population ages, more people will be susceptible to developing AD with increasing numbers of older spouses becoming caregivers. The numbers of individuals experiencing symptoms of strain will also increase as older spouses experience change due to caregiving efforts. Marital relationship quality affects older caregiving spouses and may be a factor in the increased mortality rates and tendency of older spouses to provide care at home. Roles and perceptions for spouse and family caregivers can easily become ambiguous when a spouse is physically present but psychologically absent as in the case of AD. The subsequent changes and loss that occur in the family may result in boundary ambiguity regarding who is in and who is out of the family system and create symptoms of strain for the family and spousal caregiver. There

is an indication that physical and emotional health of spousal caregivers is adversely impacted when a marital partner has AD. Spirituality appears to be an influential coping variable in caregiving for older African Americans, yet, few studies have explored its relationship to caregiver strain. A study that explores the relationships between boundary ambiguity, spirituality, marital relationship quality and caregiver strain and depression among older African American AD spousal caregivers will hopefully enhance our knowledge of variables that affect the health of older caregivers and facilitate the development of culturally relevant healthcare.

## CHAPTER III

### RESEARCH METHODOLOGY

This chapter describes the research methods and statistical procedures used in this study. Information is provided regarding the research, (a) design, (b) sample, (c) instrumentation, (d) procedures, and (e) data analysis.

#### Study Design

The current study employs a descriptive correlation design to examine relationships between boundary ambiguity, spirituality, marital relationship quality, depression, and caregiver strain among older African American spousal caregivers of persons with Alzheimer's disease. The study also explores the variables predictive of caregiver strain and depression.

#### Sample

A convenience sample of 40 African American spousal caregivers of persons with AD who met the eligibility criteria were recruited to participate in this study. A sample of 40 subjects was used because of limited access to potential participants and time limitations. The inclusion criteria for participants were: (a) African American, (b) primary care giver of a spouse with a diagnosis of AD or dementia, (c) provides at least five hours per week of care for the spouse with AD (involving tasks such as, assisting with activities of daily living, preparing meals, or supervision) (d) at least 60 years old, (e) understands the English language, and (f) lives in a community setting with the spouse. Caregivers with a self-reported current diagnosis of depression or a terminal



illness were excluded from the study. The sample was recruited from churches, Alzheimer's support groups, Alzheimer day programs, community senior centers, and a memory clinic.

### Instrumentation

Five instruments were used to operationalize the variables in this study. Boundary ambiguity was operationalized with the Boundary Ambiguity Scale (BAS) (Boss & Greenberg, 1984). Spirituality was operationalized with the Spiritual Perspective Scale (SPS) (Reed, 1987). Marital Relationship quality was operationalized with the marital satisfaction subscale of the Dyadic Adjustment Scale (Spanier, 1976). Caregiver strain was operationalized with the exhaustion subscale of the Parent Caregiver Strain Questionnaire (PCSQ) (England, 1987), and depression was operationalized with the Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977).

A background survey (Appendix A) containing 20 items was used to obtain descriptive information about the participants. Two items in a Likert scale format were used to indicate the caregiver's perception of his/her health prior to and after assuming caregiving responsibilities.

#### *The Boundary Ambiguity Scale*

The Boundary Ambiguity Scale (Appendix B) for caregivers of persons with dementia is a 14-item self report instrument that measures the degree to which a caregiver is pre-occupied and unsure of his or her relationship to the ill family member. The scale was modified from the Psychological Presence scale used in studies of wives of men missing in action (Boss, 1977, 1980; Boss & Greenberg, 1984). Items were derived from stressors related to ambiguous family boundaries (Boss & Greenberg, 1984). Participants

were asked to respond to items concerning how they feel about caring for an ill family member. The Boundary Ambiguity Scale (Appendix B) has been used with caregivers of persons with Dementia, primarily female spouses.

The items on the BAS are in a Likert-type format with five response options ranging from (a) *strongly disagree* to (e) *unsure how I feel*. For coding purposes, the items on the BAS for caregivers have the following numerical values: (1) *strongly disagree*, (2) *disagree*, (3) *agree*, (4) *strongly agree*, and (5) *unsure how I feel*. Scoring involves summing the corresponding numerical rating. The total possible score ranges from 14 to 70 with higher scores indicating greater levels of boundary ambiguity. A sample scale item is: *"I put my wife's or husbands' needs before my own."* The scoring on the BAS was altered from the authors instructions. According to the author, items 1, 2, 6, and 12 were to be recoded. Although the scale had a previously acceptable reported Cronbach's alpha of .80 (Boss, Caron, Horbal and Mortimer, 1990), the reliability coefficient with items recoded as instructed was not adequate (<.40) in this study. After examining the inter-item covariance matrix, only items 1 and 9 were recoded as suggested by the author, because of strong negative inter-item correlations. In the current study, after recoding only items 1 and 9, the reliability coefficient was .68.

#### *The Spiritual Perspective Scale*

The Spiritual Perspective Scale (Reed, 1987) is a ten-item scale that measures beliefs and behaviors associated with non-organizational forms of religion. According to Reed spirituality is the extent to which a person holds certain religious beliefs, and engages in religious interactions with others and with God or a higher being. Subjects are asked to respond to test items according to the personal meaning religion has for them.

Items on the Spiritual Perspective Scale (SPS) are in a Likert scale format with response options for questions one through four ranging from (1) *not at all* to (6) *about once a day*. The response options for questions five through ten ranged from (1) *strongly disagree* to (6) *strongly agree*, indicating either a level of agreement or frequency of occurrence. Scoring occurs by calculating the arithmetic mean across all items resulting in a total item score ranging from 1.0 to 6.0 with six indicating a greater religious perspective. A sample item entails: “*My spirituality is especially important to me because it answers many questions about the meaning of life.*” Response options for this question are: (1) *strongly disagree*, (2) *disagree*, (3) *disagree, more than agree*, (4) *agree more than disagree*, (5) *agree*, and (6) *strongly agree*. The SPS (Appendix C) has a Cronbach alpha coefficient of .92. In the current study, the Cronbach’s alpha was .82 which is adequate.

#### *The Dyadic Adjustment Scale*

Marital relationship quality was measured using one subscale from the Dyadic Adjustment Scale which represents the quality of marriage and other dyadic relationships. The instrument has four empirically verified subscales: (a) Dyadic Consensus, (b) Dyadic Satisfaction, (c) Dyadic Cohesion, and (d) Affectional Expression. The 10-item Dyadic or Marital Satisfaction subscale (Appendix D) was used in this study. Marital satisfaction indicates how much the spouse and marital relationship is affectively valued including having: (a) feelings of emotional closeness, (b) positive sentiment towards a mate, and (c) similarities in values and beliefs. The scale items are in a Likert-type format with response options for questions one, two, and five ranging from (0) *all the time* to (5) *never*. Items three, four, and eight had ratings ranging from (0) *never* to (5) *all the time*.

The responses for items 6 and 7 range from (1) *most of the time* to (5) *never*. Item 9 has ratings ranging from (0) *extremely unhappy* to (6) *perfect*. Item 10 involves the participant being asked to rate statements about the future of their relationship ranging from (5) to (0). Scoring occurs by summing the ratings with a possible score ranging from 0-51. Higher scores indicate a higher degree of marital satisfaction. A sample item from the marital satisfaction subscale is listed as follows: “*Do you confide in your mate?*” Response options for this question are: (0) *never*, (1) *rarely*, (2) *occasionally*, (3) *more often than not*, (4) *most of the time*, and (5) *all of the time*. There is no indication that this scale has been used with an African American population. The marital relationship satisfaction subscale had an adequate reliability in a previous study with a Cronbach alpha of .94. The scale has a Cronbach alpha of .85 in this study.

#### *The Parent Caregiver Strain Questionnaire*

The measure for caregiver strain, the Caregiver Strain Questionnaire (CSQ) was adopted from the The Parent Caregiver Strain Questionnaire (PCSQ) which measures the strain offspring experience when caring for a disabled parent. The instrument consists of two subscales, termed exhaustion and emotional arousal. The 25-item exhaustion subscale (Appendix E) of the PCSQ was used in this study. The exhaustion subscale measures the extent to which a respondent felt drained in response to performing caregiving tasks.

Items on the exhaustion subscale are presented in a 4 point Likert format with response options ranging from 1 “*not drained at all*” to 4 “*very drained*”. The total score is derived from the sum of ratings for the 25 items with a total score that ranges from 0 to 100. Higher scores indicate more exhaustion from involvement with spousal

care such as feeding the spouse. A sample item from the exhaustion subscale of the CSQ is as follows: Check the space that best represents how drained you feel as a result of doing the following things for your mate: Feeding:  *not drained at all*,  *a little drained*,  *somewhat drained*, and  *very drained*. For coding purposes, the response items were assigned corresponding numbers ranging from 1 to 4. The scale was reported to be reliable with a Cronbach alpha of .88. In this study, the scale was reliable with a Cronbach alpha of .93.

#### *Center for Epidemiologic Studies Depression Scale*

Caregiver depression was measured using the Center for Epidemiologic Studies Depression Scale (CES-D) (Appendix F) which is a structured self-report instrument designed to measure symptoms of depression in the general population (Radloff, 1977). The scale measures current levels of depressive symptoms.

The 20 scale items are presented in a four point Likert scale format with responses options ranging from “0” *never* to “3” *most of the time*, within a five to seven day period. Items 4, 8, 12, and 16 are reversed prior to adding scores for all items. The total possible score can range from 0 to 60 with higher scores indicating the presence of more depressive symptoms. The following is a sample item from the CESD-S: “*During the past week: I was bothered by things that usually don’t bother me:*” (0) *rarely or none of the time*, (1) *some or a little of the time*, (2) *occasionally or a moderate amount of the time*, and (3) *most or all of the time*. The instrument has been used with numerous populations including older adults. The instrument has a reported Cronbach alpha’s of .90 for a community sample and clinical samples of psychiatric inpatients (Radloff, 1977). In this study, the CES-D was reliable with a Cronbach alpha of .85.

### Data Collection Procedures

Prior to participant recruitment, the study was reviewed and approved by the Institutional Review Board (IRB) at Georgia State University. After IRB approval, agencies and organizations that service potential participants were contacted by telephone to schedule appointments with representatives to discuss the proposed study. Letters describing the study and the researcher's name and a contact telephone number were also sent to agencies and organizations that service potential participants.

People who expressed interest in participating were contacted by phone to schedule a visit at the caregiver's home if convenient or at a mutually agreeable location. Prior to any data collection, participants were asked to sign a written informed consent that states participation is voluntary, and they have a right to stop at anytime. The informed consent included information regarding the study purpose, procedures and dissemination of results. Respondents were also informed that in the event of emotional discomfort, the interview would be interrupted and the researcher would provide emotional support and if necessary refer participants to counseling. The consent form was numbered. The same number was placed on the questionnaire booklet to protect the confidentiality of the participant.

After the consent was signed and the participant's questions were answered, the researcher read the items on the questionnaires to participants, and recorded their responses. This method of administering the questionnaires was selected because visual changes consistent with normal aging may interfere with the participants ability to accurately see the items, and to provide an opportunity to clarify participants questions and to reduce the problem of missing data. The questionnaires took 45 minutes to 1 hour

to complete. Upon completion of the questionnaires, the researcher reviewed the questionnaires for missed response items and the participant was asked to complete missed items if he/she desired to do so. After data collection, participants were given an honorarium of \$10.00. The consent forms were stored in a locked metal box in the researcher's home and stored separately from the questionnaire booklets. The completed, numbered, questionnaire booklets were kept in a locked metal box inside a locked desk in the researchers' home. Data were entered into a statistical program and kept on a computer with encryption.

### Data Analysis

The independent variables in this study were boundary ambiguity, spirituality and marital relationship quality. The dependent variables were caregiver strain and depression. Data in this study were analyzed using descriptive statistics, the Pearson Product Moment Correlation Coefficient, and Multiple Regression. The statistical program used was the Statistical Package for the Social Sciences (SPSS 12, 2004). Each research question is discussed in relation to the specific tests used.

### Research Questions

1. What are the relationships between, boundary ambiguity, spirituality, marital relationship quality, caregiver strain and depression among older African American spousal caregivers of persons with AD? Data analysis involved bivariate correlations using the Pearson Product Moment Correlation.
2. Which variables are the best predictors of caregiver strain (boundary ambiguity, spirituality, and marital relationship quality). Multiple regression was utilized for this research question. This statistic was chosen because it predicts a dependent variable

- (caregiver strain) from a combination of several independent variables (boundary ambiguity, spirituality and marital relationship quality) (Morgan, Griego & Gloeckner, 2001).
3. Which variables are the best predictors of depression (boundary ambiguity, spirituality, and marital relationship quality). Multiple regression was utilized for this research question. This statistic was chosen because it predicts a dependent variable (depression) from a combination of several independent variables (boundary ambiguity, spirituality and marital relationship quality).
  4. The background survey data were analyzed using descriptive statistics.

#### Summary

A convenience sample of 40 older African American spousal caregivers was recruited to participate in a study that describes the relationships between variables that influence strain and depression among spousal caregivers. The variables in this study were boundary ambiguity, marital relationship quality, spirituality, caregiver strain, and depression. The variables were operationalized with five instruments. A background questionnaire was used to obtain descriptive information about the participants.

The rights of subjects were maintained through the use of numerical coding of participant responses and corresponding consent forms. The signed consent forms were kept in a locked container, separate from the questionnaires. The locked container was stored in a locked cabinet in the researchers' home.

The research questions pertaining to the relationships among the independent and dependent variables were examined using descriptive statistics, multiple regression and



the Pearson Product Moment correlations. Background variables were examined using descriptive statistics and Pearson Product Moment correlations.

## CHAPTER IV

### RESULTS

The results of this study are presented in this chapter. Findings reported include participant response information, description of the sample, and findings related to study questions. A summary of the findings is presented at the conclusion of the chapter.

#### Participant Response Information

The researcher contacted a total of five churches with predominately African American congregations, four senior multipurpose centers, four adult day care programs, two hospital-based clinics, and the Alzheimer's Association about the study. A meeting was held with representatives of community agencies who provide services to older adults with Alzheimer's or dementia. Flyers describing the study and contact information were distributed at each potential site. Caregivers accompanying a spouse with memory problems to clinic appointments were approached about the study, given flyers and asked if they were interested in participating. Potential subjects who expressed interest were contacted by telephone to schedule interviews at a convenient location.

A total of 47 eligible spousal caregivers agreed to participate in the study, however, 7 subsequently declined. The total number of caregivers who completed the interview was 40, producing a response rate of 40/47. One spouse stated she did not wish to participate due to personal issues. Four persons gave verbal consent but failed to confirm an interview time. Two surveys were mailed per participant request and not

returned. During one to one contact, participants were given a copy of the study questions to view while the researcher read the questions aloud. Participant responses were recorded on the forms by the researcher in all but one case. One participant preferred to complete and return the questionnaire by mail.

### The Sample

The sample size necessary to test the research questions was determined with power analysis. Based on a power of .80 with alpha set at .05, and a moderate effect size of .30, a sample of 96 subjects was needed to adequately test the proposed research questions (Cohen, 1992). The researcher was unable to obtain this sample size, therefore the scope of the study was reduced. Several variables were eliminated from the plan for analysis. A sample size of 40 was obtained. Nunnally and Bernstein (1994) propose that a minimum of ten subjects per predictor variable is adequate to conduct a regression analysis. There were three predictors in the regression equations for this study and two dependent variables. Descriptive statistics of the AA spousal caregivers in this study are in Table 1.

Participants were recruited from three primary sources: a memory clinic (27), a geriatric health clinic (5), the Alzheimer's Association (1), and senior day care centers (7). Most caregivers were female with a high school or less education and had low incomes (Table 1). The ages of study participants ranged from 60 to 87 years with a mean of 69 ( $\pm 8.0$ ) years. The length of time spent caring for a spouse on a daily basis ranged from 5 to 24 hours with a mean of 12 ( $\pm 1.0$ ) hours. Over half of the sample (58%) spent more than 11 hours a day caring for the spouse with AD. Most caregivers (55%) reported having assistance with caregiving, usually a daughter or son, with slightly

less than half providing care alone (Table 1). Over half of the respondents indicated that their spouse had been diagnosed with AD or dementia for at least three years or more suggesting a caregiving career that has extended over a period of several years (Table 1).

Table 1

*Demographic Characteristics of Sample – AA Spousal Caregivers (N = 40)*

Characteristic	N (%)
<b>Gender</b>	
Female	25 (62.5)
Male	15 (37.5)
<b>Education</b>	
Some High School	19 (47.5)
High School Graduate	19 (47.5)
College Graduate	2 (5.0)
<b>Income</b>	
Less than \$19,999/yr	32 (80.0)
\$20,000-\$29,000/yr	5 (12.5)
\$30,000-\$30,999 yr	3 (7.5)
<b>Hours Spent Providing Care Per Day</b>	
Less than 5	6 (15.0)
6-10	11 (27.5)
11-16	9 (22.5)
17-24	14 (35.0)
<b>Help with Caregiving Each Day</b>	
None	19 (47.1)
Daughter	11 (27.9)
Son	9 (22.5)
Other	1 (2.5)
<b>Number of Years Diagnosed with AD or Dementia</b>	
Less than 2 years	19 (47.0)
3-5 years	11 (27.5)
6-10 years	9 (22.5)
> 10 years	1 (2.5)
<b>Employment Status</b>	
Working Part-time	3 (7.5)
Not Working	37 (92.5)

The respondents' perception of their health at present ranged from poor to fair (50%) to good to excellent (50%) with half of the participants reporting good to excellent perceptions of health after becoming caregivers. Most caregivers rated their health before becoming caregivers as "good to excellent" (62.5%) while 37.5% rated their health before caregiving as "poor to fair". The change in health perception was significant ( $X^2 (1, N = 40) = 12.90, p < .001$ ). Respondents perceived themselves as healthier prior to becoming caregivers.

There was a significant change in the perception of the marital relationship before and after spouses became caregivers (Table 2). Prior to assuming caregiving responsibilities, only 6 respondents (15%) rated the marital relationship as poor to fair with 35 (85%) respondents rating the marital relationship as good to excellent. The mean score for the marital relationship before becoming a caregiver was 3.2 (SD = .77), indicating that the marital relationship was perceived as good. The mean score for marital relationship after becoming a spousal caregiver was 2.75 (SD = 1.1), indicating a decrease in how the marital relationship was perceived for spousal caregivers after they became caregivers of a mate ill with AD. There was a significant difference with the marital relationship being perceived as worse after becoming caregivers (Table 2).

Table 2

*Paired Samples Statistics: Perception of the Marital Relationship Before AD & Relationship Now (N = 40)*

Measure	Mean	SD	t-value	SE	Df	Sig.
Relationship Before Caregiving & Relationship Now	.475	.987	3.044	.156	39	.004*

\*p<.01

## Findings Related to Study Variables

### *Reliability of Scales*

Cronbach's alpha was computed to calculate the internal consistency score for the survey instruments used in the study. All five scales had adequate reliability except for the Boundary Ambiguity scale, which had moderate reliability (.68), slightly below the acceptable minimum for a new instrument. The highest alpha coefficients that emerged among the tools were for the Caregiver Strain Questionnaire (.93) and for the Center for Epidemiological studies Depression scale (.85).

### *Means and Standard Deviations of Study Variables*

The average total score on the CES-D was below the cutoff of 16 for possible clinical depression, but 40% scored 16 or above. On average, BAS scores fell above the midpoint of the scale indicating more boundary ambiguity. The mean score on the Exhaustion subscale of the CSQ fell below the midpoint of the scale. In reference to marital relationship quality, the mean score on the MSS was 35.16 (SD = 8.14) indicating high levels of marital relationship quality. The mean score on the SPS was 5.5 (SD = .398) on a scale ranging from 0-6 indicating high spiritual perspectives and possible ceiling effects. Table 3 presents the descriptive statistics, minimum and maximum potential scores, and observed scores for each scale.

Table 3

*Means and Standard Deviations of Variables of Interest*

Variables	Mean (SD)	Potential Range	Min.-Max
Center for Epidemiological Studies Depression Scale (CESD)	13.55 (9.4)	0-60	12-45
Boundary Ambiguity Scale (BAS)*	45.28 (6.3)	14-70	27-54
Caregiver Strain Questionnaire (CSQ) (The Exhaustion Subscale)	30.3 (13.9)	0-100	14-78
Marital Satisfaction Scale (MSS)	35.15 (8.14)	0-50	9-48
Spiritual Perspective Scale - (SPS)	5.5 (.398)	0-6	4.5-6

\*BAS modified from original scale.

*Correlations*

Bivariate correlations of study variables are reported in Table 4. Correlations among study scales are presented along with correlations of several background variables.

## Research Question 1

What are the relationships between boundary ambiguity, spirituality, marital relationship quality, and caregiver strain and depression among older African American spousal caregivers of persons with AD?

The data were analyzed using bivariate correlations (Table 4). There was a significant moderate association between marital relationship quality and caregiver strain.

Better marital relationship quality was also significantly associated with lower caregiver strain and inversely related to fewer depressive symptoms. The greater the marital relationship quality among caregivers the lower strain experienced. Caregivers with a greater quality of the marital relationship had less depression. Boundary ambiguity and spirituality were not significantly associated with the dependent variables.

#### *Other Bivariate Correlations*

There was a strong inverse association between years diagnosed and boundary ambiguity and a moderate inverse association between years diagnosed and marital relationship quality, and spirituality. The longer a spouse was diagnosed with AD, the less boundary ambiguity, less marital relationship quality, and less spirituality caregivers perceived. Spousal caregivers indicated the more boundary ambiguity, marital relationship quality, and spirituality they perceived, the fewer years a mate had been diagnosed with AD.

There was a significant strong association between caregiver strain and years diagnosed. The longer care recipients had been diagnosed with AD, the more strain caregivers experienced.

Gender was moderately associated with caregiver strain with females having more symptoms of strain. There was a strong association between income and education and a moderate inverse association between education and depression. The more educated caregivers were, the less depressed. The more depressed caregivers were the less they were educated. There were moderate significant associations between work status and marital relationship quality as well as work status and boundary ambiguity. Marital relationship quality and boundary ambiguity scores were higher for employed



spousal caregivers. This finding suggests that employed caregivers were more satisfied with the marital relationship and experience more boundary ambiguity than unemployed spousal caregivers.

Table 4

*Correlations of Study Variables*

	Education	Income	Work Status	Help w Care	Yrs W AD	Relat. B/4 AD	Relat After AD	Boundary Ambiguity	Spirituality	Marital Rel. Quality	Caregiver Strain	Depression	
Gender	-.20	-.12	-.03	.32*	.11	.03	.14	-.03	-.12	.13	-.33*	.02	
Education		.51**	-.06	-.09	-.04	.02	.14	.19	.20	-.15	.19	-.33*	
Income			.05	-.13	-.10	-.15	-.07	.14	.09	-.29*	.13	-.23	
Work Status				-.11	-.26	.32*	.36*	.34*	.09	.35*	-.16	-.25	
Help w Care					.11	.12	.08	-.09	-.01	.40	.13	-.19	
Yrs Diagnosed w AD							-.20	-.46**	-.37**	-.29*	.45**	.10	
Rel. before AD								.57**	.19	.07	.56**	-.21	-.41**
Rel after AD									.35*	-.01	.62**	-.46**	-.42**
Boundary Ambiguity										.21	.08	.16	.01
Spirituality											.01	-.06	-.17
Marital Rel. Quality												-.57**	-.36*
Caregiver Strain													.24

\*p<.05, \*\*p<.01

## Research Question 2

Which variables are the best predictors of caregiver strain (boundary ambiguity, spirituality, marital relationship quality)?

### *Factors associated with Caregiver Strain*

An hierarchical multiple regression technique was used to explore how much variance in caregiver strain was explained by marital relationship quality, spirituality, and boundary ambiguity when other variables were controlled. The demographic variables of gender, education, and income were entered into the model in Step 1. Years diagnosed was also entered in Step 1 because of the strong significant bivariate correlation with caregiver strain. The first set of predictors (gender, education, income, and years diagnosed) accounted for a significant amount of caregiver strain variability: adjusted  $R^2 = .30$ ,  $F(4,35) = 5.1$ ,  $p = .002$  (Table 5).

At Step 2, three independent variables, boundary ambiguity, spirituality, and marital relationship quality were added. The  $R^2$  change from Step 1 was significant as shown in Table 5:  $R^2$  change = .14,  $F(7, 32) = 4.69$ ,  $p = .001$ . The final model indicated that gender, years diagnosed with AD, and marital relationship quality were all significant contributors to caregiver strain. Females experienced more symptoms of strain than male spousal caregivers. The standardized beta coefficients show that the amount contributed by these variables was about equal. All together, the adjusted  $R^2$  indicates that 40% of the variance was accounted for by the model variables.

Table 5

*Hierarchical Regression for Predicting Caregiver Strain (N=40)*

Variable (Caregiver Strain)	Standardized B	Standardized Error	p value	R <sup>2</sup>	Adj. R <sup>2</sup>	R <sup>2</sup> Change
Step 1						
Gender	-.35*	3.49	.02			
Education	.09	1.71	.56			
Income	.09	2.26	.57			
Years Diagnosed w/AD	50**	1.66	.001			
Model			.002	.37**	.30**	
Step 2						
Gender	-.31*	3.49	.03			
Education	.09	1.61	.53			
Income	-.04	2.26	.78			
Years Diagnosed w AD	.40*	1.95	.02			
Marital Rel. Quality	-.41*	.23	.01			
Spirituality	.03	4.53	.82			
Boundary Ambiguity	-.45	.29	.73			
Model			.001	.51**	.40**	.14*

\*p ≤ .05

\*\*p ≤ .01

## Research Question 3

Which variables are the best predictors of depression (spirituality, boundary ambiguity, and marital relationship quality)?

*Factors associated with Caregiver Depression*

An hierarchical multiple regression technique was used to explore how much variance in depression was explained by marital relationship quality, spirituality, and boundary ambiguity. As in the previous regression equation, the caregiver characteristics of gender, education, and income were entered into the model initially at Step 1. The results of Step 1 show that the background variables of gender, education, and income did not make a significant contribution to the variance in depression. The adjusted  $R^2 = .04$ ,  $F(3,36) = 1.59$ ,  $p = .209$ .

At Step 2, the three research variables boundary ambiguity, spirituality and marital satisfaction were added. The  $R^2$  change was significant and accounted for a significant portion of variability in depression after controlling for the select caregiver characteristics (education, income, and years diagnosed),  $R^2$  change = .22,  $F(3, 33) = 3.72$ ,  $p = .021$ . The model at Step 2 was significant ( $p = .024$ ) and the adjusted  $R^2$  indicates that 22% of the variance was accounted for by the variables. However, only marital relationship quality contributed significantly to the model (Table 6). The standardized beta indicates that it was a strong contributor (.48).

Table 6

*Hierarchical Regression for Predicting Depression (N=40)*

Variable (Depression)	Standardized B	Standardized Error	p value	R <sup>2</sup>	Adj. R <sup>2</sup>	R <sup>2</sup> Change
Step 1						
Gender	-.05	3.07	.76			
Education	-.30	1.42	.12			
Income	-.09	1.88	.63			
Model			.21	.12	.04	
Step 2						
Gender	-.02	2.80	.89			
Education	-.27	1.30	.11			
Income	-.24	1.77	.17			
Marital Relationship Quality	-.48**	.17	.00			
Spirituality	-.12	3.49	.42			
Boundary Ambiguity	.13	.20	.37			
Model			.02	.34*	.22*	.22*

\*p&lt;.05

\*\*p&lt;.01

## Summary

The data from 40 participants were analyzed. Findings in the study were used to answer the three research questions. Significant correlations were found to exist between the number of years diagnosed and several other variables including marital satisfaction, boundary ambiguity, and spirituality. Quality of marital relationship was strongly

associated caregiver strain and moderately associated with depression. Surprisingly, the measures of spirituality and boundary ambiguity were not correlated with the other study variables.

The caregiver's perception of their health appeared to become less favorable after they became caregivers. A paired sample t-test revealed a significant difference in spousal caregivers perception of the marital relationship now in comparison to the marital relationship before they became caregivers. Spouses rated the marital relationship higher before becoming caregivers.

Hierarchical multiple regressions revealed that marital satisfaction, gender, and years diagnosed were significant variables in explaining 40% of the variance in caregiver strain. Only marital satisfaction was significant in explaining 22% of the variance in depression.

## CHAPTER V

### DISCUSSION AND CONCLUSION

This chapter presents a discussion of the study results and related conclusions from the data analysis. Study results include demographic findings, the research questions, congruence of findings with the literature, the relationship of findings to the theoretical model and important correlations among variables of interest. The conclusion includes strengths and limitations of the study, implications for nursing, and recommendations for further research.

In comparison to other caregivers in the literature, the sample in this study differed in some aspects. Nationally, 30% of family caregivers were 65 and older (National Family Caregivers Association, 2004). The average income for persons over sixty-five in the state of Georgia was \$44,000 (U.S. Census, 2005). Further, nationally 24% of caregivers caring for someone older than 50 had an income less than \$30,000 according to a study conducted by the National Alliance for Caregiving & American Association for Retired Persons (NAC & AARP , 2004). In contrast, over 80% of the population in this study reported incomes of less than \$20,000 per year. The majority of caregivers reported in the literature are younger, (64% between the ages of 35 and 49 with an average of 46) than the participants in this study. Over 81% of caregivers are female relatives other than the spouse (NAC & AARP, 2004). Nationally, African American caregivers are more likely to be younger (between the ages of 18 and 34), with only 44% being married and living with a partner. Nationally, over 24% of caregivers



age 50 or older perceived their health as fair to poor in comparison to 50% of the participants in this study. In this study, all caregivers were spouses or partners, 25 (62.5%) were female and 15(37.5%) were male. The average age was 70, (ranging from 60- 87). According to national statistics, only 35% of caregivers age 65 and older had completed high school (NAC & AARP, 2004) whereas half of the sample (53%) in this study had completed high school.

The demographic characteristics of the sample in this study were different from older caregivers on a national basis: more had received high school diplomas; more were older spouses caring for a mate; and more were economically disadvantaged. Further, all participants in this study were AA. Many of the demographic differences were due to the criteria used for selection of participants for the study.

### Research Questions

#### *Discussion of Research Question 1*

In regard to the relationships between boundary ambiguity, spirituality marital relationship quality, caregiver strain and depression, only marital relationship quality was significantly related to caregiver strain and depression. These findings were consistent with other studies in the literature. Beach, Schulz, Yee, and Jackson (2002) found that caregivers with higher marital relationship quality reported fewer symptoms of strain such as anxiety and health risk behavior. Williamson and Schaffer (2001) found that caregivers who experienced more relationship rewards and had communal relationships before the mates' illness evaluated past and current relationships as more rewarding with fewer symptoms of strain. Most studies in the literature addressed the marital relationship in terms of health outcomes, ethnic and gender differences. Few studies

addressed the marital relationship and caregiver strain among older AA spousal caregivers.

In the current study, a significant inverse relationship existed between marital relationship quality and depression. Caregivers who viewed the marital relationship quality as more positive were less depressed. Those who viewed the quality of the marital relationship less favorable were more depressed. In addition, study participants felt better about the marital relationship before becoming caregivers in comparison to after becoming caregivers of a spouse with AD.

Few studies in the literature addressed the relationship between marital relationship quality and caregiver depression for spousal caregivers. No studies addressed marital relationship quality and depression among older African American spousal caregivers. A study by Williamson and Schaffer (2001) supported findings in the current study. Caregivers who perceived the pre-illness relationship as rewarding were less depressed in the current relationship. Rose-Rego et al. (1998) found that spousal caregivers were less satisfied with their lives and more depressed when compared to non-caregivers. Findings in a two-year longitudinal study that explored change over time for African American and white caregivers suggested that African Americans were less vulnerable than whites to adverse psychological consequences of caregiving or depression (Roth et al., 2001). These results are inconsistent with findings in the current study. Study results indicated a significant negative association between spirituality and the length of time caregiving. These findings suggest that spirituality for caregivers may decrease the longer the spouse has been diagnosed with AD. These results were surprising considering the fact that the literature is rich in studies pertaining to the

importance of spirituality as an important coping resource for older African Americans (Shirey & Sumner, 1997; Spurlock, 2005; Taylor et al., 2004; Theis et al., 2003). The findings in this study were consistent with other studies that did not find a direct relationship between caregiver strain and spirituality (Chang et al., 1998). It is plausible that AD worsens with the passage of time and causes an increase in caregiver demands. The spousal caregiver may have less time to engage in activities involving spirituality ie; going to church or participating in religious groups. The sensitivity of the spirituality instrument may have also been a factor.

#### *Discussion of Research Question 2*

The second research question explored which variables were the best predictors of caregiver strain (boundary ambiguity, spirituality, and marital relationship quality). In the hierarchial regression equation for caregiver strain, marital relationship quality, gender and years diagnosed were significant predictors of caregiver strain. The literature supports the idea that the quality of the marital relationship is associated with the occurrence of strain for spousal caregivers. Uchino et al. (1999) found that past and current relationships were perceived as rewarding when the marital relationship was perceived favorably by caregivers. The association between the marital relationship and caregiver strain over time needs further exploration.

Boundary ambiguity was not found to be a significant predictor of caregiver strain. Boundary ambiguity, a construct that includes unclear losses and a lack of clarity in family relationships (Boss et al., 1990) has previously been explored in studies of dementia caregivers (Boss et al., 1990; Caron et al., 1999). Few studies in the literature address loss associated with providing care for a loved one with AD. The Boundary

Ambiguity scale has not been used in studies involving African American caregivers. The BAS had a low reliability for a new instrument with a Cronbach alpha of .68 after modifying the scoring instructions. The low reliability scores on the BAS may be related to several factors including cultural variation among families. The BAS had not previously been tested in African American families.

The participants in this study rated their spirituality very high with a mean of 5.5 out of a possible 6 on a Likert scale indicating a greater spiritual perspective with very little variability in the scores. The role of spiritual beliefs and coping with caregiving needs further exploration.

### *Discussion of Research Question 3*

In the hierarchical regression analysis for depression, only one of the three predictor variables, marital relationship quality, was significant. The predicted relationship between marital relationship quality and depression was both supported and refuted in the literature. Williamson and Shaffer (2001) found that caregivers who experienced more relationship rewards and had communal relationships were less depressed. According to Beach, Schulz, Yee, and Jackson (2002) a higher quality marital relationship was positively correlated with health related outcomes. In the current study there was a negative correlation between marital relationship quality and depression. The literature is limited in studies that address the marital relationship and depression for AA spousal caregivers.

## Additional Findings

### *Demographic Information*

The spouse was reported to be the primary caregiver of persons with AD residing in the home environment (Ory et al., 1999). By design, all participants in this study were spousal caregivers.

A significant positive correlation existed between years diagnosed with AD and caregiver strain. These findings suggest that longevity in caregiving increases the likelihood of adverse consequences. Wright, Hickey, Buckwalter, Hendrix and Kelechi (1999) found that AD caregivers experience more symptoms of depression over time when compared to caregivers of persons with other chronic illnesses.

Findings in the current study differ in that the quality of the marital relationship had changed significantly for spouses after they became caregivers. The literature is limited in studies that explore the quality of the marital relationship.

In the current study, spouses experienced a change in perception of health after becoming caregivers. These findings were consistent with other studies (Haley et al., 1995; National Alliance for Caregiving and AARP, 2004; Robinson & Austin, 1998).

Most caregivers (85%) in this study spent six to ten hours per day caring for the mate with AD. This finding is consistent with older caregivers nationally (National Alliance for Caregiving and AARP, 2004). A large percentage of caregivers in this study received no assistance with caregiving (49%). These findings differ from national statistics in which six of ten (59%) caregivers report someone else assists with care (National Alliance for Caregiving and AARP, 2004).

Boundary ambiguity was inversely associated with length of time diagnosed. The longer spouse's had been diagnosed with AD, the less boundary ambiguity experienced or caregivers were more susceptible to boundary ambiguity earlier in the caregiving career. One possible explanation may pertain to the idea that caregivers may adjust to changes and the alteration in roles, and relationships over time when a mate has AD.

Another interesting finding was the fact that a negative correlation existed between spirituality and the length of time spent caregiving. Spirituality decreased the longer participants were engaged in caregiving. One possible explanation for this finding could be due to a lack of sensitivity in the SPS. The measure does not differentiate whether or not participants were unable to participate in previous expressions of spirituality because of an increase in caregiver demands the longer a mate was diagnosed with AD. Spirituality scores among study participants were very high but not significant. The lack of variability in scores could have created a ceiling effect. These findings need further exploration.

#### Relationship of Findings to Theoretical Framework

Based on the theory of Ambiguous Loss, this study addressed several concepts related to family stress when caring for a mate with AD. The researcher postulated that boundary ambiguity, spirituality, and marital relationship quality influences caregiver strain and depression of older AA spousal caregivers.

Findings from the current study provide support for the influence of marital relationship quality as well as identified other significant variables in the experience of strain and depression for spousal caregivers. Boundary ambiguity and spirituality did not have significant associations with strain and depression. Correlations with caregiver

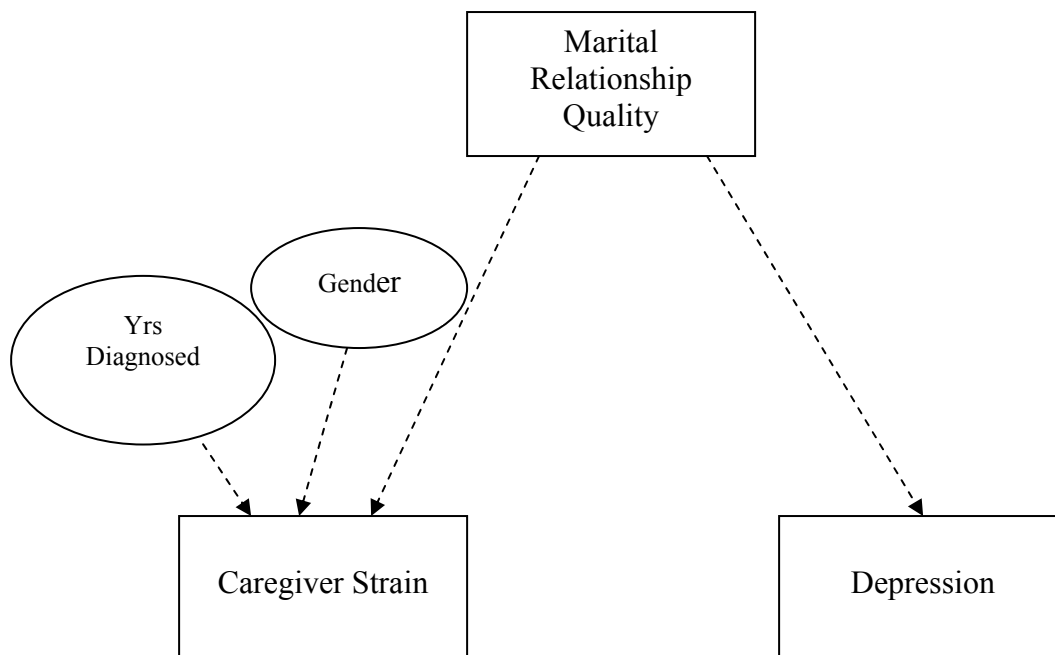
strain consisted of years diagnosed, gender, and marital relationship quality. Marital relationship quality also had a significant association with depression.

Ambiguous loss is a family systems construct that involves the strain families experience while caring for a relative who is physically present but psychologically or mentally absent (Boss, 1999). AD is a chronic illness characterized by a state of steady decline in cognitive, goal directed and subsequent physical functioning. The immediate family for many older adults consists of a couple that lives together as husband and wife or as partners. AD can cause a disruption in family relationships because the ill mate may not be able to remember past events, and present responsibilities. In the later stages of this illness, the person with AD may even forget the name of the spousal caregiver and the history of their lives together. The psychological and physical demands wrought by this illness can be a major source of strain and depression for spousal caregivers. Findings from this study suggest that the quality of the marital relationship declines the longer a mate is ill with AD. Marital relationship quality is inversely associated with caregiver strain and depression. Spousal caregivers appear to have strain and symptoms of depression the longer they are caregivers. Wives had more symptoms of strain than their male counterparts. There was a significant change in spousal caregivers perceptions regarding the marital relationship after they became caregivers of a mate with AD. Caregivers felt better about the marital relationship before they became caregivers. Given the nature of cognitive decline and subsequent inability to perform normal daily activities associated with AD, it is not surprising that spousal caregivers were more positive about the marital relationship before they became caregivers. The demands and adjustments

made in response to needs wrought by caregiving can be a major source of strain and contribute to feelings of depression for spouses providing care for a mate with AD.

The correlations to caregiver strain were years since diagnosis, and marital relationship quality. Correlations to depression were marital relationship quality. A revised model was generated based on the results of the hierarchical regressions. The original model hypothesized the existence of relationships between boundary ambiguity, spirituality, marital relationship quality, caregiver strain and depression. After data analysis only one of the proposed independent and several background characteristics were significantly related to the outcome variables. The significant variables were used to generate a revised model (Figure 1). Only variables that predicted the outcomes are included in the revised model.

*Figure 2.* Model of Variables of Interest for AA Spousal Caregivers





### Discussion and Conclusions Regarding Instrumentation

The established reliabilities of the Spiritual Perspective Scale, the Marital Satisfaction subscale, the Parent Caregiver Strain Questionnaire, and the Center for Epidemiological Studies Depression Scale were similar to those obtained in this study. The scales used in this study had reliabilities of .80 or higher except for the Boundary Ambiguity Scale. The reliability of the BAS (.68) was slightly below the acceptable required minimum. The reliability of the BAS was possibly related to low item to total correlations and difficulty in interpreting the meaning of some items. Respondents sometimes found the following scale item confusing; *“I’m not sure where \_\_\_\_\_ fits in as part of my family.”* This item may be difficult for spouses when the ill mate is sometimes the only family member. Testing of this instrument is limited and it has been used in only one prior study involving dementia caregivers (Boss et al., 1990). The lack of adequate testing of this scale with African American subjects may have been a factor in reliability.

The Exhaustion Subscale of the Parent Caregiver Strain questionnaire was a reliable measure of caregiver strain in this study. Though the scale was originally designed for offspring, the items were consistent with experiences of caregivers of persons with chronic illnesses (Clark, 2002; Irwin & Acton, 1997; Schwarz & Roberts, 1999; Toth-Cohen, 2004) regardless of consanguinial relationship to the ill person.

The Spiritual Perspective Scale was also a reliable measure in the current study. The total spirituality score was consistently above average and consistent with verbal comments of participants. The association between spirituality and other variables in this study was not found to be significant. The importance of spirituality and religion in the

lives of older African Americans is clearly documented in the literature (Chang, Noonan, & Tennesdt, 1998; Cooper, Brown, Thi, Ford, & Powe, 2001; Levin & Taylor, 1997; Picot, 1995; Taylor, Chatters, & Levin, 2004). The linkage between spirituality and caregiver strain and depression for AA spousal caregivers needs further exploration.

### Limitations of the Study

#### *Sampling*

A convenience sample was used in the study. Only spousal caregivers who were in contact with the Alzheimer's Association, two clinics at a large inter-city healthcare facility, senior centers, and local churches and willing to participate are included in the sample. Caregivers not associated with the aforementioned sites such as those treated in private physician offices, or persons who are limited or without access to healthcare may not have received information about the study. There is an indication from the literature that a delay exists between when symptoms of memory problems first appear and when actual diagnoses are received (Clark, 2002) which suggests that the study is limited to caregivers who sought some type of assistance. There may be other spousal caregivers who have not sought assistance from an agency or healthcare facility and may have responded differently to the study questions.

Another limitation is the small sample size of 40 which lowers the power in the current study. A power analysis according to Faul, Erdfelder, & Buchner (2007) was conducted on the current study. The results entailed that a power of .80 with a sample of 40 has a large effect size for multiple regression with four predictor variables.

The sample size forty (40) was small but consistent with samples of African American spousal caregivers in other studies (Lindgren, Connelly, & Glasper, 1999; Mui,

1992; Picot, 1995; 1997; Robinson & Austin, 1998; Rose-Rego et al., 1998; Williamson & Schafer, 2001). The lack of trust and negative feelings regarding research may have been a factor in the willingness to participate. Several potential participants were involved with getting health concerns addressed and found it difficult to confirm an interview time further limiting the sample to persons who were available.

The sensitive nature of marriage and being able to admit negative feelings about caring for a mate who is ill may have been difficult for some participants. One gentleman, while completing the caregiver strain instrument, stated he had no problems as a caregiver, however, when asked about medication administration, he stated he had an extremely difficult time getting his wife to take medicines.

#### *Instruments*

A major limitation of the study was related to lack of previous testing of the instruments with older African American samples. The CES-D has been used with African Americans. The Spiritual Perspective Scale though reliable, appears to lack sensitivity. Extensive pilot testing of instruments would be extremely useful in future research with this population.

#### Implications for Nursing

Alzheimer's disease has been described as an epidemic for African Americans that will continue to expand over the next 30 years as people entering the age of risk exceeds 6.9 million (Alzheimer's Association, 2005). Given the current and future projections of increases in older adults in this country, the number of older spousal caregivers and their health care needs will grow exponentially. Nurses working in any healthcare arena can benefit from the findings in this study.

Based on the study results, the older AA spousal caregiver will provide care for an ill mate with or without assistance within the home environment and for an extended period. Spousal caregivers often experience symptoms of physical and emotional strain such as depression when caring for a mate with AD. Caregivers also view themselves as less healthy after years of caregiving. Nurses can be instrumental in early detection, prevention and treatment of adverse consequences related to caregiving.

Nurses should be aware that the changes in the marital relationship due to caregiving is also related to the strain and depression caregivers experience. Married caregivers should be referred for counseling and community support groups to help reduce the psychological and emotional stress associated with caring for a spouse with a chronic deteriorating illness.

Rendering culturally sensitive care is extremely important with older caregivers. Nurses should be cognizant of the fact that older African Americans, especially males, may not readily admit to any adverse physical or psychological symptoms or needs while providing care for an ill mate. Assessment, education, referral and mobilizing support resources are necessary tools nurses need to adequately care for the older spousal caregiver.

Caregiver strain was positively associated with years diagnosed in the current study. These results suggest that nurses should complete health assessments on the caregiver and care recipient when either comes in contact with a healthcare provider. An assessment of the marital relationship may also be a useful cue regarding strain for caregivers. A depression screen should be administered as a standard practice for older adults especially caregivers to identify mental health needs. Nurses should refer the older

caregiver to appropriate resources such as, in home sitters, home health agencies, in home mental health services.

Education was negatively correlated with depression in this study. Education is an extremely important tool for nurses caring for caregivers. Spousal caregivers who lack knowledge about the physical, cognitive, emotional and behavioral changes Alzheimer's disease causes can become highly susceptible to depression stemming from the demands of caregiving. Nurses can be extremely helpful by educating caregivers about AD so they can understand that behaviors such as repetitive questions, forgetting food on the stove, wandering or getting lost, are symptoms of an irreversible illness that affects cognitive functioning. This study reinforces the fact that older adults will care for a spouse in home setting regardless of any negative health consequences. Nurses should educate and inform caregivers about Alzheimer's disease and interventions that aid in caregiving efforts. Explaining the physiological changes and associated impact on cognitive functioning related to Alzheimer's may increase understanding and acceptance for caregivers. Knowledge about community resources and techniques to manage difficult behavior may aid in decreasing the depression related to a lack of knowledge for caregivers.

This study did not support the idea that spirituality is an important factor related to strain and depression for AA spousal caregivers. The high scores on the spirituality measure suggest that it is a common issue for spousal caregivers in this study. Participant comments regarding the importance of spirituality during the interview process suggest that getting spiritual needs met is important to caregivers. Nurses should be advocates for caregivers by mobilizing support resources to help get spiritual needs met. One way of helping meet this need would be to contact the health ministries or pastors of churches

and suggest that volunteers sit with the ill spouse while the mate attends services. Another suggestion would be to provide sitter services at church for the ill mate when possible. Large churches have children's church or nurseries during service, a similar service for mobile people with cognitive impairments may provide relief for the older caregiver who enjoys attending church. Nurses can also be instrumental in educating church congregations about Alzheimer's disease and the needs of caregivers and care recipients.

## Conclusions

### *Strengths of the Study*

An important strength of this study is that it decreases the gap in research involving older African American caregivers. Over one-third of the participants in this study were African American males, a rarity in caregiver research. This study addresses the older spousal caregiver and some of the variables that impact caregiving for this population. Little is known about the importance of the marital relationship in caring for an ill spouse nor the associations between caregiver strain, depression and the quality of the marital relationship for African Americans.

An additional strength of this study is that it decreases the gap in the literature pertaining to an inadequate number of studies that address characteristics of older AA spousal caregivers. Few studies on AD caregiving involve a sample of older African Americans. This study adds to the body of literature concerning caring for a partner with in the home environment. African American spousal caregivers perceive themselves as less healthy after becoming caregivers. This implies that strain associated with caregiving can adversely impact the health of older caregivers.

This study supports the importance of quality of the marital relationship in providing in-home care for a mate with a chronic illness. The retrospective ratings on marital or partner relationship decreased after spouses became caregivers. Caregivers who perceived the quality of their marriage more favorably reported less strain and depression. Changes in perceptions about health and the marital relationship suggest that caregiving can have a negative impact on spouses. Specifics regarding psychological and physical changes that impact the AA spousal caregiver after assuming the caregiver role need further exploration.

There was also support for an association between years diagnosed and the occurrence of strain. The caregiving career for one-half of the spouses in this study ranged from three to six years. Caregivers were more susceptible to strain the longer they provided care for a mate with AD.

The high ratings on the Spiritual Perspective scale suggest that AA spousal caregivers view spirituality as very important in their lives. A linkage between spiritual beliefs and caregiver strain and depression was not supported by findings in this study. Given the verbally expressed beliefs about the meaningfulness of spirituality in their lives, a qualitative exploration of the role of spirituality and coping for AA spousal caregivers may yield valuable information for healthcare professionals.

Caregiving of persons with AD and other chronic illnesses is probably one of the most studied topics today, yet, numerous gaps in the literature still exist. This study has attempted to address some issues related to caregiving for older African American spouses. Alzheimer's disease and its attendant health care problems are currently considered an emerging public health crisis among African Americans. The numbers of

individuals with Alzheimer's as well as AD caregivers are expected to almost double in the next 30 years according to the Alzheimer's Association Report (2004).

The current study has enhanced knowledge concerning the association between marital relationship quality, caregiver strain, and depression for older African American spousal caregivers. These individuals often provide care anywhere from 6 to 16 hours a day for ill partners without assistance. Thus, it is understandable that these older caregivers experienced a decline in their perception of health and a decline in the quality of the marital relationship after becoming caregivers.

Marital relationship quality is an important variable in relation to caregiver strain and depression for spousal caregivers. Caregivers who perceive the marital relationship quality as negative may experience more strain and depression than those who perceive the relationship in a positive light. The quality of the marital relationship should be assessed prior to planning interventions to meet healthcare needs of caregivers.

The occurrence of depression among older adults is clearly documented in the literature. Research pertaining to depression among older African American spousal caregivers contains contradictions. Findings in the current study support the need for assessment and intervention strategies that address the healthcare needs of older African American spousal caregivers.

Findings in the current study support the literature regarding the association between gender and caregiver strain. The strain experienced by female caregivers was significantly higher than that for male caregivers. Nurses should assess caregivers for symptoms of strain and provide appropriate referral resources.



Though limitations exist in the current study, the findings enhances our knowledge regarding the occurrence of strain and depression for older African American spousal caregivers of persons with AD.

## References

- Abrams, M. (2001). Resilience in ambiguous loss: *Journal of Psychotherapy*, 55(2), 283-292.
- Adams, T. (1996). Informal family caregiving to older people with dementia: Research Priorities in community psychiatric nursing. *Journal of Advanced Nursing*, 24, 703-710.
- Almberg, B., Grafstrom, M., & Windbald, B. (1997). Caring for a demented elderly person-burden and burnout among caregiving relatives. *Journal of Advanced Nursing*, 25, 109-115.
- Alzheimer's Association. (2005). Alzheimer's disease statistics. Retrieved March 30, 2007 from <http://www.alz.org>
- Beach, S.R., Schulz R., Yee, J.L., & Jackson, S. (2002). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the caregiver effects study. *Psychology and Aging*, 15(2), 259-275.
- Bergman-Evans, B. (1994). A health profile of spousal Alzheimer's caregivers depression and physical characteristics. *Journal of Psychosocial Nursing*, 32(9), 25-30.
- Buckwalter, K.C., Gerdner, L., Kohout, F., Hall, G.R., Kelly, A., Richards, B., & Sime, M. (1999). A nursing intervention to decrease depression in family caregivers of persons with dementia. *Archives of Psychiatric Nursing*, 8(2), 80-88.
- Boss, P. (1977). A clarification of the concept of psychological father presence in families experiencing ambiguity of boundary. *Journal of Marriage and the Family*, February, 141-151.

- Boss, P. (1980). Normative family stress. Family boundary changes across the life-span. *Family Relations*, October, 445-449.
- Boss, P., & Greenburg, J. (1984). Family boundary ambiguity: A new variable in family stress theory. *Family Process*, 23, 535-546.
- Boss, P., Caron, W., Horbal, J., & Mortimer, J. (1990). Predictors of depression in caregivers of dementia patients: Boundary ambiguity and mastery. *Family Process*, 29, 245-254.
- Boss, P., Greenberg, J., Caron, W. (1990). Boundary ambiguity scale for caregivers of patients with dementia. *Measurement of Boundary Ambiguity in Families*. Station Bulletin 593-1990 Minnesota Agricultural Experiment Station, University of Minnesota. St. Paul, MN.
- Boss, P. (1991). Ambiguous loss: In Walsh and M. McGoldrick. (Eds). *Living Beyond Loss: Death in the Family*, 164-175. New York, W.W. Norton and Company.
- Boss, P. (1999). *Ambiguous loss: Learning to live with unsolved grief*. Harvard University Press, Cambridge.
- Burgess, A.W. (1998). *Psychiatric Nursing: Promoting Mental Health*, (Chapter 20). Appleton & Lange. Stamford, CT.
- Caron, W., Boss, P., & Mortimer, J., (1999). Family boundary ambiguity predicts Alzheimer's outcomes. *Psychiatry*, 62, Winter.
- Chang, B.H., Noonan, A.E., & Tennstedt, S.L. (1998). The role of religion/spirituality in coping with caregiving for disabled elders. *The Gerontologist*, 38(4), 75-88.
- Clark, P.C. (2002). Effects of individual and family hardiness on caregiver depression and fatigue. *Research in Nursing & Health*.

- Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*(2), 133-139.
- Connell, C.M., & Gibson, G.D. (1997). Race, ethnic and cultural differences in dementia caregiving. *The Gerontologist*, *37*(3), 355-364.
- Cooper, L.A., Brown, C., Thi, V. H., Ford, D.W., & Powe, N.R. (2001). How important is intrinsic spirituality in depression care? A comparison of White and African-American primary care patients. *Journal of Internal Medicine*, *16*(9), 634-638.
- Dilworth-Anderson, P., Williams, I.C., & Gibson, B.E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review. *The Gerontologist*, *(42)*, 237-272.
- England, M. (1990). *Test of a model for caregiver strain*. Case Western Reserve University.
- Farran, C.J., Miller, B.H., Kaufman, J.E., & Davis, L. (1997). Race, finding meaning, and caregiver distress. *Journal of Aging and Health*, *9*, 316-333.
- Faul, F., Erdfelder, E., & Buchner, A. 2007. (In Press) G\*Power 3 Behavior Research Methods. University of Mannheim, Mannheim Germany Web retrieved May 2007.
- Fredman, L., Paly, M., & Lazur, A. (1995). Burden among white and black caregivers of elderly adults. *Journal of Gerontology: Social Services*, *50B*, 5110-5118.
- Gilliland, G., & Fleming, S. (1998). A comparison of spousal anticipatory grief and conventional grief. *Death Studies*, *22*, 541-569.
- Given, C.W., Given, B.A., Stommel, N., & Azzouz, F. (1999). The impact of new demands for assistance on caregiver depression: Tests using an inception cohort. *The Gerontologist*, *39*, 76-85.

- Gonzalez, E. (1996). Resourcefulness, appraisals and coping efforts of family caregivers. *Issues in Mental Health Nursing, 18*, 209-227.
- Grant, I., Adler, K.A., Patterson, T.L., Dimsdale, J.E., Ziegler, M., & Irwin, M. (2002). Health consequences of Alzheimer's caregiving transitions: Effects of placement and bereavement. *Psychosomatic Medicine, 64*(3), 477-486.
- Haley, W.E., West, C.A., Wadley, V.C., Ford, G.R., White, F.A., Barrett, J.J., Harrell, L.E., & Roth, D.L. (1995). Psychological, social, and health impact of caregiving: A comparison of black and white dementia family caregivers and noncaregivers. *Psychology and Aging, 10*(4), 540-552.
- Hepburn, K., Tornatore, J., Center, B., & Oswald, T. (2001). Dementia family caregiver training: Affecting beliefs about caregiving and caregiver outcomes. *JAGS, 49*(4), 450-457.
- Hoffman, C., Rice, D., & Sung, H. (1996). Persons with chronic conditions: Their prevalence & costs. *JAMA, 7*(18), 1473-9.
- Hooker, K., Manooogion O., Frazier, L.D., Monaham, D J., & Shifren, K. (2000). Does type matter? Gender differences among Alzheimer caregivers. *The Gerontologist, 40*(5), 568-573.
- Irwin, B., & Acton, G. (1997). Stress, hope and well-being of women caring for family members with Alzheimer's disease. *Holistic Nursing Practice, 11*, 69-79.
- Kirby, S.E., Coleman, P.G., & Daley, D. (2004). Spirituality and well-being in frail and nonfrail older adults. *Journal of Gerontology: Psychological Sciences, 59B*(3), 123-129.

- Levin, J., & Taylor, J. (1997). Age differences in patterns and correlates of the frequency of prayer. *The Gerontologist*, Vol. 37, (1), 75-88.
- Lawrence, R.H., Tennstedt, S.L., & Assman, S.F. (1998). *Psychology and Aging*, 13(1), 150-158.
- Lichtenstein, P., Gatz, S., & Berg, S. (1998). A twin study of mortality after spousal bereavement. *Psychological Medicine*, 28, 635-648.
- Lindgren, C.L., Connelly, C.T., & Glasper, H.L. (1999). Grief in spouse and children caregivers of dementia patients. *Western Journal of Nursing Research*, 21(4), 521-537.
- Moore, I. (1997). Living with Alzheimer's: Understanding the family and patient's perspective. *Geriatrics*, 52, (suppl. no. 2), S33-S36.
- Morgan, G.A., Griego, O.V. & Gloeckner, G.W. (2001). *SPSS for Windows: An Introduction to Use and Interpretation in Research*. Lawrence Erlbaum Associates. Mahwah, NJ.
- Mui, A. (1992). Caregiver strain among black and white daughter caregivers: A role theory perspective. *The Gerontologist*, 32(2), 203-212.
- National Alliance for Caregiving and American Association for Retired Persons (NAC & AARP). (2004). *Caregiving in the U.S.: Findings from a National Survey*. Retrieved March 30, 2007 from [http://www.Caregiving.Org/data/94 final report.pdf](http://www.Caregiving.Org/data/94%20final%20report.pdf)
- Nunnally, J.C., & Bernstein, I.H. (1994). *Psychometric theory* (3<sup>rd</sup> ed.). New York: McGraw-Hill.

- Ory, M., Hoffman, L., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *Gerontologist, 39*, 177-85.
- Pearlin, L., Mullan, J., Semples, S., & Skaff, M. (1990). Caregiving and the stress process an overview of concepts and their measures. *The Gerontologist, 30*(5), 583-591.
- Picot, S. (1995). Rewards, costs, and coping of African American caregivers. *Nursing Research, 44*(3), 147-152.
- Picot, S.J., Debanne, S.M., Namazi, K.H., & Wykle, M.L. (1997). Religiosity and perceived rewards of black and white caregivers. *The Gerontologist, 17*(1), 89-101.
- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 1-27.
- Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources and health: An updated meta-analysis. *The Journal of Gerontology. Psychological Sciences*. Vol. 61B; P33-P39.
- Ponder, J., & Pomeroy, E.C. (1996). The grief of caregivers: How pervasive is it? *Journal of Gerontological Social Work, 27*(2), 3-21.
- Radloff, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*(3), 385-401.
- Reed, P.G. (1986). Religiousness among terminally ill and healthy adults. *Research in Nursing and Health, 9*, 35-42.

- Reed, P.G. (1987). Spirituality and well-being in terminally ill hospitalized adults. *Research in Nursing and Health, 10*, 335-344.
- Robinson, L., & Austin, J. (1998). Wife caregivers' and supportive others' perceptions of the caregivers health and social support. *Research in Nursing & Health, 21*, 51-57.
- Rose-Rego, S.K., Strauss, M.E., & Smith, K.A. (1998). Differences in perceived well-being of wives and husbands caring for persons with Alzheimer's disease. *The Gerontologist, 38*(2), 224-230.
- Rosseau, P. (2000). The losses and suffering of terminal illness. *Mayo Clinic Proceedings, 75*(2), 197-219.
- Roth, D.L., Haley, W.E., Owen, J.E., Clay, O.J., & Goode, K.T. (2001). Latent growth models of the longitudinal effects of dementia caregiving: A comparison of African American and white family caregivers. *Psychology and Aging, 16*(3), 427-436.
- Rudd, M.G., Viney, L.L., & Preston, C.A. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *International Journal of Aging and Human Development, 48*(3), 217-40.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver effects study. *JAMA, 282*(23), 2215-2219.
- Schwarz, K.A., & Roberts, B.L. (2000). Social support and strain of family caregivers of older adults. *Holistic Nursing Practice, 14*(2), 77-90.



- Shirey, L., & Sumner, L. (1997). Chronic and disabling conditions: Challenges for the 21<sup>st</sup> century. National Academy on an Aging Society. Retrieved May 15, 2002, from <http://www.agingsociety.org>
- Spanier, G.B. (1976, February). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 15-28.
- Spurlock, W.R. (2005). *Spiritual well-being & caregiver burden in Alzheimer's caregivers*, 26(37), 154-161.
- Stolley, J.M., & Koenig, H. (1997). Religion, spirituality, and health among elderly African Americans and Hispanics. *Journal of Psychosocial Nursing*, 35, 32-37.
- Stuckey, J.C. (2001). Blessed assurance: The role of religion and spirituality in Alzheimer's disease and other significant events. *Journal of Aging Studies*, 15, 676-84.
- Taylor, R.J., Chatters, L.M., & Levin, J. (2004). *Religion in the lives of African Americans: Social, Psychological and Health Perspectives* (Chapter 8). Thousand Oaks, London. Sage Publications.
- Theis, S.L., Biordi, D.L., Coeling, H., Nalepka, C., & Miller, B. (2003). Spirituality in caregiving and care receiving. *Holistic Nursing Practice*, 17(1), 48-55.
- Toth-Cohen, S. (2004). Factors influencing appraisal of upset in black caregivers of persons with Alzheimer disease and related dememias. *Alzheimer Disease & Associated Disorders: An International Journal*, 18(4), 247-255.

- Uchino, B.N., Kiecolt-Glaser, J.K., & Cacioppo, J.T. (1999). Construals of pre-illness relationship quality predict cardiovascular response in family caregiver of Alzheimer's disease. *Psychology and Aging, 9*(1), 113-120.
- United States Census. (2005). Retrieved May 15, 2007, from [www.census.gov](http://www.census.gov)
- Walker, J.R., & Pomeroy, E.C. (1997). The impact of anticipatory grief on caregivers of persons with Alzheimer's disease. *Home Health Care Services Quarterly, 16*(2), 55-75.
- Williams, W.S., & Dilworth-Anderson, P. (2002). Systems of social support in families who care for dependent African American elders. *The Gerontologist, 42*(2), 224-236
- Williamson, G.M., & Shaffer, D.R. (2001). Relationship quality and potentially harmful behaviors by spousal caregivers: How we were then, how we are now. *Psychology and Aging, 16*(2), 217-226.
- Winslow, B. (1997). Effects of formal supports on stress outcomes in family caregivers of Alzheimer's patients. *Research in Nursing & Health, 20*, 27-37.
- Wood, J., & Parham, I. (1990). Coping with perceived burden. Ethnic and cultural issues in Alzheimer's family caregiving. *Journal of Applied Gerontology, 9*(3), 325-339.
- Wright, L.K., Clipp, E.C., & George, L.K. (1993). Health consequences of caregiver stress. *Medicine, Medicine, Exercise, Nutrition and Nurse, 2*, 181-195.
- Wright, L., Hickey, J.V., Buckwalter, K.C., Hendrix, S., & Kelechi, T. (1999). Emotional and physical health of spouse caregivers of persons with Alzheimer's disease and stroke. *Journal of Advanced Nursing, 30*(3), 552-563.

- Yin, T., Zhou, Q., & Bashford, C. (2002). Burden on family members: Caring for Frail elderly: A meta-analysis of interventions. *Nursing Research*, *51*(3), 199-208.
- Yates, P., & Stetz, K.M. (1999). Families awareness of and response to dying. *Hospice & Palliative Care*, *26*, 113-120.
- Young, R.F., & Kahana, E. (1995). The context of caregiving and well-being outcomes among African and Caucasian Americans. *The Gerontologist*, *35*(2), 225-232.

Appendix A  
Background Survey

## Background Questionnaire

The questions listed below will help us describe the people participating in this study. No names will be used.

**Instructions:** Please check or fill in all responses that apply to you.

## 1. Gender

1.  female2.  male

## 2. Your Age

\_\_\_\_\_

## 3. Race or Ethnic Origin

1.  African-American/Black2.  White3.  Asian4.  Hispanic or Latino5.  American Indian/Alaskan Native6.  Native Hawaiian/Pacific Islander7.  Other, please list \_\_\_\_\_.

Please place an X in front of the response that applies to you.

## 4. Highest grade completed in school.

1.  none2.  some grade school3.  some high school4.  high school graduate5.  some college6.  college graduate

5. Marital status
  1. \_\_\_\_ never married
  2. \_\_\_\_ married or living with a partner
  3. \_\_\_\_ married but separated
  4. \_\_\_\_ divorced
  5. \_\_\_\_ widow or widower
6. Income level
  1. \_\_\_\_ less than \$ 9,999 per year
  2. \_\_\_\_ \$10,000-\$19,999 per year
  3. \_\_\_\_ \$20,000-\$29,999 per year
  4. \_\_\_\_ \$30,000-\$39,999 per year
  5. \_\_\_\_ \$40,000 and over per year
7. Employment status
  1. \_\_\_\_ not currently employed
  2. \_\_\_\_ employed full-time
  3. \_\_\_\_ employed part-time (20 hours or less per week)
  4. \_\_\_\_ retired
8. Your relationship to the person with Alzheimer's Disease
  1. \_\_\_\_ spouse or significant other or life partner
  2. \_\_\_\_ sister
  3. \_\_\_\_ brother
  4. \_\_\_\_ daughter or son
  5. \_\_\_\_ other (please describe)

9. How many hours a day do you spend caring for the person with Alzheimer's or dementia.
1. \_\_\_\_ less than 5
  2. \_\_\_\_ 6-10 hours
  3. \_\_\_\_ 11-16 hours
  4. \_\_\_\_ 17-24 hours
10. Is there someone else helps you take care of your mate or partner?
1. \_\_no
  2. \_\_yes, if so who? \_\_\_\_\_
11. How long has your loved one been diagnosed with Alzheimer's Disease or dementia.
1. \_\_\_\_ less than a year
  2. \_\_\_\_ 1-2 years
  3. \_\_\_\_ 3-5 years
  4. \_\_\_\_ 6-10 years
  5. \_\_\_\_ greater than 10 years
12. What type of care do you provide for your spouse with Alzheimer's disease?
1. \_\_\_\_ None
  2. \_\_\_\_ Supervision
  3. \_\_\_\_ Help with grooming( bathing, and putting on clothes)
  4. \_\_\_\_ Help with meals
  5. \_\_\_\_ Transportation to medical appointments.

13. How would you rate your health before you became your mates' caregiver?
1. \_\_\_\_ poor
  2. \_\_\_\_ fair
  3. \_\_\_\_ good
  4. \_\_\_\_ excellent
14. How would you rate your health now?
1. \_\_\_\_ poor
  2. \_\_\_\_ fair
  3. \_\_\_\_ good
  4. \_\_\_\_ excellent
15. How would you rate your relationship before your partner or mate became ill with Alzheimer's Disease?
1. \_\_\_\_ poor
  2. \_\_\_\_ fair
  3. \_\_\_\_ good
  4. \_\_\_\_ excellent
16. How would you rate your relationship with your partner or mate who has Alzheimer's Disease now?
1. \_\_\_\_ poor
  2. \_\_\_\_ fair
  3. \_\_\_\_ good
  4. \_\_\_\_ excellent
17. Do you have any health problems?
1. \_\_\_\_ Yes. Please describe \_\_\_\_\_
  - \_\_\_\_ No



18. Have you ever been diagnosed or treated for depression?

1. \_\_\_\_ Yes

2. \_\_\_\_ No

19. What kind of doctors are you seeing? \_\_\_\_\_

\_\_\_\_\_

20. Do you work outside the home?

1. \_\_\_\_ yes, if so how many hours per week? \_\_\_\_\_

2. \_\_\_\_ no

Appendix B

The Boundary Ambiguity Scale

*The Boundary Ambiguity Scale*

<i>Strongly</i>	<i>Agree</i>	<i>Unsure</i>	<i>Disagree</i>	<i>Strongly</i>
<i>Agree</i>				<i>Disagree</i>

I feel:

C1. I continue to keep Alive my deepest hope that _____ will be like his/her old self again.	A	B	C	D	E
---	---	---	---	---	---

C3. I feel guilty when I get out of the house to Do something enjoyable While _____ remains at Home.	A	B	C	D	E
--	---	---	---	---	---

C7. I feel I cannot go anywhere without first considering____'s needs.	A	B	C	D	E
--	---	---	---	---	---

C8. I feel like I have no time to myself.	A	B	C	D	E
--	---	---	---	---	---

Appendix C

The Spiritual Perspective Scale

## The Spiritual Perspective Scale

**Introduction and Directions:** In general, spirituality refers to an awareness of one's inner self and a sense of connection to a higher being, nature, others, or to some purpose greater than oneself. Respond to the questions below about spirituality as it relates to your life. Mark an X in the space above that group of words that best describe you.

1. In talking with your family or friends, how often do you mention spiritual matters?

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
 Not at all    Less than    About once    About once    About once    About once  
                          once a year    a year    a month    a week    a day

2. How often do you read spiritually-related material?

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
 Not at all    Less than    About once    About once    About once    About once  
                          once a year    a year    a month    a week    a day

3. My spirituality is a significant part of my life.

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
 Strongly    Disagree    Disagree more    Agree more    Agree    Strongly Agree  
                          than agree    than disagree

Appendix D

The Marital Satisfaction Subscale

The Marital Satisfaction Sub-scale of the Dyadic Adjustment Scale

Please place an X by the number that best indicates how you feel about your relationship with your spouse.

1. How often do you discuss or have you considered divorce, separation, or terminating your relationship?

- 0 \_\_\_ All of the time
- 1 \_\_\_ Most of the time
- 2 \_\_\_ More often than not
- 3 \_\_\_ Occasionally
- 4 \_\_\_ Rarely
- 5 \_\_\_ Never

5. Do you ever regret that you married or lived together?

- 0 \_\_\_ All of the time
- 1 \_\_\_ Most of the time
- 2 \_\_\_ More often than not
- 3 \_\_\_ Occasionally
- 4 \_\_\_ Rarely
- 5 \_\_\_ Never

6. Do you kiss your mate?

- 0 \_\_\_ Never
- 1 \_\_\_ Rarely
- 2 \_\_\_ Occasionally
- 3 \_\_\_ Almost every day
- 4 \_\_\_ Every day

10. Which of the following statements best describes how you feel about the future of your relationship?

- 5 \_\_\_ I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- 4 \_\_\_ I want very much for my relationship to succeed, and will do all I can to see that it does.
- 3 \_\_\_ I want very much for my relationship to succeed, and will do my fair share to see that it does.
- 2 \_\_\_ It would be nice if my relationship succeeded, but I can't do much more than I am doing now to keep the relationship going.
- 1 \_\_\_ It would be nice if my relationship succeeded, but I refuse to do anymore than I am doing now to keep the relationship going.
- 0 \_\_\_ My relationship can never succeed, and there is no more that I can do to keep the relationship going.

Appendix E

The Exhaustion Subscale of the Caregiver Strain Questionnaire



Parent Caregiver Strain Questionnaire

*The Exhaustion Scale*

Sometimes doing things for an ill mate can be very wearing. These questions deal with how much effort you put into helping your spouse or significant other. Select the item that best describes how drained you feel as a result of doing the following things for (name) your significant other. Only respond to the things you actually do.

	Not at all Drained	A Little Drained	Somewhat Drained	Very Drained
1. Feeding	_____	_____	_____	_____
2. Toileting	_____	_____	_____	_____
3. Bathing	_____	_____	_____	_____
11. Money Affairs	_____	_____	_____	_____
12. Legal Affairs	_____	_____	_____	_____
13. Checking On (_____)	_____	_____	_____	_____

Appendix F

The Center for Epidemiological Studies Depression Scale

**Center for Epidemiologic Studies Depression Scale**  
National Institute of Mental Health

Format for Self-Administered Use.

Circle the number for each statement which best describes how often you felt or behaved this way—  
DURING THE PAST WEEK.

	0	1	2	3
	Rarely or None of the Time	Some or a Little of the Time	Occasionally or a Moderate Amount of Time	Most or All of the Time
	(Less than 1 Day)	(1-2 Days)	(3-4 Days)	(5-7 Days)
DURING THE PAST WEEK:				
1. I was bothered by things that usually don't bother me.....	0	1	2	3
2. I did not feel like eating; my appetite was poor.....	0	1	2	3
3. I felt I could not shake off the blues even with help from my family or friends.....	0	1	2	3
4. I felt that I was just as good as other people.....	0	1	2	3
5. I had trouble keeping my mind on what I was doing.....	0	1	2	3
6. I felt depressed.....	0	1	2	3
7. I felt that everything I did was an effort.....	0	1	2	3
8. I felt hopeful about the future.....	0	1	2	3
9. I thought my life had been a failure.....	0	1	2	3
10. I felt fearful.....	0	1	2	3
11. My sleep was restless.....	0	1	2	3
12. I was happy.....	0	1	2	3
13. I talked less than usual.....	0	1	2	3
14. I felt lonely.....	0	1	2	3
15. People were unfriendly.....	0	1	2	3
16. I enjoyed life.....	0	1	2	3
17. I had crying spells.....	0	1	2	3
18. I felt sad.....	0	1	2	3
19. I felt that people dislike me.....	0	1	2	3
20. I could not get "going".....	0	1	2	3

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