

AN ANALYSIS OF STRESSORS, MEDIATORS AND HEALTH OUTCOMES AMONG  
AFRICAN AMERICAN CAREGIVERS OF OLDER ADULTS WITH CHRONIC ILLNESS

by

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ABSTRACT

The purpose of this investigation was to define the stress process and health outcomes of African American caregivers who provide care to older adults with chronic illness. This study sought to investigate what background characteristics of caregivers are associated with caregivers' health outcomes (physical and mental), what primary and secondary stressors affect health outcomes, and what variables mediate caregivers' health outcomes.

Guided by the stress process model (Pearlin, Mullan, Semple, & Skaff, 1990), this study examined 152 African American caregivers who provide day-to-day, specific task care and/or emotional care for African American older adults with chronic illness. All caregivers were interviewed, using a structured questionnaire, which included caregivers' and care-recipients' demographic information, other background characteristics (caregiving history, caregiver justifications), primary stressors (cognitive status, behavior problems, ADLS/IADLS, role overload, and loss of relationship), secondary stressors (family and work conflict), mediators (religious/spiritual coping, informal social support, and formal social support), and health outcomes (physical and mental). Univariate, bivariate, and mediation analyses were employed to analyze the outcome data of this study.

Univariate analyses revealed caregivers who were older, no immediate relation with the care recipient, who were unemployed, lower income, three health problems, and who provided care for 43 + hours a week for over 121 months, showed poorer physical health outcomes. Caregivers who resided with care recipient demonstrated lower mental health outcomes. At the bivariate level increased amounts of role overload, loss of relationship with care recipient, and work conflict resulted in negative physical and mental health outcomes. Elevated levels of family conflict were a significant predictor for elevated levels of mental health, while increased amounts of caregiving justification, religious/spiritual coping, and informal social support relieved mental health outcomes. Lastly, family conflict significantly mediated the relationship between the loss of relationship and mental health outcomes.

Based on the findings of this study, directions for future research were suggested, particularly for African American caregivers who provide care for older adults with chronic illness.

**INDEX WORDS:** Caregiver stress, Social support, Coping strategies, African American caregivers, Older adults with chronic illness, Pearlin model, Stress and coping, Physical health, Mental health, Social work practice

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## TABLE OF CONTENTS

	Page
LIST OF TABLES .....	vii
LIST OF FIGURES .....	viii
CHAPTER	
1 INTRODUCTION .....	1
African American Older Adults .....	1
African American Caregiving .....	7
Problem Statement .....	12
Purpose of the Study .....	15
Significance of the Study .....	16
Summary .....	17
2 LITERATURE REVIEW .....	19
Chronic Illness and African American Older Adults .....	19
Conceptual Framework: Pearlin Stress Process Model .....	37
Components of the Stress Process Model .....	43
Summary .....	75
3 RESEARCH METHODOLOGY .....	76
Research Design .....	76
Research Measurements .....	84
Data Analysis and Statistical Procedure .....	91

Summary .....	93
4 RESULTS .....	95
Descriptive Analyses .....	99
Univariate Analyses .....	102
Bivariate Analyses.....	110
Mediation Analyses .....	112
Summary of Findings .....	120
5 DISCUSSION.....	124
Interpretations for Data Results.....	124
Limitations.....	131
Directions for Future Studies .....	133
Conclusion.....	135
REFERENCES .....	137
APPENDICES .....	159
A QUESTIONNAIRE .....	160
A-1: Caregiver’s Background Characteristics.....	161
A-2: Care-recipient’s Background Characteristics.....	163
A-3: Caregiving History .....	164
A-4: Caregiving Justifications.....	166
A-5: Primary Stressors .....	167
A-6: Secondary Stressors .....	171
A-7: Caregiver Social Support Systems.....	175
A-8: Religious/Spiritual Coping.....	178

A-9: Health Outcomes.....179

A-10: Final Questions .....183

## LIST OF TABLES

	Page
Table 4.1: Caregivers' Characteristics .....	100
Table 4.2: Care-recipients' Characteristics.....	103
Table 4.3: T-test or ANOVAs for Effects of Caregiver Socioeconomic Characteristics on Physical and Mental Health .....	106
Table 4.4: T-test or ANOVAs for Effects of Caregiver History on Physical and Mental Health.....	108
Table 4.5: Bivariate Correlation between Physical Health and Mental Health and Primary Stressors, Secondary Stressors and Mediator Variables .....	111
Table 4.6 Significant Correlations between Primary Stressors, Secondary Stressors, and Health Outcomes .....	116
Table 4.7 Standardized Regression Coefficients for Relevant Variables in Models Testing for Mediating Effects (Research Question 6) .....	118
Table 4.8 Significant Predictors of Physical Health and Mental Health Outcomes .....	122

LIST OF FIGURES

	Page
Figure 2.1: Pearlin's Stress Process Model .....	41
Figure 3.1: The Proposed Conceptual Framework .....	78

## CHAPTER 1

### INTRODUCTION

In Chapter 1, the purpose was to provide an overview of the African American community of older adults and their caregivers. The chapter begins by discussing how the demographic, socioeconomic, and healthcare trends of African American older adults impact their need for family caregivers. Second, the chapter will briefly present demographic trends, stressors, mental health outcomes, physical health outcomes, and the cultural trends of caregiving. Lastly, a discussion will follow regarding the problems faced by African American caregivers, the purpose of this study, the significance of studying stressors, and health outcomes for African American caregivers.

#### African American Older Adults

##### *Demographic Trends*

The most salient issue affecting the field of gerontology in the United States is the growing number of older adults. People over the age of 65 only accounted for 4% of the population in 1900 (U. S. Census Bureau, 2002). Today the population has changed dramatically. In 2006, individuals over the age of 65 represented 12% of the population, which translates to over 37 million individuals in the United States (Federal Interagency Forum on Aging-Related Statistics, 2008; U.S. Department of Health and Human Services, 2008b). This is consistent with population growth trends.

People are living longer due to advances in medical technology, public health improvements, effective health promotion, sanitation, and nutrition. Another major contributor

to population growth trends is due primarily to the baby boomers, which are considered individuals born between 1946 -1964, who will start to reach age 65 by 2011 (Hooyman & Kiyak, 2005). Following this occurrence, it is predicted that there will be well over 71.5 million older adults in the United States, approximately 20% of the population. Further prediction includes that over the next thirty-five to forty years, older adults over age 65 are projected to double, and those aged 85 and older are likely to triple. These figures account for the general population in the United States (Federal Interagency Forum on Aging-Related Statistics, 2008; U.S. Department of Health and Human Services, 2008b). However, there are other vital demographic trends developing within this population. One is the expected growth of racial and ethnic older adults. Collectively, racial and ethnic older adults will be the fastest growing segment of the older population (Federal Interagency Forum on Aging-Related Statistics, 2008).

As the predicted demographic trends continue for the general population, ethnic minority populations will live longer, and become more racially and ethnically diverse. Currently, ethnic minority older persons now encompass over 16% of the older adult population, and this is expected to increase to over 40% by 2050 (U.S. Department of Health and Human Services, 2008b). In 2006, approximately 81% of the population age 65 or older was Caucasian, 18% Hispanic, 9% were African American, 6% Asian/Pacific Islander, and 3% represent other populations of color (Federal Interagency Forum on Aging-Related Statistics, 2008). Interestingly, fifty years later, African American older adults will increase from 9% to 12 %; yet, the Caucasian older adult population will decrease by 20% from 81% to 61% (Federal Interagency Forum on Aging-Related Statistics, 2008). This decrease in the Caucasian older adult population is based on the United States census prediction that overall Caucasians will only increase by 32.4% and African Americans will increase by 71.3% (Administration on Aging,

2008a). The number of Caucasian elderly will double in the years 2000-2050, and the number of African-American elderly will quadruple. The Administration on Aging (2008a) further indicates that between 1999 and 2030, the Caucasian elderly population will increase by 81% while the African American elderly will increase by 128%.

Demographically for African American older adults there is an upward shift in numerical population growth and individual life expectancy. Although this cohort of African American older adults will be living longer, they will also experience an increase in chronic illnesses and disabilities compared to earlier generations. Jackson and Sellers (2001) further indicate African American elderly "past history, including racial inequality, socioeconomic disparities, and individual and group coping resources, will influence their morbidity, family and community relationships, and mortality" (p.81). As a result, African American older adults who have been plagued by a lifetime of discrimination in general, discrimination in healthcare, socioeconomic, and disabling health issues will have an increased need for caregivers.

#### *Socioeconomic Trends*

Three times as many African American elderly live in poverty than Caucasians. The poverty rates for African Americans older adults 65 years and over in 2006 was 23%, as compared to Caucasian elderly having a rate of 7 % (Federal Interagency Forum on Aging-Related Statistics, 2008). Between 65 and 74 years of age, over 19% of African American elderly and 7.6% Caucasian elderly are impoverished, and, even more astonishing, 26.4% and 10.4% of African-Americans and Caucasians over the age of 75 are living in poverty (Proctor & Dalaker, 2002). The median income for African-American men over 65 is about 60% of what Caucasian males are receiving. For African-American women, income is about 66% of what Caucasian women are receiving (Gelfand, 2003). Some of the primary reasons for this trend

are a lifetime of discrimination, educational and employment inequalities, increased likelihood health complications, fewer pension earners, and an increasing dependency on social security income or supplemental security income (Flippen & Tienda, 2002).

### *Healthcare Trends*

*African Americans.* Socioeconomic status has a deep impact on the health status of African Americans, as well as other ethnic/racial groups. Conditions of powerlessness and poverty result in a lack of appropriate access to medical and mental healthcare, appropriate facilities, appropriate prevention medicine, to inadequate follow-up care, and higher rates of mortality due to high prevalence of chronic illness (i.e., hypertension, diabetes, stroke, cardiac, kidney disease, etc). In the United States cardiovascular diseases (primarily heart disease and stroke), cancer, and diabetes are the most prevalent diseases among all African Americans. These diseases alone cause the highest rates of death, functional disability, and illness (U.S. Department of Health and Human Services: National Center for Health Statistics (NCHS), 2007).

Historically, African Americans have experienced high rates of mortality and morbidity (Quaye, 2005). Recent statistics from the REACH 2010 study continue to confirm that the three most prevalent and deadly diseases (cardiovascular disease, cancer, and diabetes) afflict African Americans at alarming rates (Center for Disease Control and Prevention: National Center for Chronic Disease Prevention and Health Promotion, 2006). For example, African Americans have the highest incidence of cancer than any other groups. In 2002, for African Americans, the death rates for disease of the heart and strokes were 30% and 41%, respectively (Center for Disease Control and Prevention: National Center for Chronic Disease Prevention and Health Promotion, 2006). In addition, African Americans are 1.6 times more likely to be diagnosed

with diabetes than Caucasians (Center for Disease Control and Prevention: National Center for Chronic Disease Prevention and Health Promotion, 2006).

*Health of African American older adults.* The health of African Americans continues to be poorer than their Caucasian counterparts, coupled with the fact that over 25% of African Americans lack appropriate health insurance. By the time many African American older adults reach adulthood, they are already faced with extensive histories of disease (Center for Disease Control and Prevention: National Center for Chronic Disease Prevention and Health Promotion, 2006). As a result, more than half of African American elderly are in poor health. Due to years of poverty and racism, the prevalence of chronic illnesses and mortality is higher for African Americans than for Caucasians (Braithwaite & Taylor, 1992; Braithwaite & Taylor, 2001; Reed, Darity, Roman, Baquet, & Roberson, 1992).

Until age 45, older African Americans experience higher rate of diabetes, hypertension, stroke, cancer and heart disease, then they begin to decline moderately in comparison to Caucasians until a crossover effect at 75 (Braithwaite & Taylor, 2001; Hooyman & Kiyak, 2005; Reed et al., 1992). African American elderly self reported high levels of prevalence for hypertension, diabetes, cancer, and stroke on The National Health Interview Survey conducted from 1986-1990 (Beckles, Blount, & Jiles, 1994). The study also reported that African American adult females over the age of 65 was 80% higher for hypertension, 200% higher for diabetes, and 22% higher for stroke than those of white women of the same age. Prevalence of these diseases for African American males was 34%, 69% and 35% higher than for white males (Beckles et al., 1994).

African American elderly are constantly dealing with several disparities in healthcare. For instance, attributable to a history of mistrust of the medical system, especially in the South,

older African Americans may turn to family members and friends for medical advice. Secondly, having few African American patients on a consistent basis, some physicians may not be aware of how ethnicity can affect the perception of a disease and lead to a misdiagnosis (Belgrave & Wykle, 1993; Davis & Curley, 1999).

The three main chronic illnesses or diseases (cardiovascular disease, cancer and diabetes) experienced by African American older adults affects them physically, psychologically, economically, socially (Braithwaite & Taylor, 2001). Biegel and colleagues (1991) report, "There has been a shift in the epidemiology of disease from acute to chronic diseases as well as a decrease in accidental deaths, resulting in an increase in the number of persons with limitations on functional activity and mobility" (p.10). Biegel, Sales, & Schulz (1991) further confirm the following about patients with chronic illnesses, "typical interrelated problems faced by patients include restrictions in life-style and activities, negative body perception, sexual stress, intrafamily conflicts, increased dependency and decreased self-sufficiency, economic pressures, work restrictions or termination from work and social stigma" (p.20). Research has shown that African American families compared to Whites are less likely to institutionalize their family members and are more likely to care for frail and dependant older persons (Belgrave & Wykle, 1993). As a result, African American older adults with chronic illness will require the assistance of caregivers to assist with activities of daily living (ADLS) (i.e. bathing, dressing, toileting, eating, transfers, and walking) and/or instrumental activities of daily living (IADLS) (i.e. home and money management, meal preparation, phone calls, grocery shopping, and medication assistance).

## African American Caregiving

### *Cultural Trends of African American Caregiving*

African American elders and their caregivers culturally tend to rely heavily on social supports from family/friends and the community. Research indicates that African Americans have a broader range of supports and tend to use more informal support than Caucasians (Haley, Levine, Brown, & Bartolucci, 1987; Peng, Navaie-Waliser, & Feldman, 2003). For example, in African American communities there are large extended families, or even "fictive kin", who are individuals that are as close as, or closer, than a relative to provide support as needed. Multigenerational households are common for both support obligation and socioeconomic reasons for both the elderly and other family members (Choi, 1999). This sense of duty in family caregiving reflects "cultural socialization in African American communities and helps create beliefs and attitudes for dependant others in the family that encourage developing coping strategies (resources) to deal with stressors in the caregiving situation" (Dilworth-Anderson, Goodwin, & Williams, 2004, p. S139).

Overall family caregiving has been defined in several ways. Walker, Pratt and Eddy (1995) define family caregiving as "one or more family members giving aid or assistance to other family members beyond that required as part of normal everyday life, which is a result of the need by the elder on another individual for activity essential to daily living" (p.402-403). The National Family Caregiving Association (NFCA) explains that family caregivers are those individuals who provide unpaid care for their loved ones that suffer with or from chronic illnesses and/or disabilities. The NFCA website further quotes the definition of family caregiving by Carol Levine, Director of the Families and Health Care Project at the United Hospital Fund of New York, and a family caregiver herself, as follows:

"The two parts of the term are equally important. 'Family' denotes a special personal relationship with the care recipient; one based on birth, adoption, marriage, or declared commitment. 'Caregiver' is the job description, which may include providing personal care, carrying out medical procedures, managing a household, and interacting with the formal health care and social service systems on another's behalf. Caregivers are more than the sum of their responsibilities; they are real people with complex and often conflicted responses to the situations they face" (National Family Caregivers Association, 2004).

In the African American community, there is a common trend of filial responsibility or obligation in regard to caring for their elderly. The family provides the majority of the care to the elderly family member (Administration on Aging, 2002; Dilworth-Anderson, P., Wallace-Williams, S. & Cooper, T., 1999a). Research has shown that African American families compared to Caucasians are less likely to institutionalize their family members and are more likely to care for frail and dependant older persons (Belgrave & Wykle, 1993; Dilworth-Anderson, 2005; Dilworth-Anderson, Brummett, Goodwin, Williams, Williams, & Siegler, 2005; Dilworth-Anderson, P., Wallace-Williams, S., & Cooper, T., 1999b). Moreover, African American caregivers will also rely on their own children, extended family, neighbors and friends to assist them with caring for a family member over fifty percent of the time.

#### *Demographic Trends of African American Caregivers*

While the number of Caucasian older adults will double between 2000 and 2050, African American older adults will quadruple. (U. S. Census Bureau, 2002). African American households represent over 10% of the nation's 22.4 million caregiving households of older adults (Administration on Aging, 2008b; National Alliance for Caregiving and AARP, 2004). This

anticipated growing number of African American elderly will undoubtedly increase the need for more caregivers.

Caregiving experiences and dynamics differ across the communities as well (Dilworth-Anderson, Williams, & Gibson, 2002). In the United States, adult children (42%) and spouses (25%) are providing the majority of the care to older adults. African American caregivers tend to be older and single, when compared to other racial and ethnic caregivers. Therefore, they are least likely to provide care for a spouse when compared to Caucasians (National Family Caregivers Association, 2004). The majority of African American caregivers are female, under the age of 50, and tend to have their own children or grandchildren in the home (Belgrave, 1998; Belgrave & Wykle, 1993; Gelfand, 2003). They are sandwiched between caring for the needs of the care recipient and their own families. This group has been termed the "sandwich generation" or "women in the middle" (Hooyman & Kiyak, 2005). Similar to other groups of caregivers, the majority of African American caregivers are women, and many of the caregivers and care recipients have suffered years of disparities that include a lower socioeconomic status and poorer health status (Dilworth-Anderson et al., 1999a; Dilworth-Anderson et al., 2002).

#### *Stressors, Mediators, and Health Outcomes of Caregiving*

*Stressors.* African-American caregivers typically spend more hours providing hands-on-care per week than any other group (Bullock, K., Crawford, S., & Tennstedt, S., 2003). This is attributable to health status of care recipients and issues of reciprocity and filial obligations (Gelfand, 2003). African American caregivers tend to be caring for multiple older adults, as well as grandchildren at the same time. However, the burdens of caring for an older person, as well as the primary caregivers' own individual responsibilities can be very demanding. Lawton, Rajagopal, Brody, & Kleban (1992) reported, "for African American caregivers, greater burden

was directly associated with greater depression” (S158). They also noticed that caregiver burden was the determining factor between depression, caregiver physical health, hours spent caregiving, and caregiver contentment (Lawton et al., 1992).

The Administration on Aging (2008b) further states, “More than half of African American caregivers find themselves ‘sandwiched’ between caring for an older person and a younger person, and caring for more than one older person. African American caregivers are also more likely to live with the care recipient and spend an average of 20.6 hours per week providing care. In addition, 66% of African American caregivers are employed full or part-time” (p.13).

*Mediators.* Caregiving literature has tended to mainly focus on the negative aspects of caregiving. However, more recent research is beginning to examine the positive appraisals also termed uplifts, gains, coping or rewards experienced by caregivers. A recent qualitative study of 85 caregivers was able to capture caregiver gain themes by 81% of the caregivers of older adults with dementia. Spiritual growth and increased faith, personal growth, accomplishments and mastery were identified as rewards of caregiving. The study indicated that male caregivers primarily felt these reward experiences, and the gains allowed them the ability to turn a challenging negative experience into a positive caregiving experience (Sanders, 2005). Tarlow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson (2004) conducted a quantitative study using the Positive Aspects in Caregiving Scale with 1,229 participants from the Resources for Enhancing Alzheimer's Caregivers Health (REACH) project. The majority of the caregivers frequently reported that caregiving made them feel needed, useful, and good about themselves. Most of the caregivers felt the caregiving gave them more quality to their life, appreciation of life and positive attitude about life. Neither study examined the specific aspects of African-Americans.

The literature is limited on a within group study of African Americans and rewards/coping in caregiving. African Americans in comparison to Caucasian caregivers tend to display more positive regard for their caregiving experience. One of the highest responses to rewards/coping in caregiving research for African American's was based on their religious beliefs, traditions and faith. These views were considered mediators and coping mechanisms in the stress process (Dilworth-Anderson & Gibson, 2002; Picot, 1994, 1995; Picot, Debanne, Namazi, & Wykle, 1997; Sorensen & Pinquart, 2005). Faith in God, and feeling that God would bless them later in life for providing care, was a considered a reward for 100% of the 85 African American caregivers living in the Midwest (Picot, 1994).

*Health outcomes.* Stressors that effect physical and mental health outcomes for the caregiver include role demand or role strain, which for this population is due to caregivers juggling employment obligations (Bullock, Crawford, & Tennstedt, 2003) , caring for multiple family members (Dilworth-Anderson et al., 1999a), and competency issues (caregiving mastery) related to caregiving tasks (Cox, 1995; Dilworth-Anderson et al., 1999a). In regards to physical health, African American caregivers indicate that they have several morbidities, and they rank their overall physical health as poor (Dilworth-Anderson et al., 2004; Mui, 1992). In addition, African American female caregivers are less likely to receive healthcare, and, when they do receive healthcare, it is too late. They are also less likely to pursue or receive treatment for depression than Caucasians (Black Women's Health Imparative, 2003). Therefore, additional research is needed to determine which aspects may contribute to poor physical and mental health of African American caregivers.

Much of the quantitative research in the area of African American caregiver stress is a comparison of African Americans to Caucasians. For example, the results of these studies

indicate that Caucasian caregivers experience a higher amount of burden than African American caregivers (Fredman, Daly, & Lazur, 1995; Hinrichsen & Ramirez, ; Knight, Silverstein, McCallum, & Fox, 2000; Lawton et al., 1992; Miller, Campbell, Farran, Kaufman, & Davis, 1995) and other studies indicate that there is no difference in caregiver burden between Blacks and Caucasians (Cox, 1999a; Wood & Parham, 1990; Young & Kahana, 1995). Despite the results of some quantitative research efforts, qualitative research argues that African American caregivers experience and discuss a tremendous amount of burden, loss, emptiness and loneliness. Qualitative researchers feel the other studies have not taken in account the complexities of cultural analyses of caregiving burden, along with the personal, family and socioeconomic factors (Fox, Hinton, & Levkoff, 1999; Levkoff, Levy, & Weitzman, 1999). As a result it is believed that a high percentage of African American caregivers are suffering physically, emotionally and mentally due to the daily demands of caregiving (Black Womens Health Imperative, 2003).

#### Problem Statement

As a result of the demographic, socioeconomic, and health trends for African American elderly, and the rapid increase in the need for African-American family caregivers, it is imperative for researchers and practitioners to have knowledge of caregivers' experience. Limited empirical theory driven research has been conducted on the experiences of African American caregiver exclusively (Chadiha, Rafferty, & Pickard, 2003; Dilworth-Anderson et al., 2004; Dilworth-Anderson et al., 1999a; Harris, Thomas, Wicks, Faulkner, & Hathaway, 2000; Knight et al., 2000). Only two of these studies focus on caregiving issues of a specific medical diagnosis, dementia (Knight et al., 2000) and end stage renal disease (Harris et al., 2000). The other studies examined frail African American elderly (non disease specific) (Chadiha et al.,

2003; Dilworth-Anderson et al., 2004; Dilworth-Anderson et al., 1999a; Harris et al., 2000; Zauszniewski, Picot, Roberts, Debanne, & Wykle, 2005).

African American elderly are self-reporting high prevalence of cardiovascular diseases (including heart disease, stroke, and hypertension), cancer and diabetes (Braithwaite & Taylor, 1992; Braithwaite & Taylor, 2001; Center for Disease Control and Prevention: National Center for Chronic Disease Prevention and Health Promotion, 2006), which are the most functionally debilitating diseases for the elderly (Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008). These chronic illnesses have been proven to affect an elderly person and their caregivers' life physically, psychologically, socially, and economically (Biegel et al., 1991).

African American family caregivers tend to be caring for older adults who require the most hands-on-care, and have high physical and financial burden. Due to the stressors of providing care, these caregivers also suffer from physical and mental health problems. This warrants an exploration of this group of caregivers' exclusive stressors and their impact on the caregivers' emotional and physical health. Within this context, this researcher plans to utilize a stress process theoretical model, and incorporate a culturally relevant measure to predict caregiving outcome.

Kleinman, Eisenberg and Good (1998) indicate that for African American populations, it is vital to find out which levels of depression are represented within that culture. Similarly, African-American caregivers report poorer overall physical health and functioning than other caregivers (Chadiha et al., 2003; Dilworth-Anderson et al., 2004; Dilworth-Anderson et al., 1999b; Young & Kahana, 1995). Therefore, a within group study of African-American caregivers, which incorporates a cultural background characteristic context may assist in

determining the depressive symptomatology and physical health norms for this population of caregivers.

Caregiving researchers have clearly indicated that the majority of research on racial/ethnic minorities that measure levels of emotional distress (depression) and/or physical health, tend to utilize the stress and coping, and stress process models, as a way to compare racial/ethnic groups. Dilworth-Anderson and associates (2002) summarize what we know about this method:

Similarities in scores do not indicate a lack of cultural differences between two racial or ethnic groups. There are several reasons for this; first, using race or ethnicity as a proxy for culture ignores cultural differences (e.g., various level of acculturation) within racial and ethnic categories. Therefore, specific measures of culture are necessary to assess differences between groups living in a multicultural society. Second, the processes through which levels of depression are affected often represent differential cultural influences across groups. Third, findings of statistically significant mean differences are contingent on sample sizes, variance measures and the use of various controls (e.g. socio-economic status) (p.268).

These authors argue that caregiving research would then "move from a static and limited view of culture as race to a more dynamic view of culture as it shapes and is shaped by racially and ethnically diverse groups of caregivers" (Dilworth-Anderson et al., 2002). Therefore, previous research recommendations of making stress process models more culturally relevant by adding sociocultural variables and within group studies, would assist in a conducting more through investigation of African American caregivers. In an attempt to overcome these

limitations, this researcher is investigating African American caregivers exclusively, and adding a cultural measure to the background characteristics of the research model.

### Purpose of the Study

For the purposes of this study, the stress process model of Pearlin et al., (1990) was used to test theory driven research questions. Physical and mental health outcomes experienced by the caregiver were measured by analyzing several psychosocial variables. The psychosocial variables include caregiver background characteristics (socio-economic, caregiving history, and caregiving justifications), primary stressors (care recipient functional limitations and caregiver role overload), secondary role strains (work, and family conflicts), and mediating variables (religious/spiritual coping, informal and formal social support). These variables were measured based on the caregivers' perception, as answered by specific questions.

This study sought to define the stress process of physical and mental health experienced by African American caregivers who provide care to older adults with major chronic illnesses. A self-reported caregiver health outcomes scale was used as an index to determine caregivers' level of physical and mental health. In addition, this study investigated the background characteristics of caregivers associated with caregivers' health outcomes, the primary and secondary stressors affecting caregivers' health outcomes, and the variables that mediated the caregivers' level of health outcomes. This study attempted to:

1. Identify which caregivers' background characteristics (socio-economic, caregiving history, caregiving justifications) might contribute to caregivers' mental and physical health outcome.

2. Identify the strength of the relationship or association between the primary stressors, secondary stressors, mediators, and the caregivers' perceived mental and physical health outcomes.
3. Identify if religious/spiritual coping, informal and/or formal social supports mediate the relationship between primary and secondary stressors.
4. Identify if religious/spiritual coping, informal and/or formal social supports mediate the relationship between secondary stressors and health outcomes.
5. Identify if religious/spiritual coping, informal and/or formal social supports mediate the relationship between primary stressors and health outcomes.
6. Identify if family conflict and/or work conflict mediate the relationship between primary stressors and health outcomes.

#### Significance of the Study

This study is significant to the practice of social work in the areas of research, policy, and practice. In the area of African American caregiver research, most of the quantitative studies about the stressors, resources, burden and psychological outcomes of caregiving experienced by African American caregivers tend to compare African American to Caucasians, and/or other ethnic minority groups. These studies indicate that African American caregivers, compared to the other groups, experience low rates of caregiver stress (e.g. Drentea & Goldner, 2006; Williams, 2005; Haley et.al, 2004). Other researchers have indicated there is no difference in caregiver burden between African Americans and Caucasians (Cox, 1999a; Wood & Parham, 1990; Young & Kahana, 1995).

Despite the inconsistent results of quantitative research efforts, qualitative researchers argue that African Americans experience and discuss a tremendous amount of physical health

issues, such as depression, burden, loss, emptiness and loneliness. Qualitative researchers, Fox et al. (1999) and Levkoff et al. (1999), suggest that other studies have not taken into account the complexities of cultural analyses of caregiving burden, as well as the personal, family and socioeconomic factors. This study sought to provide an integrated model for the caregiving stress process of African American caregivers of older adults with chronic illnesses.

Second, this study is important in the area of practice. Overall, African American caregivers are providing care to elderly that are in the poorest health, have the lowest socioeconomic status, and they tend to utilize fewer resources than their Caucasian counterparts. African American caregivers are at an increased risk for neglecting their own physical and mental healthcare needs (Dilworth-Anderson et al., 1999). Empirical research in the area of African American caregiving burden becomes vital to social work. The traditional dynamics of the family is ever changing to multigenerational households. As the aging field continues to grow in social work, caregiving of the elderly will affect social workers whether they are working in an elementary school or in a home health program. This within group study of African American caregivers is pertinent for social workers to be able to identify the particular cultural issues within this group, the caregiving stressors endured, and the physical and mental outcomes of caregiving. Therefore, in the future, social workers may begin to develop culturally sensitive assessment and intervention skills to better serve African American caregivers.

### Summary

This chapter presented an introduction to the demographic, socioeconomic, and health trends of African-American older adults. This chapter also discussed the African American cultural tradition of providing care to their older adults when they have chronic illness, resulting in functional disability and/or limitations. African American caregivers tend to be younger,

share multiple caregiving responsibilities, and provide care to older adults with several physical needs. As a result, these caregivers may experience several stressors that are explored in this study to determine how they affect the caregivers' emotional and physical health. Furthermore, research findings from this investigation will contribute to the literature on the needs of African American caregivers.

The following chapter provides a literature review of the health issues within African American communities, the chronic illnesses of African American older adults, and the caregiving requirements. A review of the Pearlin et al. (1990) stress process model, and its variables, are also included in Chapter 2.

## CHAPTER 2

### LITERATURE REVIEW

This chapter has two aims. First, this chapter provides a review of empirical and conceptual literature relevant to the health of African American older adults, specific chronic diseases related to them, and their caregiving concerns.

Secondly, this chapter describes the stress process model by Pearlin et al. (1990). This model serves as the conceptual framework used to guide this study. An overview of the stress process conceptual framework is presented, as well as an analysis and critique of the African American and/or ethnically/racially diverse caregiving literature relevant to the variables (background characteristics, stressors, mediators, and outcomes) considered in this study. The caregiving literature analysis focuses on the quantitative and qualitative research results from studies that employed the stress process model of Pearlin and associates (1990).

#### Chronic Illnesses and African-American Older Adults

##### *Chronic Illness*

According to the Center for Disease Control: National Center for Chronic Disease and Promotion (2008), more than 1.7 million people die due to chronic illness. They calculate this to be approximately 7 of every 10 Americans. Center for Disease Control (2005) reported, "The profile of diseases contributing most heavily to death, illness, and disability among Americans changed dramatically during the last century. Today, chronic diseases—such as cardiovascular disease (primarily heart disease and stroke), cancer, and diabetes—are among the most prevalent, costly, and preventable of all health problems" (p. 1).

Chronic illness is defined as "the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (Lubkin, 1986, p. 6). The U.S. Center of Health Statistics medically consider chronic diseases to be a disease that lasts for more than three months, cannot be prevented by vaccines, cured by medications, or even disappear (Center for Disease Control and Prevention: U.S. National Center for Health Statistics, 2006). Overall, more than 90 million individuals suffer with chronic illness, and over 70% of all deaths in the United States are due to chronic diseases (Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008).

The Center for Disease Control and Prevention (2005) has found that for more than 25 million people with chronic illness (1 out of 10), individuals have major limitations in activity (Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008). Chronic diseases account for the leading cause of death among individuals over the age of 65 (Sahyoun, Lentzner, Hoyert, & Robinson, 2001). Heart disease and cancer are two of the leading causes of death among older adults over the age of 65. Other chronic diseases accounting for death among older adults are stroke (cerebrovascular disease), chronic obstructive pulmonary diseases, diabetes, pneumonia, and influenza (Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008; Sahyoun et al., 2001)

#### *Chronic Illness and African American Elderly*

Although chronic illness is the cause of mortality for the majority of the older adult population, the rates are significantly higher among African Americans than Caucasians. This is especially true for African Americans between the ages of 65 to 84 (National Caucus and Center on Black Aged, 2003). After age 85 there is a cross over effect and the death rate increases for

older Caucasians. However the occurrence is minuet considering the death rates of African Americans between 65 to 84 years of age (National Caucus and Center on Black Aged, 2003; U.S. Department of Health and Human Services, 2008a). Research has shown that from 1996 to 1998 the death rate for individuals 65 to 74 years of age was 38.5% higher for African Americans than for Caucasians from all causes (Federal Interagency Forum on Aging-Related Statistics, 2008). The study also indicates African Americans 75 to 84 years old have an overall death rate of 18.1% higher than Caucasians in the same age group. However, African Americans did show an 8.4% reduction in death rate as compared to Caucasians for older adults over 85 (Federal Interagency Forum on Aging-Related Statistics, 2008).

The five leading causes of death for African-Americans over the age of 65 are 1) heart diseases, 2) cancer, 3) stroke, 4) diabetes and 5) pneumonia/influenza (Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008; Sahyoun et al., 2001). These causes of death are worth examining among older African Americans because The Center for Disease Control (CDC) reports individuals who suffer from these chronic diseases (cardiovascular diseases, cancer, and diabetes), particularly older adults, tend to suffer major limitations in activity (Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008). "There has been a shift in the epidemiology of disease from acute to chronic diseases, as well as a decrease in accidental deaths, resulting in an increase in the number of persons with limitations on functional activity and mobility"(Biegel et al., 1991 p.10). Due to chronic health issues alone, "five out of six people over the age of sixty-five have at least one chronic health problem" (Biegel et al., 1991 p. 124-125). Individuals with chronic illness tend to suffer many years of physical, psychological, social, and economical challenges.

Older adults will require the assistance of caregivers to assist them in coping psychologically, physically, and financially.

*Caregiving concerns for chronically ill.* Chronic illnesses can cause individuals and families to endure several changes within their life and cause a tremendous amount of stress. These stressful changes can cause potential threats to an individual's functioning. Falvo (1999) found potential threats may occur because an individual has adapted to a certain lifestyle, and a disease course may threaten their lifestyle. The following chronic illness threats have been identified by Falvo (1999, p.2):

- Threats to life and physical well being
- Threats to body integrity and comfort as a result of the illness or disability itself, diagnostic procedures, or treatment
- Threats to independence, privacy, autonomy and control
- Threats to self-concept and fulfillment of customary roles
- Threats to life goals and future plans
- Threats to relationships with family, friends and colleagues
- Threats to the ability to remain in familiar surroundings
- Threats to the economic well-being

These stressful changes can deeply impact not only the individual with the chronic illness, but also family members as well.

According to the chronic illness statistics mentioned above for African American older adults, they are suffering medically with high rates of disability due to chronic conditions, mortality and morbidity in comparison to other racial/ethnic groups. Research has indicated African American caregivers typically provide care to their older adults, but use institutionalized

care less often as compared to other racial/ ethnic groups (Belgrave & Wykle, 1993; Dilworth-Anderson, 2005; Dilworth-Anderson et al., 2005; Dilworth-Anderson et al., 1999b). However, literature on African American caregivers who provide care with specific chronic illnesses is limited to care for children. Additional theoretically guided research is needed for those who provide care for older adults and their stressors, coping mediators, and health outcomes in order to assist in reducing their negative health outcomes. Myers and colleagues (2004) further support the following:

The research on African American families is rather fragmented and is often not guided by well-articulated theoretical perspectives. This is especially true in studies of family contributions to physical illnesses, where attention is focused separately on the external forces or on the biological factors and/or on health behaviors, without a systematic effort to integrate these effects. There can be little doubt that risk factors for chronic illnesses operate simultaneously and are likely to be more damaging if the family is also impacted by the family conflict, poor health habits, and limited social support resources than if these additional risk factors were not present. Such integrative analyses would enhance our understanding of family influences on health (p. 490).

Prior to discussing the disease specific caregiving concerns of older adults with chronic illness, this dissertation will define two categories of major chronic illnesses contributing significantly to African American older adults high rate of mortality. Chronic diseases can be considered fatal, shortening the lifespan, and nonfatal. The two categories of disease are cardiovascular diseases and diabetes. Both of these diseases are considered chronic life shortening (Biegel et al., 1991). The African American older adult care recipients in this study will have at least a diagnosis of cardiovascular disease and/or diabetes mellitus.

### *Cardiovascular Diseases*

The term cardiovascular disease refers to several specific heart diseases. According to the International Classification of Diseases (ICD), used by the Center for Disease Control National Center for Health Statistics, diseases of the heart includes acute rheumatic fever, chronic rheumatic heart disease, hypertensive heart disease, coronary heart disease, pulmonary heart disease, congestive heart failure, and any other heart condition or disease (Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008). Cardiovascular disease accounts for over 83% of deaths in individuals 65 and older. In 2002, 63% of individuals 65 and older discharged from short stay hospitals were diagnosed with cardiovascular disease (American Heart Association, 2006b). Schoenborn et al. (2006) conducted a study based on the 2000-2003 National Health Interview Surveys with 39,990 adults over the age of 55, and found one in four adults had heart disease. Among African American older adults 55-64 years of age, the prevalence of heart disease was 17.6 %, and for African American older heart disease accounted for 25.8% (Schoenborn et. al., 2006).

Cardiovascular disease and cerebrovascular disease (stroke) are the number one and number three killers of African Americans; they account for 33% of all African American deaths (American Heart Association, 2006a). The most common and disabling heart conditions are coronary heart disease and stroke. The American Heart Association (2006) indicates coronary heart disease occurs when the coronary arteries, which supplies blood to the heart muscle, become hardened and narrowed due to plaque buildup. The plaque buildup causes the arteries to narrow and harden. This is referred to as an atherosclerosis. As the plaque continues to buildup within the heart, blood flow and oxygen supply can be blocked and cause angina and/or heart attack (American Heart Association, 2006a).

In African American older adults, the annual rates per 1,000 of new and recurrent heart attacks are 21.9% for men ages 65 to 74 and 31.4% for men ages 75 and older. For African American females, the rates of heart attacks are 28.1% (American Heart Association, 2006a). Annual rates for angina episodes per 1,000 of the population are even higher. African American males represent 26.1% for ages 65 to 74, 52.2% for ages 75 to 84, and 43.5% for ages 85 and older. Female episodes are 29.4% for ages 65 to 74, 37.7% for ages 75 to 84, and 15.2% for ages 85 and older. Angina is basically a precursor to a heart attack. The rates are extremely high among African American older adults, and it is important to consider their impact on the older adult's cardiovascular disease process

"Stroke is one of the most frequently occurring acute health crisis events afflicting older persons" (Rau, 1991, p. 129). Stroke is defined as an attack on the brain. The brain attack occurs when a blood clot forms and blocks an artery in the heart and/or a blood vessel breaks. The brain will not receive any blood and nourishment; parts of the brain will die and cause a stroke to occur (American Heart Association, 2006a). As the brain cells begin to die, brain damage occurs, and the abilities controlled by that area of the brain are lost. These abilities include speech, movement and memory. The effect on the brain is dependant upon where the stroke occurs in the brain and how much of the brain is damaged (American Heart Association, 2006a; Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008). African Americans are twice as likely to die from strokes compared to their Caucasian counterparts. The rate of first strokes in African Americans is almost double that of Caucasians (American Heart Association, 2006a; Center for Disease Control and Prevention: National Center for Chronic Disease and Promotion, 2008). Between 1994 to 1998, African

American older adults age 65 to 74 have a 90.1% higher death rate from stroke than Caucasians (Center for Disease Control and Prevention, 2000).

Coronary artery disease and stroke are crucial aspects of cardiovascular disease. They are the leading causes of death among African American older adults. They both have high rates of functional limitations among older adults, particularly African Americans. These functional limitations will be discussed further. Limited research has been conducted with African American older adults who have these highly prevalent diseases and their caregivers.

*Risk factors for cardiovascular diseases.* Recently researchers conducted a study of over 350,000 individuals with heart disease from 1999 to 2000 and found approximately 90% of the subjects confirmed at least one or more of the following characteristics or risk factors: hypertension, high cholesterol, diabetes, smoking, physical inactivity, obesity, and family history of heart disease (Greenland et al., 2003). Due to diabetes being highly widespread in the African American community, diabetes will be discussed as its own chronic illness category.

"Although there usually are no symptoms associated with primary hypertension, the consequences of untreated hypertension can be severe, causing end stage renal disease, myocardial infarction (heart attack), or stroke. Consequently, treatment of hypertension is essential to preventing disability and/or death" (Falvo, 1999, p. 267). Hypertension is one of the main contributors and/or risk factors of heart disease, and it is highly prevalent in African Americans. Schoenborn et al. (2006) found about 4 in 10 adults (44.9%) over the age of 55 had hypertension. Of adults 55 to 64 years of age, 38% had hypertension, and over 50% of adults over 85 had hypertension. The incidence of hypertension in African American older adults is at alarming rates compared to other racial and ethnic groups, resulting in, a higher incidence of cardiovascular mortality and morbidity.

The Older Americans 2008: Key Indicators to Well Being Report indicates that African Americans over the age of 65 reported higher levels of hypertension than Caucasians (66% vs. 49%) (Federal Interagency Forum on Aging-Related Statistics, 2008). In addition, a study from the National Health Interview Survey, examined two age groups of African American older adults and found 55.9% of African American adults 55 to 64 had hypertension compared to 36% of Caucasians and 36.9% of Hispanic adults (Schoenborn et al., 2006). African American adults 75 to 84 years of age also reported a rate of 71% in hypertension, compared to 52% of Caucasians (Federal Interagency Forum on Aging-Related Statistics, 2008).

Elevations in blood pressure (hypertension) have been linked to poor cognitive function, especially with older adults (Robbins, Elias, Elias, & Budge, 2005). Robbins et al. (2005) conducted a study with 147 African American older adults and 1416 Caucasian Americans and they found high levels of hypertension was correlated with high rates of cognitive deficiencies. Robbins et al. (2005) further state, "cognitive domains for which associations between BP (blood pressure) and cognitive performance are consistently observed and tend to be high in magnitude include abstract reasoning, psychomotor, and visual organization abilities" (p. 713). The lack of these cognitive skills for an older adult may have a significant impact on their need for caregivers.

*Caregiving concerns with cardiovascular disease.* Cardiovascular diseases have several potential physical and mental limitations for the care recipient. These are diseases which require long-term family/caregiver assistance and entail a reduction of the care recipient's personal and social functioning (Biegel et al., 1991). As a result, cardiovascular diseases are included among the 10 most frequent causes of disability adjusted life years (DALYS). DALYS was developed by the World Health Organization in order to measure the burden of disease. It reflects the total

amount of healthy life lost to all causes, whether from premature mortality or from some degree of disability during a period of time (Mathers et al., 2003).

*Coronary artery caregiving.* An individual with cardiac and stroke complications can suffer from physical limitations, depression, loss of employment, and frequent hospitalizations and medical appointments (Biegel et al., 1991). The specific caregiving demands will differ depending on diagnosis, extent of injuries, and length and frequency of symptoms. For example, the spouse of an individual who has experienced the crisis of a heart attack (myocardial infarction) may experience more burdens related to psychological distress as opposed to a spouse caring for a stroke patient who may endure both physical and psychological distress.

It has been said that the patient may recover from his coronary but that his wife may not. She has often seen her husband when he looked near death, she may have been warned that he could die .... She has the same fears, lack of knowledge, and misconceptions as her husband .... Months after the infarct many wives report they lie awake listening to their husbands' breathing to make sure that he is still alive .... Alternatively, wives may take over decision-making and bread-winning roles and become highly overprotective; this may increase the patient's feelings of helplessness and despondency (Gulledge, 1979).

Skelton and Dominian (1973) were the first to study the psychological distress experienced by family members following the crisis of a heart attack. A longitudinal study was conducted with sixty-five British wives. They were interviewed throughout their husbands' hospitalization and then again at three, six, and twelve month intervals. Younger wives experienced more distress than their older counterparts. The wives reported feelings of guilt and self blame for their husbands' heart attack. Twenty-eight of the women experienced symptoms

of anxiety and depression within the severe range. They also confirmed feeling headache, stomachache and chest pains (Skelton & Dominian, 1973). Three months following hospitalization, the wives continued to experience anxiety and depression, with symptoms of sleep disturbances and fear of reoccurrence. One year after the heart attack, 16 out of 65 wives continued to experience depression anxiety and sleep disturbances (Skelton & Dominian, 1973). Other findings indicated the husbands' reaction to their heart attack had a direct impact on their wives symptomology. Hence, when husbands had difficulty accepting or reacting to their illness, their wives were more dependent, irritable and suffered adjustment issues (Skelton & Dominian, 1973). Later studies supported Skelton and Dominan (1973) seminal research regarding psychological distress experienced by caregivers. Mayou et al. (1978) found that 100 British wives reported similar types of anxiety and depression following their husbands' heart attack. Likewise in Dhooper's (1983) research with 40 American families, nearly one quarter of the families experienced psychological stress following a myocardial infarction.

Only one study utilized a sample of African American caregivers who provide care to older adults with coronary artery disease. Young and Kahuna (1995) conducted a longitudinal study of 180 caregiver-care recipient dyads to explore the effects of race on caregiver well being outcomes following a heart attack. The sample included 55 African Americans (30%), 125 Caucasians (68%), and 3 participants categorized themselves as other (2%). The results were from a longitudinal study and they only included the first wave of the two waves because the researchers felt the initial onset of the heart attack predicted during the first wave of data collection would account for the most threat of burden to the caregiver (Young & Kahana, 1995). In comparison to the Caucasian sample, the African American caregivers were younger, more likely to be caring for a parent, less educated, and the care recipient exhibited more health

problems (Young & Kahana, 1995). The African American caregivers also provided twice as many caregiving hours, and their care recipients had more physical limitations. Additional racial differences existed in regards to caregiver attitude and outcome. Overall, Caucasian caregivers were less willing to provide care. Moreover, their burden and depression scores were higher in comparison to African American caregivers (Young & Kahana, 1995). However, the 55 African American caregivers did experience caregiver burden (31.6%) and depression (14.1%) within their own group. With the high percentage of African American older adults with heart disease and the need for caregivers, this research will seek to contribute to the limited literature on African American caregivers of older adults with chronic illness.

*Stroke caregiving.* "Stroke is the leading cause of not only mortality in older persons, but also of chronic long-term disability" (Biegel et al., 1991, p. 131). Freese (1980) found that 40% of stroke survivors require caregiving assistance. Stroke survivors tend to suffer from several problems, especially anxiety, frustration, and depression (Binder, 1993). In addition, other complications for the brain injured stroke patient may include overdependence on others, stubborn thought processes, inappropriate social interaction, exhaustion, confusion, and agitation (Binder, 1993). Thompson et al. (1989) found a direct relationship between the severity of stroke patients physical and psychological symptoms and the patients predicted caregiver depression. Seminal work with caregivers of stroke patients by Lezak (1978) presented the following likely categories of caregiver distress (p.596):

1. Impaired capacity for social perceptiveness manifested as self-centeredness, and diminished empathy and self-reflective or self critical attitudes.
2. Impaired capacity for control and self-regulation, resulting in impulsivity, random restlessness, impatience, and conceptual and behavioral rigidity

3. Stimulus-bound behavior, reflected as social dependency, difficulty in planning and organizing activities or projects, decreased of absent behavioral initiative and rigidity.
4. Emotional alterations manifested as apathy, silliness, labiality, irritability and changes in the sex drive.
5. Inability to profit from experience, leading to lessened capacity for social learning

Several studies since 1978 describe the difficulties in caring for older adults who have suffered a stroke, and the impact on caregivers physiological and psychological functioning. Recent research has just begun to take into consideration the caregiver burden and/or stress experienced by caregivers of various racial/ethnic backgrounds. However, studies which take into account the caregiver stress experienced by African American caregivers appear to be limited. Morimoto, Schreiner, and Asano (2003) explored the relationship between caregiver burden and health-related quality of life of older adult Japanese stroke caregivers. One hundred caregivers of stroke patients participated in the study. The subjects were interviewed using the Zarit Buden Interview, Modified Barthel Index, the Geriatric Depression scale and the SF-12 Health Survey for health-related quality of life. Health-related quality of life was decreased if the caregiver burden was increased. However, there was no relationship in regards to caregiver physical functioning. The Japanese caregivers did not report a decrease in social functioning. Higher levels of caregiver burden and depression were related to caregivers' age, sex, chronic illness, use of respite care, caregiving hours, and care recipient functional status (Morimoto et al., 2003).

Similarly, a cross sectional study was conducted with 147 Korean stroke caregivers in order to assess the factors contributing to caregiver burden (Choi-Kwon, Hwa-Sung, Kwon, & Kim, 2005). The researchers found Korean caregivers burden to be high when the patient was

unemployed, had diabetes mellitus, aphasia, dysthymia, dysphasia, cognitive dysfunction, depression and/or emotional problems, incontinence, and/or severe MRS (Choi-Kwon et al., 2005). The patients' demographic factors did not have any effect on caregiver burden. However, depression and anxiety as experienced by the caregiver did predict caregiver burden. Several factors influenced caregiver depression and anxiety. For instance, being an older caregiver, female caregiver, daughter-in-law caregiver, low levels of education, being single, unemployed, and having poor health, significantly contributed to high levels of caregiver depression and anxiety, and positively predicted caregiver burden (Choi-Kwon et al., 2005). Choi-Kwon et al. (2005) also found that in caring for stroke patients, caregiver's physical health was not a contributor to caregiver burden. Other researchers have also found stroke (Morimoto et al., 2003; Tsai-Chung, Yih-Dar, Cheng-Chieh, & Amidon, 2004) and diabetic (Tsai-Chung et al., 2004) caregivers of older adults have better physical health than emotional health outcomes.

### *Diabetes Mellitus*

The American Diabetes Association (2004, p.5) defines diabetes mellitus as "a group of metabolic diseases characterized by hyperglycemia resulting from the defects in insulin secretion, insulin action, or both". There are two types of diabetes. Insulin dependant diabetes mellitus (IDDM), or juvenile-onset diabetes called Type 1. Type 1 diabetes occurs when the pancreas no longer makes the hormone insulin to regulate blood glucose levels within the body (American Diabetes Association, 2004). This type of diabetes can occur at any age although it is typically diagnosed in children and young adults. Type 1 account for 5% to 10% of diabetes cases (American Diabetes Association, 2003). Individuals with this type of diabetes must take insulin daily for the remainder of their lives through an injection or pump. The risk factors for Type 1 diabetes are typically autoimmune, genetic or environmental (American Diabetes

Association, 2004; Falvo, 1999). The other type of diabetes is Type 2, which was previously called non-insulin-dependant diabetes mellitus (NIDDM) or adult-onset diabetes. Basically with Type 2 diabetes, the pancreas cells do not work properly with insulin production and over time becomes unable to produce insulin. These diabetics are able to control their insulin via diet and exercise regimen and/or oral medication (National Center for Chronic Disease Prevention and Health Promotion, 2005) This type of diabetes affects 90% to 95% of all diabetic patients (American Diabetes Association, 2003). The risk factors for this type of diabetes include "older age, obesity, family history, history of gestational diabetes, impaired glucose metabolism, physical inactivity, and race/ethnicity. African-Americans, Hispanic/Latino Americans, American Indians, and some Asian Americans, and native Hawaiians or Other Pacific Islanders are a particularly high risk for type 2 diabetes and its complications" (National Center for Chronic Disease Prevention and Health Promotion, 2005, p.1)

*Prevalence of diabetes mellitus.* Although diabetes is considered a chronic illness alone, it is also one of the major risk factors for heart disease, especially for African Americans. In fact, "cardiovascular disease (CVD) represents perhaps the most life threatening complication for individuals with diabetes. An adult diagnosed with diabetes carries the same cardiovascular risk as someone who already has had a heart attack" (Francoeur & Elkins, 2006, p.30). Heart disease and stroke account for 65% of deaths in people with diabetes. In addition, about 73% of adults with diabetes have high blood pressure (hypertension) (National Center for Chronic Disease Prevention and Health Promotion, 2005).

The National Center for Chronic Disease Prevention and Health Promotion (2005) report that 20.8 million people (7% of the population) in the United States have diabetes. However, only 14.6 million people are diagnosed with the disease, and over 6.2 million people have the

disease and are undiagnosed (National Center for Chronic Disease Prevention and Health Promotion, 2005). Older adults over the age of 60 represent 10.3 million, or 20.9% of people in this age group who are diagnosed with diabetes (National Center for Chronic Disease Prevention and Health Promotion, 2005). According to the American Diabetes Association (2003), this is an increase from 2002 when 8.6 million older adults over the age of 60 were diagnosed with diabetes. Boyle et al. (2001) predict by 2050, older adults 75+ will represent the largest percentage of increase in the prevalence of diabetes (336%).

There is a disparity in the number of African Americans affected with diabetes compared to other groups. African Americans will represent the largest percentage of increase in diabetes diagnosis in ethnic groups by 2050 (275%) (Boyle et al., 2001). The American Diabetes Association (2006) reports the current results as follows:

- 3.2 million or 13.3% of all African Americans aged 20 years or older have diabetes.
- African Americans are 1.8 times more likely to have diabetes as non Hispanic whites.
- Twenty-five percent of African Americans between the ages of 65 and 74 have diabetes.
- One in four African American women over 55 years of age has diabetes.
- Among African American adults 55 to 64, 21.5% have diabetes (Schoenborn et al., 2006)

"Although Whites account for the majority of the projected people with diabetes in general, the largest percentage of increases will occur among Blacks as an ethnic group, with ~ 4.6 times as many Black males with diabetes in 2050 as in 2000" (Boyle et al., 2001, p. 1930). Among African American older adults (75 years and older), Boyle and associates (2001), found the

incidence of diabetes to increase between 2000 to 2050 for African American males (from 84,000 to 932,000) and females (from 168,000 to 1.1 million) (Boyle et al., 2001).

*Caregiving concerns for diabetics.* According to the statistics on the prevalence of diabetes with older adults, they are at an even higher risk to develop some of the disease complications. Older adults are particularly highly susceptible to developing cardiovascular complications, kidney damage, cognitive impairment, foot problems, and neuropathy (National Center for Chronic Disease Prevention and Health Promotion, 2005). In addition, older adults with diabetes can suffer numerous psychosocial complications related to disease management (DeCoster, 2003). Depression is highly likely in individuals with diabetes, particularly older adults, because the self-management process of the treatment recommendations can become very overwhelming (DeCoster, 2003). If the treatment recommendations are not followed the lack of appropriate medical follow-up can cause further medical complications. For example, an individual with diabetes has to be able to monitor blood glucose levels several times daily, develop a diet and exercise regimen, and a daily scheduled eating pattern. Fisher et al. (1982) emphasize the regimen best indicating:

the regimen for diabetes is probably the most complex and demanding of any common disease...[including] complex nutritional practices, weight management, frequent monitoring of blood or urine glucose, foot care, special procedures in the event of common maladies such as cold or flu, and in many cases insulin injections (p.993).

Trief and colleagues (2003) conducted a study to compare younger and older adults with diabetes. Older adults admitted to having more physical problems and role limitations due to diabetes regimen and its complications. Potential diabetic-related complications consist of heart disease, stroke, visual impairments, amputations, kidney disease, cognitive impairment,

incontinence, neuropathy and depression (American Diabetes Association, 2004; Falvo, 1999). According to Langa et al. (2002), who conducted the first study of burden in informal caregivers of diabetic older adults, "diabetes imposes a substantial burden on elderly individuals, their families, and society, both through increased rates of disability and the significant time that informal caregivers must spend helping address the associated functional limitations" (p. S177). Diabetic informal care (unpaid) refers to assisting an older adult with daily diabetic care, which consists of helping with diet, medications, foot care, and checking blood sugars. Other support may be needed to assist with diabetic-related complications such as limitations on mobility, lower extremity amputations, blindness, or even assistance with instrumental activities of daily living (e.g. cooking, shopping, cleaning), and transportation to numerous medical appointments (Falvo, 1999). All of these actions by the caregiver require a considerable amount of time and effort.

Langa et al. (2002) seminal work on caregiver burden with diabetic caregivers explored the amount of time spent by unpaid caregivers to assist older adults with functional limitations due to diabetes. The study used a nationally represented sample of older adults 70 and older from the 1993 Asset and Health Dynamics Among the Oldest Old Study (n=7,443). The research consisted of non diabetics (n= 6,445) and diabetics (n=993). The diabetics were divided into three groups: those taking no medication (n=166), only oral medication (n=528) and taking insulin (n=299). The findings indicated the population of those diagnosed with diabetics tended to be younger, African American, not married, living with others, poor, had history of heart disease, stroke, visual impairment, urinary incontinence, arthritis, and cognitive impairment similar to dementia (Langa et al., 2002). The diabetics in the study reported difficulty with ADLS and IADLS. In particular, the majority had difficulty walking across the room and

grocery shopping. In regards, to medication, the diabetics who took insulin reported having to take 4.6 additional medications daily (Langa et al., 2002).

When considering caregivers of diabetic elderly it is important to consider the hours of care provided to them. Langa et al. (2002) was the first to study the impact of hours of care necessary for diabetic older adults. For example, the diabetic subjects were compared to non diabetics, and, overall, the diabetic older adults received significantly more hours of weekly care. Non-diabetics reported receiving on the average 6.1 hours of informal care per week. Diabetics with no medication received 10.5 hours of care per week, while diabetics taking oral medication received 10.1 hours of care per week, and those taking insulin receive 14.4 hours of care weekly (Langa et al., 2002). The researchers concluded that diabetic older adults require a significant amount of caregiving for daily diabetic management, as well as care for complications due to the physical limitations of the disease process (Langa et al., 2002).

Langa et al. (2002) felt additional research is needed with caregivers of various racial/ethnic groups, particularly African Americans because of the high prevalence of diabetes, co morbidities, and functional limitations.

#### Conceptual Framework: Pearlin Stress Model

The stress process model of Pearlin et al. (1990) was used as the conceptual framework to analyze the stress factors influencing the emotional distress of African American caregivers over the age of 18 who care for older adults with chronic illness. The stress process model used in caregiving was developed by Pearlin et al., (1990) from several years of research with Alzheimer's family caregivers.

The researchers defined stressors as "undesirable life events, conditions and experiences that are problematic for people; that is, that threaten them, thwart their efforts, fatigue them, and

defeat their dreams" (Pearlin et al., 1990, p.586). Thus, caregiving for chronically ill relatives has been viewed as causing substantial stress not only to the care recipient but to the caregiver (Ferrario, Zotti, Ippoliti, & Zotti, 2003). The stress process examines not only the reasons that contributed to the caregivers stress, but also how the stressful situations arose and the interrelationship between the caregiver and the environmental circumstances in which he or she provides care.

### *Transactional Stress and Coping Model*

Prior to the development of the Pearlin et al. (1990) stress process model for caregivers, much of the empirical research on caregiving was operationalized by the major constructs (primary appraisals, secondary appraisals, mediators and outcomes) of the transactional stress and coping model of Lazarus and his colleagues (Folkman, Lazarus, Pimley, & Novacek, 1987; Lazarus, 1966; Lazarus & Folkman, 1984; Lazarus & DeLongis, 1983). Early stress research of Lazarus (1966) defined stressors as, "the external and internal forces that produce stress reactions, the form that these reactions take, and the structures and processes that intervene between the stress stimulus and the stress response" (p.23). The transactional stress and coping model further viewed psychological stress as a "particular relationship between the person and the environment that is appraised by the person as taxing, or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.19).

Initially the Lazarus and Folkman (1984) transactional stress and coping model was developed to research individuals and his or her response (transaction) to stressful events resulting from daily hassles and major life events. The model specifies psychological stressors as potentially harmful environmental circumstances. Stressors are appraised by the individual to determine the potential for harm. This is considered the primary appraisal by the model. Once

the stressor has been appraised as a threat, a secondary appraisal assesses the individual's ability to cope with the external situation. An individual is then judged to determine his or her ability to manage the potential stress by utilizing coping mechanisms or mediators. According to Lazarus and Folkman (1984) "coping is the process through which the individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions they generate" (p.19). Depending on the adequacy of coping mechanisms within this model, they can directly assist in mediating the individual's outcome response to the stressor (Lazarus & Folkman, 1984).

### *Stress Process Model and Caregiving*

Over the years, the Lazarus and Folkman (1984) model has been applied to caregiving research, particularly with dementia caregivers. Haley, Levine, Brown, & Bartolucci (1987) were the first researchers to apply the transactional stress and coping model to caregiving research. Fifty-one dementia elder-caregiver dyads were studied to determine caregiver stressors, appraisals, coping responses, social support and their effect on caregiver well-being. The results indicated positive caregiver outcomes (well-being) was determined by decreased stress and increased self-efficacy scores. Overall, the model indicated appraisal, coping responses, and social support significantly predicted the caregiver's outcome (well-being). Additional caregiver researchers have applied this model in order to determine the direct impact caregiving stressors as appraised by the caregiver has on the physical and psychological well-being of the caregiver when mediated by certain coping resources.

Drawing from the transactional stress and coping model, Pearlin et al. (1990) developed a stress proliferation model from several years of research with Alzheimer caregivers. The concept of stress proliferation defines the Pearlin model, as opposed to the transaction of stress used with

the Lazarus and Folkman model. This key model expands the initial work of Lazarus and Folkman's stress and coping model, because it explains the dynamics specific to the caregiving process. In other words, the caregivers psychological well-being can be determined or assessed by numerous factors represented (proliferated) throughout the life of the caregiver (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin et al., 1990). Although the stress process model was initially created for use with Alzheimer's caregivers, several researchers have applied the theory to their caregiver research in an effort to explore the impact of caregiving on the caregiver's physical and/or mental health.

According to Pearlin et al. (1990), the model would examine the stress of caregiving across the daily life of the caregiver. The domains of the Pearlin model are background context, stressors, mediators of stress, and the outcomes of stress (Figure 2.1). Caregiver stress is defined as "the demands and obstacles that exceed or push to the limit one's capacity to adapt" (Aneshensel et al., 1995, p. 34). Stress starts with the experience of a situation that an individual confronts and the perception of that situation. Daily caregiving duties include a relationship exchange between the caregiver and care receiver. The caregiver's perception of daily stressors, and the way he or she copes with daily stressors, could affect the outcome of the stress related event (Pearlin et al., 1990). As social psychology indicates, perceptions are a vital part of daily life for individuals, and perceptions can unknowingly influence behavior (Ferguson & Bargh, 2004). Therefore, caregivers who perceive caregiving as stressful may experience higher levels of mental and physical health concerns than caregivers who perceive a positive caregiving experience. Pearlin et al. (1990) view caregivers' perceptions of stress as a process appearing in four domains of the model (see Figure 2.1).

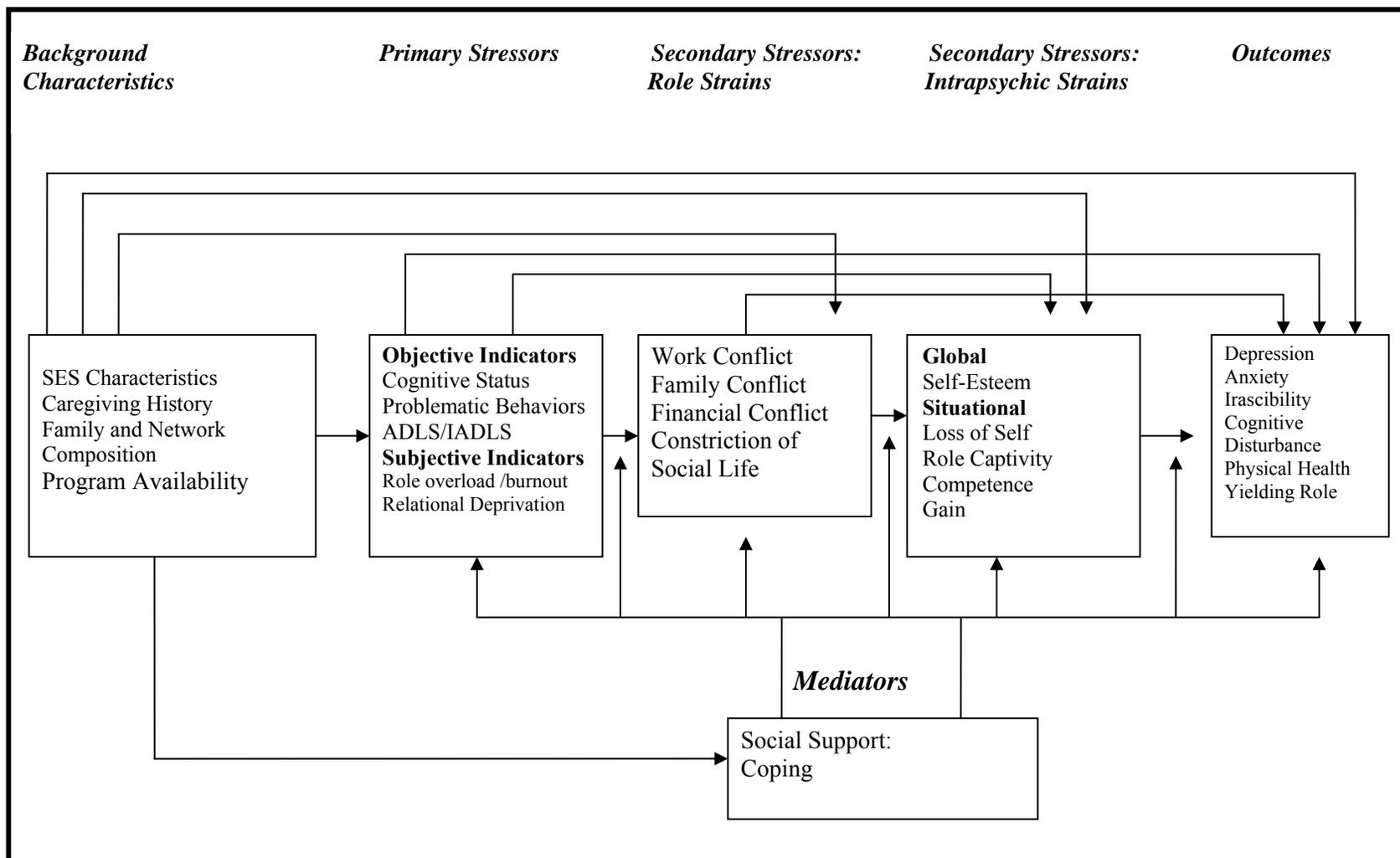


Figure 2.1. Pearlin's Stress Process Model

Sources: Pearlin, et al., (1990)

The stress process model's main purpose in caregiving research is to demonstrate how caregiver's background and stress context variables can lead to the primary and secondary stressors, which lead to secondary intrapsychic strains, which lead to caregiver outcomes. Mediators are the forms of various types of resources, such as social support and coping. They are formed by the background and context variables, and have a crucial impact on the development of the other domains (i.e. primary stressors, secondary stressors, intrapsychic strains, and outcomes) throughout the stress process (Pearlin et al., 1990).

*Cultural component.* Since the 1980s caregiver research began examining the effects of caregiving based on race, ethnicity, and culture. Throughout the caregiving literature, explorations of caregiving for people of color have been based on a variety of theoretical, empirical generalizations, and conceptual frameworks. The majority of caregiving research on African American caregivers has employed the stress process model of Pearlin et al. (1990) as the theoretical framework. The stress process "unfolds within the context of social, economic, cultural and political factors" (Aneshensel et al., 1995, p.35). According to Dilworth-Anderson et al. (1993), it is imperative when studying African American families researchers must include the values and belief systems of the minority group being studied. Previous studies with African American caregivers utilizing the Pearlin model have not included a cultural component. In a 20 year review (1980-2000) of race, ethnicity and culture in caregiving research, Dilworth-Anderson et al. (2002), indicated the most frequently used model in caregiving research are the stress and coping, and stress process models. However, they have indicated these models need to be made "more culturally relevant" (Dilworth-Anderson et al., 2002, p.267). They further state "constructs that measure culture should be included in the stress model" (Dilworth-Anderson et al., 2002, p.267). The Pearlin model is suitable for this research on African American caregivers

because relative to the background characteristics category of the model (family network composition) a cultural component can be included in the model (Pearlin et al., 1990). In this study, cultural justifications for caregiving will be added as the cultural component to the model. Therefore, in order to build a knowledge base about the mental and physical health related caregiving experiences of African Americans caring for chronically ill older adults (see figure 2.1), this cultural component will serve will serve as the conceptual tool based on Pearlin et al. (1990) stress process model. The model describes the caregiver stress process as comprising a number of interrelated conditions (1) background characteristics, (2) primary stressors, (3) secondary role strains, (4) secondary intrapsychic strains, (5) mediators, and (6) outcomes.

#### Components of the Stress Process Model

Studies on race, ethnicity, and cultural issues of caregiving have utilized Andersen and Newman's behavioral model (Cox, 1999a), the structural model of caregiving (Lawton et al., 1992), the illness help seeking model (Levkoff et al., 1999), role theory (Burnette, 1999; Mui, 1992), social exchange theory (Martin, 2000; Picot, 1994, 1995; Picot et al., 1997), Rosenbaum's theory of resourcefulness (Zauszniewski et al., 2005), stress-health process (Schultz, 2000), sociocultural stress and coping model (Aranda & Knight, 1997; Knight et al., 2000; Knight, Robinson, Longmire, Chun, Nakao, & Kim, 2002), as well as a contextual approach to the stress process model for use with ethnic minority caregivers (Dilworth-Anderson & Anderson, 1994; Dilworth-Anderson et al., 1999b; Williams, 2005). Empirical generalizations have also been widely used in caregiving research with ethnically diverse populations in an effort to provide a summary of research findings, link them to other research findings, and to generate additional information regarding the population (Cox, 1993; Cox & Monk, 1990, 1993; Delgado & Tennstedt, 1997a, 1997b; Haley et al., 1995; White, Townsend, & Stephens, 2000).

Although caregiving research on culturally diverse populations has utilized those theories and empirical generalizations, the majority of caregiving literature on racial and ethnic groups has employed the stress process model of Pearlin, Mullan, Semple, and Skaff, (1990). The literature has proven to be scant for exploring Pearlin's stress process framework for African American caregivers exclusively. Therefore, this section will pay particular attention to studies that employed the Pearlin stress process (proliferation) model as each construct relates to African American caregivers, as well as to studies comparing African-American caregivers to Caucasian's and other racial/ethnic groups.

### *Background Characteristics*

This area of the model explores the key characteristics of the caregiver to include age, gender, ethnicity, educational attainment, employment status, length of time caregiving, relationship to care recipient, range of health problems of the care recipient and caregiving, family and network composition, and availability of community-based formal programs (Pearlin et al., 1990). By taking into account these vital aspects of the caregiver, Pearlin et al. (1990) find it useful to "signify where people stand within stratified orders having unequal distributions of rewards, privileges, opportunities, and responsibilities" (p. 585). These background characteristics are woven throughout the caregivers' life, and tend to affect the stress process. These background characteristics existed prior to the caregiver taking on the caregiving role, and may have potential effects on the emotional and physical affects of the African American caregiver. Pearlin et al. (1990) recommended the background characteristics be divided into the following groups, which will be analyzed in this study: (1) socioeconomic characteristics, (2) caregiving history, (3) family cultural context, and (4) formal program availability.

*Socioeconomic characteristics.* Social economic characteristics are characterized as "the larger social orders of the society and the statuses of the people within them" (Pearlin et al., 1990, p.585). Pearlin et al. (1990) contend, "the effects of ascribed status such as age, gender, and ethnicity, along with educational, occupational, and economic attainments are expected to be threaded throughout the stress process" (p.585). The conceptual model of this study includes socioeconomic constructs of age, gender, education, income, living arrangements, and employment status as components of the background characteristics. These constructs reflect previous caregiving research with African American caregivers utilizing the stress process model. Previous research on socioeconomic conditions has clearly indicated that life experiences over time can impact an individual's advantages and disadvantages within society, particularly as they relate to health behaviors (Lantz, House, Lepkowski, Williams, Mero, & Chen, 1998). For African Americans, a historical lack of resources and several limitations on opportunities influence physical and emotional health (Braithwaite & Taylor, 2001). Within the caregiving role these factors may impact African-American caregivers' ability to provide adequate care to older adults with chronic illness. Further research is necessary with a sample of African-American caregivers to explore the socioeconomic (age, gender, education, income, living arrangements, and employment status) impact on caregivers' emotional and physical health as they proliferate throughout the stress process. By utilizing the stress process, several studies have found the following background characteristics to affect stress outcomes of emotional and physical health, age, gender, income, marital status, employment status, and caregiver living arrangement.

*Age.* For example, caregiving literature has shown age to be related to depression (Young & Kahana, 1995), physical health (Dilworth-Anderson et al., 2004; Fredman et al., 1995;

Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999), burden (Fredman et al., 1995; Young & Kahana, 1995) and role strain (Cox & Monk, 1996) among younger African American caregivers (Cox, 1995). Gender has also influenced stress outcomes. Female caregivers are reporting higher levels of negative stress outcomes than male caregivers (Chadiha et al., 2003; Fredman et al., 1995; Young & Kahana, 1995). African American female caregivers and care recipients tend to be in poorer health, which adversely affects the emotional (Dilworth-Anderson et al., 1999a; Young & Kahana, 1995) and physical health outcomes (Chadiha et al., 2003; Dilworth-Anderson et al., 2004).

*Income/Education.* Education, income, marital status, living arrangements, and caregiver employment also have been shown to influence stress outcomes among African American caregivers. Fredman et al. (1995) found more African American caregivers to have incomes less than \$12,000 per year compared to Caucasian caregivers. Moreover, African American caregivers tended to be single. In addition, lower income and education levels in African-American caregivers resulted in an decrease in physical health outcome among this subgroup (Chadiha et al., 2003; Dilworth-Anderson et al., 2004), and higher levels of depressive symptomology as compared to Caucasian caregivers (Drentea & Goldner, 2006).

Dilworth-Anderson et al. (2004) conducted a longitudinal study on African American caregivers. They found higher education of caregivers at wave 1 was associated with an increase in caregivers' physical functioning (outcome variable) at wave 3. However, Freedman et al. (1995) completed an investigation with 1,062 Caucasian caregivers and 159 African American caregivers. The researchers found that although African Americans reported decreases in education, lower income, and fewer spouses in the caregiving role than Caucasians, these background characteristics did not have an ill effect on caregiver depression or role strain

outcomes. However, Cox and Monk (1996) found a positive relationship between income and personal strain among African-American and Hispanic caregivers.

*Living arrangements.* Caregiving research has also demonstrated the impact of co-residing with care recipient (Biegel et al., 1991; Macera et al., 1992; Soldo, Wolf, & Agree, 1990) and caregivers' employment status significantly predict caregivers' stress and impacts health outcomes (Bullock et al., 2003; Starrels, Ingersoll-Dayton, Dowler, & Neal, 1997). When the stress process model was applied, Fredman et al. (1995) found a significant increase in caregiver burden among both African-American and Caucasian caregivers when they co-reside with care recipient.

*Employment.* Several studies have been conducted to explore how employment affects caregiving. However, they do not include African American caregivers (Anastas, Gibeau, & Larson, 1990; Cantor, 1983; Starrels et al., 1997). White and Means (1996) conducted a study on 111 African American caregivers of indigent elderly. The purpose of this study was to examine the well-being of the caregivers. In this study, when employment and the hours of care were combined for African American caregivers, the result yielded a negative effect on caregivers' well-being (White-Means & Thornton, 1996). Exchange theory and a cultural variant model were used in the first study to predict the effect of employment status with 119 African American caregivers (Bullock et al., 2003). Researchers found employed caregivers to be younger, in better health, and more likely to be a child of the care recipient. Conversely the Bullock study found no relationship between employment status and the hours of care (Bullock et al., 2003). The majority of caregivers of color tend to work jobs that do not allow for flexibility (i.e. sick benefits, leave, paid time off), and as a result this increases caregiving stress as it relates to employment of the caregiver (Aranda & Knight, 1997). Further research with

African American caregivers and the effect of employment status on emotional and physical health is warranted.

*Caregiving history.* Several additional background context variables are examined as caregiving history variables. Initially, Pearlin et al. (1990) defined this area of the model to include information that consists of the caregivers' history (i.e., relationship of caregiver to patient, previous conflict and relationships between caregiver and care receiver, physical health concerns, and length of time caregiving) Consistent with Pearlin's model, caregiving literature has indicated that African American caregivers' physical and emotional health outcomes can also be predicted by the number of caregiving roles, length of time caregiving, relationship to care recipient, duration of caregiving role, caregiver and care recipient health conditions. This study will further examine the relationship of the African American caregiver to the care recipient in an effort to determine if the relationship significantly predicts caregivers' emotional and/or physical health.

For example, studies that utilized the stress proliferation model found African American caregivers spent more time weekly in caregiving roles than Caucasian caregivers'. Although the results for black caregivers were statistically significant, Caucasian caregivers experienced more caregiver burden (Fredman et al., 1995). Cox (1995) found levels for depression of African American caregivers, compared to Caucasian caregivers, increased as the caregiving hours became more intense. Recent research found African American caregivers provided more weeks of care within a year than Caucasian caregivers, but both groups of caregivers provided equal amounts of caregiving hours (Drentea & Goldner, 2006). The researchers further discovered that duration of caregiving did increase depressive symptomatology and physical health experienced by African American caregivers.

Ho et al., (2000) compared African American, Chinese, Latino, and Caucasian caregivers. They found the relationship with the care recipient not to have a significant impact on depression of the caregiver. Cox and Monk (1996) also found among African American caregivers (n=76) and Hispanic caregivers (n=86) that the relationship to the care recipient did not have an impact on caregivers' role strain. African American caregivers were primarily females caring for a relative, and Hispanic caregivers were primarily daughters caring for a parent. Similarly, Cox (1995) found that African American daughter caregivers did not experience role strain in regards to their caregiving role. While, Caucasian daughter caregivers did experience more strain in their role as a caregiver. In addition, Hughes et al., (1999) found African American and Indian caregivers reported less subjective burden than did Caucasian caregivers. The subjective burden was found to negatively impact spousal, children, and other relative relationships. Subjective burden in this study was defined as "caregivers perception of the degree of stress experienced in the caregiving role" (Hughes et al., 1999 p. 535). A recent study conducted by Drentea and Goldner (2006) did not support these findings. Instead, it was found that African American and Caucasian daughter caregivers do have increased levels of depression when compared to other caregivers (i.e., spousal and relative).

*Family cultural context.* This area of the Pearlin model is also referred to as Family and Network Composition. The purpose is to explore the familial and cultural networks of the caregiver and care recipient. Culture is defined as "the means by which a person can adapt and adjust to changes in the environment with some feeling of security and familiarity. "Culture includes all the accumulated ways a group of people solve problems, which are reflected in the people's language, dress and in a number of their traditions and customs" (Clavon, 1986 p. 8). The caregivers' cultural context "provides information on the cultural beliefs and attitudes of

caregivers, such as beliefs about providing care to dependant family members" (Dilworth-Anderson et al., 1999a p. 391). Other caregiver researchers support Dilworth-Anderson and colleagues, indicating an individuals' decision to provide care to an older person. Their ability to handle burden and stress is dependant on their cultural beliefs and attitudes (Lawton et al., 1992). For ethnic/racial groups this area includes issues of filial obligation, duty, reciprocity (giving back) and sense of responsibility. Czaja, Eisdorfer, and Schultz (2000) wrote "culture plays an important role in caregiving and the increased ethnic diversity of the population points to the need to devote attention to ethnic differences in attitudes towards caregiving and responses to caregiving responsibilities. By 2030 elders from minority populations will account for approximately 25% of older Americans. The number of black elderly will account for 10% of those aged 65+" (p. 288).

Dilworth-Anderson et al, (2002) conducted a 20 year review of race, ethnicity, and culture in caregiving research. This meta analysis informed researchers that between 1980-2000, only 20 studies explored the cultural effects of culture in research. Fourteen of the twenty studies were based on empirical generalizations. Seven utilized various conceptual models/frameworks (Dilworth-Anderson et al., 1999a; Fox et al., 1999; Lawton et al., 1992; Ortiz, Simmions, & Hinton, 1999; Strong, 1984; Thornton, White-Means, & Choi, 1993) or grounded theory (Hicks & Lam, 1999). During this time period (1980-2000), none of these studies utilized the Pearlin stress process to determine the impact of culture on caregivers' emotional and/or physical health. African American caregivers were explored exclusively in two theoretically guided studies (Dilworth-Anderson et al., 1999a; Fox et al., 1999) and compared to Caucasian caregivers in one theoretical study (Lawton et al., 1992).

Lawton et al. (1992) utilized a four factor index to measure traditional caregiving ideology. They defined caregiving ideology as attitudinal variables toward caregiving (i.e., wishing to repay a debt of care, continue family tradition, fulfilling personal values, setting example for children etc.). When race and background factors were interacted with caregiving ideology, African American caregivers showed higher caregiving ideology than did Caucasian caregivers. Knight and McCallum (1998) also found cultural factors (based on race differences) impacting African American versus Caucasian caregivers heart rate response to emotional and physical reactions to caregiving stress. They wrote,

Ethnic differences were interpreted as providing support for the view that African-American cultural values support a view of caregiving as a valued part of family life, whereas white cultural values tend to see the familial obligation of caregiving as disruptive of individual life goals. (p.220)

Future studies explored African American caregivers quantitatively and qualitatively to determine cultural responses to care for older adults. For example, Fox (1999) conducted a qualitative analysis of 10 African-American urban dementia caregivers with a medical anthropological approach. Researchers found cultural norms, perceptions, and meanings about illness and disease affected African American caregivers' provision of care, emotional, and physical distress. Dilworth-Anderson et al. (1999a) used a contextual approach informed by a stress and coping model with 187 African American caregivers, and they found their cultural justifications for care scale did not significantly predict caregivers' emotional distress.

Consequently, in another study, Dilworth-Anderson et al. (2004) conducted a longitudinal study utilizing the Pearlin stress model to examine if culture effects African American caregivers (n=107) physical health (psychosocial and physical functioning) in three

waves. Wave 1 was the initial interview, and the other two waves were at nine month intervals. Cultural beliefs/values scores did explain health outcomes for African American caregivers. The cultural justifications for caregiving scale specifically showed baseline caregiver psychosocial health scores significantly predicted wave 3 caregiver psychosocial health. In addition, cultural justification for caregiving had a curvilinear effect on psychosocial health. Therefore, very weak or very strong cultural justifications for caregiving are predictive of poor physical health in African American caregivers. (Dilworth-Anderson et al., 2004).

Likewise, this study included the cultural context to the stress model as recommended by caregiving researchers. Dilworth-Anderson et al. (2004) state,

The inclusion of the cultural justifications of caregiving as a response in this study reflects the cultural values and beliefs (e.g., reciprocity, sense of duty, and God's will) of African-Americans that can influence providing care to older family members. Cultural socialization in the African-American community helps create beliefs and attitudes about caring for dependant others in the family that encourage developing coping strategies (resources) to deal with stressors in the caregiving situation.

Therefore, an expectation of this study is that cultural justifications of caregiving as a family cultural context variable will influence emotional and physical health outcomes for African American caregivers. Moreover, it is expected that findings from this study will contribute significantly to the caregiving knowledge base.

### *Primary Stressors*

Pearlin et al., (1990) defined stressors as "the conditions, experiences, and activities that are problematic for people, that is, that threaten them, thwart their efforts, fatigue them, and defeat their dreams" (p. 586). Research has demonstrated that providing care to chronically ill

older adults can affect the stressors experienced by the caregiver. This study explored the two categories of stressors and their individual components as identified by the stress process model (primary and secondary stressors) in an effort to determine if they were adequate predictors of emotional and physical health among African-American caregivers.

"We view primary stressors as driving the process that follows. By and large, they stem directly from the needs of the patient and the nature and magnitude of the care demanded by these needs" (Pearlin et al., 1990 p. 587). These stressors are caused directly by activities performed by the caregiver. Primary stressors are divided into objective (e.g., care recipient's cognitive status, problematic behaviors, and ADL/IADL's dependencies) and subjective (role overload and relational deprivation) indicators that stem from the needs of the care recipient (Aneshensel et al., 1995; Pearlin et al., 1990).

*Primary objective stressors.* Objective stressors are those that are based on the health, behavior and functional capabilities of the care recipient. In this study they were characterized by the care recipients (1) total instrumental activities of daily living (TIADLS), made up of activities of daily living (ADLs) and instrumental activities of daily living (IADLS), and (2) cognitive status and problematic behaviors.

*ADLS/IADLS.* ADLS and IADLS are defined as activities a person may require assistance with in order to assist them with a disability or chronic condition. ADLS activities include getting in/out of bed/chair, walking, dressing or undressing, bathing or showering, toileting, feeding, changing diapers and/or other device (Hooyman & Kiyak, 2005; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). IADLS activities include assistance with transportation, grocery shopping, housework (dishes, laundry, cleaning up etc.), managing finances, preparing

meals, giving/preparing medications, and arranging/managing services (Hooyman & Kiyak, 2005; Lawton & Brody, 1969).

Several Alzheimer and Dementia (AD) caregiving studies have been conducted on cognitive status and problematic behaviors as predicting caregivers' emotional and physical health. Limited research has been done on cognitive status and problematic behavior for older adults with chronic illness. As previously mentioned, caregiving can be a challenging role for many caregivers. Difficulty in caring for the care recipient can potentially have a direct relationship on the number of physical and cognitive limitations of the care recipient. Research was conducted with 148 African American caregiver dyads in order to determine the predictors of caregiver role strain and caregiver depression. The relationship between caregiver roles and available resources was assessed (Wallace Williams, Dilworth-Anderson, & Goodwin, 2003). Wallace Williams et al. (2003) found when African American elderly care recipients (non disease specific) had lower levels of ADLS, and high levels of IADLS, the caregivers reported higher levels of role strain. In addition, this study also found high levels of role strain increased the care recipients' levels of depression. Therefore, severe ADLS and IADLS had an impact on caregiver role strain and caregiver depression within this study.

Additional research by Poulshock and Deimling (1984) found the mental health status of the care recipient had an impact on their ability to complete their own ADLS. As a result, the care recipients did not realize they were not performing their ADLS adequately. This impacted the caregivers' burden as they tried to work with the care recipient with the needed task. Further research has indicated that when caregiver and care recipients disagree about the ability of the care recipient to perform IADLS, the caregiver becomes stressed and has difficulty assisting with the IADLS (Zweibel & Lydens, 1990). Previous discussion regarding chronic illnesses

(cardiovascular diseases and diabetes) indicated both have high incidences of depression and/or anxiety among the care recipient. This would warrant further explorations since those chronic illnesses have several physical limitations. Therefore, this current study explored how the ADLS and IADLS of this population affect the health outcomes of the caregivers.

*Cognitive status and problematic behaviors.* Cognitive status and problematic behaviors are two other indicators of objective stress. Cognitive status includes an assessment of the care recipients' memory loss, communication deficits, and recognition failures (Pearlin et al., 1990). Problematic behaviors include potential disruptive behavior by the care recipient, and the control the caregiver must exert in order for the care recipient not to harm (Aneshensel et al., 1995; Pearlin et al., 1990). Previous research has indicated the severity of a care recipient's cognitive impairment may predict caregivers' burden (Zarit, Reever, & Bach Peterson, 1980).

When compared to African-American caregivers, Caucasian dementia caregivers' levels of depressive symptomology and personal strain were significantly increased when the care recipient displayed stressors, such as disruptive behaviors or problems, task distress, (Cox, 1995; Farran, Miller, & Kaufman, 1997; Miller et al., 1995) and a decrease in cognitive functioning (Cox, 1995). Freeman et al. (1995) also found African-American and Caucasian caregivers demonstrated high levels of caregiver burden as predicted by the number of functional disabilities (ADLS and IADLS) and cognitive impairment. Likewise, current research has found challenging behavioral problems by the care recipient can have an effect on caregivers' mental health. For example, a recent study of 653 Caucasian, 278 African-American and 218 Hispanic Alzheimer caregivers examined racial differences in caregiving stressors, caregiver depression and physical health. In the area of care recipient stressors, the research revealed cognitive status and problematic behaviors of the care recipient did significantly impact poor perceived physical

health of the caregiver (Sorensen & Pinquart, 2005). However, the study did not reveal any significant difference racially, and no adverse impact of care recipient cognitive function and behavioral problems on caregiver depression. Minimal research has been conducted on the impact of cognitive status and problematic behaviors for chronic illness caregivers. Therefore, this investigation explored both the cognitive status and problematic behaviors for chronic illness caregivers.

*Subjective primary stressors.* Subjective primary stressors are those that are related to the fatigue felt by the caregiver. Examples of subjective primary stressors that were used in this study are role overload/burnout, relational deprivation, and role captivity felt by the caregiver.

*Role overload/burnout, relational deprivation and role captivity.* Role overload/burnout refers to the level of fatigue felt by the caregiver due to the amount of time and energy put into the caregiving role (Pearlin et al., 1990). Relational deprivation describes how the relationship has changed (i.e., loss of intimacy and social exchanges) between the caregiver and the care recipient as a result of the caregiving role (Pearlin et al., 1990). The feelings of being trapped, or loss of life for the caregiver as a result of the caregiver's role, describes role captivity (Pearlin et al., 1990). The role and demands of caregiving for older adults can affect the various types of fatigue felt by the caregiver. These feelings may also affect the caregivers' physical and/or emotional health.

Role strain, role demand, and role conflict were studied in a sample of African American and Caucasian caregivers of older adults (Mui, 1992). Among Caucasians caregivers when parent-daughter relationships were poor, high levels of role strain was predicted. However, this was not a significant result among African American caregivers (Mui, 1992). Mui (1992) also found that overall Caucasian caregivers experienced higher levels of role strain, and African

American caregivers reported higher role demand. Lastly, the researchers found that when African Americans regarded their health as poor, combined with a lack of respite support services, the level of role strain was higher for African American caregivers (Mui, 1992). The following year Cox (1993) conducted a study comparing African American and Caucasian caregivers. Both groups reported relationship strain. Cox (1993) defined relationship strain as the "caregiver's feelings of being pressured, angry, depressed, manipulated, strained, resentful, depended upon, and feeling that the relationship had a negative effect on the other family members" (p. 35). It was be important for this study to examine these subjective primary stressors experienced in a sample of African American caregivers to see how they felt regarding their role strain and relationships in caring for older adults with chronic illnesses.

This study included all four indicators of primary stress: (1) total instrumental activities of daily living, made up of activities of daily living (ADLS) and instrumental activities of daily living (IADLS), (2) cognitive status and problematic behaviors, (3) role overload, and (4) relational deprivation.

### *Secondary Stressors*

Two types of secondary stressors exist in the model. Stressors that come from the demands outside of caregiving (role strain) and those that emerge from the relationship of the caregiver and care recipient intrapsychic strains (Aneshensel et al., 1995; Pearlin et al., 1990).

*Role strains: Family, work and financial conflict.* Role strains are considered the conflicts that come from every day life. Items considered secondary role strains are family, employment, and financial conflict (Pearlin et al., 1990). A study with 278 female caregivers examined four caregiver roles (parent care provider, mother to children at home, wife, and employee) (Stephens, Townsend, Martire, & Druley, 2001). The findings indicated that women

who had difficulty caring for their elderly parent tended to have financial difficulty, older children, and the parent had more functional and cognitive impairments. In addition, women caregivers who experienced difficulty between employment and parent care, tended to be older, and were more educated, in long marriages (Stephens et al., 2001).

A sample of African American caregivers from UC Berkeley was compared to other racial/ethnic caregivers regarding dual caregiving role responsibilities (n= 4256) . African American caregivers (14%), Caucasian (62%), Asian (12%), and Hispanic (8%) caregivers comprised the study. The findings indicated minority caregivers tended to be challenged financially, and employed as staff (90%), as opposed to faculty or administrative positions. Yet, African American caregivers tended to have less flexibility with their jobs, provided the most hours of care, and cared for older adults with the highest number of impairments (Fredriksen-Goldsen & Farwell, 2004). African American caregivers also tended to care for multiple individuals in the home. (Fredriksen-Goldsen & Farwell, 2004) Caregivers may experience role strain conflicts at various levels. Limited research focuses on African American caregivers in regards to the impact of family, work, and financial conflicts in caregiving.

*Intrapsychic strains: Global and situational strains.* Global intrapsychic strains refer to an examination of the self. These strains are self-esteem and mastery, or caregiver satisfaction. In relation to caregiving, this area would examine how the caregiver feels about themselves (self-esteem) and their ability to complete the task of caregiving role adequately (mastery) (Pearlin et al., 1990). Situational strains and include loss of self and competence and gain. Loss of self refers to how much the caregiver feels they have lost of themselves due to the caregiving role. Competence and gain describes how the caregiver rates their ability to complete a caregiving task and make the necessary progress. This is added to the stress model in order to see if the

perception of personal positive regard affects the caregivers' health outcomes (Pearlin et al., 1990).

Miller et al. (1995) conducted an empirical study to explore the relationship between race, control, mastery and caregiver distress among 77 African American and 138 spousal dementia caregivers. Caregiver mastery significantly predicted role strain as a psychological resource, and mastery acted as a buffer between the stressors and depression (Miller et al., 1995). African American and Caucasian caregivers' sense of control was negatively related to depression (Miller et al., 1995). Current research with African American caregivers (107) of frail older adults (non disease specific) also used the Pearlin model to determine over time how culture can predict the physical effects of caregiving (Dilworth-Anderson et al., 2004). African American caregivers were interviewed in three waves with 9 month intervals. Caregiver mastery and cultural justifications of caregiving were added in the model as a mediator (resources). Caregiving mastery was measured with the Caregiving Mastery Scale of Lawton et al. (1989). Higher scores on this measure indicate higher levels of caregiver mastery and competence. The results of this study showed higher levels of caregiver mastery and cultural justifications of care at wave 3. The results significantly predicted a decrease in physical health symptoms from wave 1 (Dilworth-Anderson et al., 2004).

Competency was measured in a study comparing the caregiving experiences of African American (n=76) and Caucasian (n=88) dementia caregivers (Cox, 1995). In this study competency was used as a mediator in the Pearlin model in order to describe "the competency caregivers felt in dealing with a difficult situation, confidence in caregiving, ability to learn new things, and feelings of being a good caregiver" (Cox, 1995, p. 345). African American caregivers experienced greater perceived depression when they were concerned about level of

competency regarding the caregiving role, as compared to Caucasian caregivers (Cox, 1995). According to Cox (1995), "..... competence was a significant predictor of stress only in the Black group, this may stem from cultural variations associated with filial responsibility. Given their stronger adherence to cultural values that prescribe care to elderly people, black caregivers may be susceptible to stress when they feel unable to meet these responsibilities" (p.347). Moreover, competency in the caregiving role affected levels of depression with African-American caregivers in both the Cox (1995) and Miller et al. (1995) studies.

Loss of self has not been investigated in African American caregivers utilizing the Pearlin model. However, in a qualitative study of Chinese-Canadian female Alzheimer caregivers, loss of self and feelings of anxiety and fatigue were experienced by caregivers. Twelve females participated in the study. Due to the caregiving role, three underwent change in their lives and believed they were different people since taking on the caregiving role. In addition, five caregivers experienced constant anxiety and four experienced fatigue due to the 24 hour caregiver day (Ho, Friedland, Rappolt, & Noh, 2003).

The studies reviewed were primarily with care recipients who had Alzheimers, Dementia or non disease specific issues. The results showed intrapsychic strains as significant predictors in caregiver health outcome. Similarly, this study collected data on African Americans caregivers of the chronically ill to determine if intrapsychic strains significantly predict health outcomes.

### *Mediating Conditions*

Coping and social support are considered to be the salient mediators in the Pearlin model. The purpose of the mediators is to explain the variability of the outcome. In stress research, the

caregivers coping skills and/or use of social support may act as a buffer to determine the strength of the relationship between the stressor and the outcome (Pearlin & Aneshensel, 1986) .

*Coping -religious/spirituality.* Coping refers to the actions people take on their own behalf as they attempt to avoid or lessen the impact of life's problems (Pearlin & Schooler, 1979). For example, in the stress process model, coping regarding caregiver issues has three major functions of managing the specific situation that caused the stress, reducing the threat of the stress reoccurring, and monitoring the symptoms that caused the stress. For the purposes of this study religious/spirituality coping were used to identify coping strategies as experienced by African American caregivers.

In caregiving studies, African American caregivers utilize religion as a form of coping with caregiving stress (Picot et al., 1997; Wood & Parham, 1990). Researchers further discovered that religiosity for African American caregivers acted as a buffer for predicting lower levels of depression (Drentea & Goldner, 2006; Picot et al., 1997; Wood & Parham, 1990). Dilworth-Anderson and Gibson (2002) contend that African American caregivers tend to cope with the challenges of caregiving through prayer, faith in God, and religion. African American caregivers reported higher levels of rewards in caregiving when compared to Caucasian caregivers. This was due largely to higher levels of religiosity (Picot et al., 1997).

The first study to examine the effects of religious/spiritual coping among African-American caregivers utilizing the Pearlin et. al., (1990) stress process model, was conducted with an African American wife caregivers sample of 100 caregivers. This sample was recruited from a larger study of rural and urban African-American caregivers (n=521). The purpose of this study was to determine the impact that caregiving stressors, social support, and caregiving appraisal has on the marital function of African-American wife caregivers (Chadiha et al., 2003). Overall,

the stressors of husbands functioning and wife caregivers' involvement in grandparent caregiving were not a significant predictor of marital functioning. Perceived social support, church support, caregiving appraisal/caregiver satisfactions (mediators), proved to significantly increase marital functioning. However, high levels of caregiver burden decreased marital functioning when care recipients' physical functioning was increased, and when wife caregivers cared for grandchildren.

Limited studies have explored religiosity as a mediator with ethnically diverse samples using the Pearlin model. Recently, Morano and King (2005) conducted research with 384 Alzheimers disease caregivers (Caucasians n=147, Hispanic n=113 and African American n=88). The findings indicated high levels of religiosity was found to significantly mediate the caregivers perceived self-acceptance of the caregiving role. Similar to earlier research, African American caregivers had the highest level of religiosity, self acceptance, and lower levels of mental health outcome (depression) (Morano & King, 2005; Picot et al., 1997). Lastly, religiosity did not significantly mediate perceived caregiver strain for any of the caregivers. Therefore, this study used religiosity/spirituality as a coping mediator in order to determine if it significantly acts as a buffer to predict physical and mental health in African American chronic illness caregivers.

*Social support.* Social support also acts as a stress process mediator by either preventing or inhibiting secondary stressors from occurring. This mediator has been instrumental in minimizing stress outcomes for caregivers of chronically ill older adults. Social support refers to the unpaid support a caregiver actually receives from relatives, friends, neighbors, church (informal support) and/or support they perceive as occurring from community-based informal programs to assist with the caregiving role (formal) (Aneshensel et al., 1995; Pearlin et al., 1990; Pearlin & Aneshensel, 1986).

*Informal social support.* Informal social supports, as experienced by the caregiver, will be used to describe one of the social support mediators. The use of informal social supports by African American caregivers has been well documented in the caregiving literature. Typically African American caregivers are compared to Caucasian caregivers utilizing various theoretical perspectives. Few utilize the Pearlin model relative to African American caregivers when typical diagnosis of the care recipient has been Alzheimers or Dementia (AD). For example, research demonstrates in comparison to Caucasian (AD) caregivers, that African American (AD) caregivers typically receive a network of support from a friend, neighbor, church community (Cox, 1993; Hinrichsen & Ramirez, 1992).

Cox & Monk (1996) conducted quantitative research on 76 African American and 86 Hispanic Alzheimer caregivers to determine strain experienced using the Pearlin model. The mediator variable of social support was significant for both groups, especially when caregivers were able to receive support from relatives and friends frequently, which was related to the outcome variable of personal strain, but not role strain. Speaking infrequently with informal supports was associated with personal strain and role strain for both groups of caregivers. African American showed significantly lower personal strain when they were able to speak to an informal support by phone. Overall, Hispanic caregivers reported significantly higher personal strain and role strain than African American caregivers in this sample (Cox & Monk, 1996).

In studies with African American caregivers, research has documented social support for African American caregivers' effects their psychological and physical well-being, especially when support is received from systems of social support (Dilworth-Anderson et al., 2002; Williams & Dilworth-Anderson, 2002). Williams and Dilworth-Anderson (2002) conducted a study with 187 African American caregivers of older adults. They examined the connection

between informal, church, and formal supports for African American caregivers. All of the caregivers utilized some form of informal social support. For example, 121 (65%) of the caregivers used 1 to 2 persons to assist with the caregiving needs and 66 (35%) caregivers used 3 to 4 persons as their network of informal supports. None of the background characteristics of both the caregiver or care recipient significantly influenced the use of informal social supports, and neither did the cognitive impairment of the care recipient. However, as the number (network) of informal supports increased, caregivers had higher levels of perceived informal social supports and family cohesion (Williams & Dilworth-Anderson, 2002). In regards to church support, the background characteristic of whether or not the care recipient received Medicaid, determined the likelihood of using church support. If the care recipient had Medicaid, less church support was used. Also as the number of informal supports increased the caregiver was 1.5 times more likely to use church support (Williams & Dilworth-Anderson, 2002). Although formal support will be discussed in the next section, this study found caregivers with higher levels of education (1 to 3 years of college) utilized the more formal support than those with less. However, caregivers were more likely to use informal supports if the care recipient had higher levels of IADL needs (Williams & Dilworth-Anderson, 2002).

*Formal social support.* The purpose of this area in the Pearlin stress model is to adequately examine community-based formal programs available to care recipients and/or caregivers. Pearlin and colleagues (1990) felt this component was vital to the stress process of caregivers because "one can escape some of the vicissitudes and hardships of caregiving one might otherwise experience"(p.586).

In the United States there are several formal support programs for caregivers of older adults. Caregiver support programs are administered on many levels and from various resources.

Private organizations that may be medically related, psychosocial, religiously affiliated, community-based, and university sponsored are available to provide formal support services to family caregivers in person, by phone, or even via the internet. Typical services may be psychoeducational support groups, internet chats, newsletters, information and referral, and respite care, just to name a few. Funding sources for these type programs vary, as well as length of time, scope of service, and availability to serve all groups.

The federal government has enacted laws for elderly through the Older Americans Act since 1965. The Administration on Aging authorizes the grant funding for the programs and services. They have several programs for older adults to participate in that include but are not limited to social, nutritional, and long-term planning. Older adults participating in these programs ultimately assist their caregivers with some support. However, until recently there were no programs from the federal government to assist in supporting caregivers. The purpose of this section is to discuss the caregiver support programs implemented by the federal government and service utilization by African Americans.

The Family Medical Leave Act of 1993 is a legislative response to the crisis of caregiving in the United States. This law enables businesses with more than 50 employees the ability to grant up to 12 weeks of unpaid leave when the employee or an immediate family member is in need of care due to serious illness, adoption of a child, or child birth. An employee is guaranteed to be reinstated to their job and health insurance benefits upon return. One of the disadvantages of this program is that 60% of Americans are employed by small businesses with less than 50 employees. The leave is unpaid, whereby only individuals who can financially afford the loss of income are utilizing the program. The drawback for ethnic minority

caregivers, especially African Americans, is that the act does not apply to extended family members (Hudson & Gonyea, 2000).

The Older American's Act implemented a component funded through the Administration of Aging that required states to partner with local Area Agencies on Aging and other service providers to provide services to all family caregivers. NFCA provides a diversity of support services that includes five categories: information and assistance, individual counseling, support groups and training, respite, and supplemental services. Services are available to caregivers of older adults as well as other caregivers (i.e., older kin caregivers of children, etc.). Another component to the NFCS is the Native American Caregiver Support Program, which provides the same services. The purpose is to serve family caregivers of American Indian, Alaska Native, and Native Hawaiian descent (Administration on Aging, 2004). The Older American's Act main mission has been to service impoverished older adults especially racial/ethnic groups. According to their most recent statistics from 1997, 21.8 % of the service recipients were from racial/ethnic minority groups. Nearly half of those clients were African American (49.1%). The National Caregiver Support Program does not have any service usage statistics available at this time.

A recent REACH study compared African American caregivers to Caucasians and found no difference in formal service use between both groups (Williams, 2005). This is consistent with the findings of Ho, Weizman, Cui, & Levkoff (2000) who conducted an exploratory qualitative study to examine stress and service use among four ethnic groups (African American, Chinese American, Latino, and Caucasian) dementia caregivers. Pearlin's stress model was employed to determine the relationship between stress and service use. The outcome variable service utilization was divided into "met" and "unmet" needs in order introduce a new variable of stress. Caregiver themes emerged regarding the domains of the stress process. Background

variables of the 117 dementia caregivers were in two categories of ethnicity/other demographic variables and non caregiving stressors. Ethnicity did not predict service use when African Americans, Chinese Americans and Latinos were compared to the reference group of Euro American caregivers. However, ethnicity was a predictor for unmet service needs. Latino and Chinese caregivers showed a greater degree of unmet service needs when compared to Euro Americans, while African Americans and the reference group were similar in reporting unmet needs. The non caregiving stressors scale (background variables), as well as the primary stressors (care recipients' status), both proved to be powerful predictors of service utilization across all ethnic groups. Surprisingly, the secondary stressor of depression did not significantly predict service utilization in this study for any ethnic groups (Ho et al., 2000).

In a study by Cox and Monk (1996), African American and Hispanic caregivers tended to underutilize formal services, but preferred informal services, which is consistent to cultural dynamics. A review of three additional empirical studies indicates that African American caregivers reported a greater need for formal services than Caucasians (Cox, 1993, 1999b; Hinrichsen & Ramirez, 1992). Further, Levkoff et al., (1999) conducted qualitative research with ethnic minority caregivers and found that African American caregivers who had used formal services indicated they were not satisfied because the services were not culturally relevant. In addition to caregivers feeling discrimination from agencies, other discouraging factors included lack of insurance, transportation, religious reasons, employment, and other commitments (Dilworth-Anderson et al., 1999b).

Families vary in their knowledge, availability, and comfort level of utilizing caregiver formal caregiving programs. Due to recommendations of the Pearlin model to assess caregivers'

formal program availability, and its relationship to health outcomes, this study asked specific questions to African American caregivers regarding their formal and informal social supports.

### *Health Outcomes*

The manifestations of stress are considered health outcomes in the stress process model. Empirical studies of the stress process have documented the physical and mental health consequences of life events and stressors (Pearlin et al., 1990). Depression, anxiety, irascibility, cognitive disturbance, physical health, and yielding of role are examples of stressful outcomes throughout caregiving according to the stress process model (Pearlin et al., 1990). The aim of this study was to explore the background characteristics, stressors, and mediators as guided by the Pearlin stress process, which were used to predict emotional and physical health outcomes in African American caregivers without comparison to Caucasian caregivers.

*Emotional health.* Only five studies investigating African American caregiver emotional distress, caregiver burden, and/or depression as compared to Caucasians (Cox, 1995; Drentea & Goldner, 2006; Farran et al., 1997; Fredman et al., 1995; Miller et al., 1995), and Hispanics (Cox & Monk, 1996) were guided by stress proliferation model of Pearlin. The other studies in the caregiving literature used empirical generalizations (Haley et al., 1995; Hinrichsen & Ramirez, 1992; White et al., 2000), structural model of caregiving dynamics (Lawton et al., 1992) Lazarus and Folkman stress theory (Haley et al., 1996), social exchange theory (Martin, 2000) and conceptual model of caregiving (Young & Kahana, 1995) to compare African American caregivers to Caucasian caregivers. Few caregiving studies explored the predictors of emotional stress with a sample of African American caregivers independently without any comparisons to any other groups. Dilworth and associates (1994) and (1999a)

utilized a contextual approach to the Pearlin model. They explored the psychological effects of caregiving with African American caregivers.

Caregiving research guided by the Pearlin model, as well as other conceptual frameworks, provide contradictory results in predicting emotional or psychological distress among African American caregivers compared to Caucasian caregivers. In addition, limited research has been conducted using the Pearlin model for African American caregivers in predicting emotional distress. A seminal work guided by Pearlin stress process model found African American caregivers when compared to Caucasian caregivers reported lower levels of caregiver burden in multivariate analyses, but in univariate analyses African American and Caucasian caregiver burden were equal (Fredman et al., 1995). These racial differences were found in a sample of 1,062 Caucasian and 159 African American (non disease specific) caregivers from the National Long-term Care survey. In this study, caregiver burden was measured with a 6 item personal burden scale to determine the caregivers' emotional distress. The multivariate analyses only found caregivers health, assistance with ADL's increased hours of care, and cognitive function of the care recipient to be significant and account for 33% of the variance. Overall, Caucasian caregivers reported more caregiver burden in this study. Likewise, Miller et al. (1995) researched 77 African American and 138 Caucasian caregivers of spouses with dementia to determine if race, control, and mastery significantly predicted caregiver distress. Caregivers' level of depression was measured with the CES-D scale. African American caregivers were less depressed in this study as compared to Caucasian caregivers. Caregivers' sense of control was also negatively related to depression for both Caucasian and African American caregivers.

Cox and Monk (1996) compared African Americans to Hispanics and found low levels of stress experienced by African American Alzheimer relative caregivers. Personal and role strain predictors were examined in 76 African American and 86 Hispanic relative caregivers. This study used the Zarit Burden Interview as a measure of caregiver strain (outcome measure) and the items considered were personal or role strain. Similar, to the other studies reviewed, African American caregivers reported less stress than did Hispanic caregivers.

Caregiver distress among African American (n=77) and Caucasian (n=138) spousal dementia caregivers was also measured the following year by Farran et al. (1997). These researchers sought to determine the relationship of caregiver distress using race and provisional meaning through caregiving. Outcome measures in this study included caregiving distress, role strain, and provisional meaning. Caregiving distress was measured with the CES-D scale and defined as depression. Provisional meaning was measured with a subscale of the finding meaning through caregiving scale. Provisional meaning was defined as "positive psychological resource" (Farran et. al., 1997). More African American caregivers favored their caregiving situation as positive. More so than the Caucasian caregivers, and they reported less psychological distress. Caregiver depression was significantly predicted if the caregiver was Caucasian, had poor physical health, distressed with behavior problems of the care recipient, had higher levels of task distress, and high amounts of total activities of daily living (TADLS). Caregiver role strain was significant according to the variables above, except for caregiver physical health. Overall, in comparison to Caucasian caregivers, African American caregivers were significantly less likely to report depression and role strain.

Contradictory to the above reviewed studies that used the Pearlin model as a conceptual framework, as well as other studies in caregiving literature, a recent study found African

American caregivers to experience higher depressive symptomatology. Drentea and Goldner (2006) used a sample of 275 (11%) African American and 2,218 (89%) Caucasian caregivers from the 1992-1994 National Survey of Family and Households. These were caregivers who provided informal care outside of their home. Medically, the diagnosis of the care recipients represented numerous medical conditions. The top five medical conditions included general old age (11.8%), cancer (11.2%), serious heart trouble (6.6%), serious neurological disorders (5.4%) and stroke (5.1%). Depression of the caregiver was measured with the CES-D scale, and an ordinary least square regression (OLS) analysis with progression adjustment was used to analyze the prediction. The regression analysis showed various predictions for depression symptomatology factors of African American caregivers. High depression scores were found for sociodemographic variables (African American, female, age, per capita income, education and employed), parental help, caring for a parent versus caring for other relatives, number of hours of care, number of weeks of care, and caregiver physical impairments. Marital status and religious beliefs predicted low levels of depression scores. Family structure did not prove to be a significant predictor for depression in African American caregivers. For example, the number of children a caregiver was caring for at home, and the number of siblings the caregiver had, did not have an effect on African American caregivers' depressive symptomatology.

Despite the fact that African-American caregivers and care recipients have limited financial resources, poorer health, and more stressors than Caucasian caregivers, and given the mixed results in caregiver research utilizing the Pearlin model, it was imperative for this study to further explore the mental health outcome of African American caregivers independent of any other racial/ethnic groups. In addition, the majority of the above studies were conducted on Alzheimer/dementia caregivers, other studies did not specify a disease. This study aims to

contribute to the literature by identifying which stressors predict emotional health in caregivers providing care to African American older adults with cardiovascular disease and diabetes.

*Physical health.* Physical health is a major concern for African American caregivers and care recipients. The Report of the Secretary's Task Force on Black and Minority Health (1986) indicated nearly 60,000 "excess deaths" are suffered annually by people of color in comparison to Caucasians. Over the course of a lifetime, African American caregivers and care recipients tend to have known healthcare disparities. "Further this disparity has widened in some areas. Conditions of powerlessness and poverty have continued to impact the lives and health status of American Blacks. These conditions have created widespread social, economic, physical, and spiritual disease in black families and communities, thereby resulting in the highest indices of morbidity and mortality in this group, and the lowest access to primary care, with little or no access to preventative programs" (Logan & Freeman, 2000 p. 8). Caregiving demands have been shown to have negative effects on the physical health and wellbeing of the caregiver (Haley et al., 1987; Schulz, Visintainer, & Williamson, 1990). In a study with dementia caregivers, Schulz et al. (1995) found the stressful demands of caregiving have a direct impact on the caregivers' physical health. Researchers have also discovered caregiving can increase caregivers' blood pressure (hypertension) (King, Oka, & Young, 1994), heart rate reactivity (Knight & McCallum, 1998), immune functioning (Pariante, Carpinello, Oru, Sitzia, Piras, & Farci, 1997), and mortality among older caregivers (Schulz & Beach, 1999). Since African Americans overall are in poor health, and tend to bring more health problems to the caregiving situation, this study proposes caregiving will offer valuable insight reflect on the health status and physical health of caregivers. Limited research has been completed on the health status of African American caregivers and care recipients and its prediction of health outcomes,

particularly utilizing the Pearlin stress process model. Fredman et al. (1995) found African American caregivers tended to rate health poorer than Caucasian caregivers. Physical health was measured as a self-report-item. Caregivers were asked how they rate their health as excellent, good, fair and/or poor. The study also concluded that among African American and Caucasian caregivers, care recipients with increased health conditions significantly predicted high levels of caregiver burden.

A recent longitudinal study by Dilworth-Anderson et al., (2004) utilized the Pearlin stress process model to assess if culture affects the physical health of 107 African American caregivers who provide care to dependant older adults (non disease specific). Physical health outcome was divided into two groups (psychosocial health and physical functioning). Psychosocial health was measured using the 5 item subscale of the MOS-36 (McHorney, Ware, Lu, & Sherbourne, 1994). One question included caregivers responding to a general health question. They rated their health either "excellent", "very good", "good", "fair", or "poor". The other four questions required caregivers to rate their health in comparison to others, their own health expectations, and the condition of their health. Physical functioning was measured with 10 items on the MOS-36 (McHorney et al., 1994). Caregivers were able to assess the effect their health has on their ability to perform physical activities.

This research was conducted over three waves with 9 month intervals. The results of the study revealed that when controlling for baseline physical health, a high number of morbidities significantly predicted caregivers' physical health by the third year of care. Also fewer health conditions experienced by caregivers at wave 1, predicted higher levels of physical functioning at wave 3 than those caregivers who reported several health conditions (Dilworth-Anderson et al., 2004). The physical functioning of care recipient and caregivers with higher education

(background variables) at wave 1 was associated with an increase in caregivers' physical functioning (outcome variable) at wave 3 (Dilworth-Anderson et al., 2004). When the resource mediators of caregiving mastery and cultural justifications for caregiving are added to the model, they did not significantly predict physical functioning at wave 3, while controlling for baseline physical functioning and number of caregiver morbidities. In addition, cultural justifications of care only significantly predicted psychosocial health and not physical health. According to Dilworth and colleagues (2004), "the findings suggest that specific attributes about caregivers, specifically their prior physical functioning and level of education, are more powerful predictors of their future physical functioning than stressors and supportive resources that typically effect health outcomes for caregiver" (p. S143) Findings show a combination of caregiver background, stressors, and resources are important predictors of African-American physical health outcomes.

Additional research is needed with African American caregivers in order to determine which specific stressors impact African American caregivers' physical health. The previous study was a secondary data analysis. This study was limited because " it showed few of the caregiving stressors typically used in caregiving research .... further studies are needed to uncover the caregiving stressors related to caregiving ..." (Dilworth-Anderson et al., 2004, p. S144). The aim of this study was explored the typical stressors experienced by caregivers within a primary sample of African American caregivers. The care recipients were diagnosed with cardiovascular disease and/or diabetes mellitus. The purpose of the study was to determine which specific and/or combination of stressors and mediators predict emotional and physical health outcomes.

## Summary

Chapter 2 presented an overview of the literature related to the chronic illnesses prevalent within the African American community, as well as a review of the conceptual framework proposed for this study. Cardiovascular disease and diabetes mellitus are particularly prevalent with African American older adults. These diseases were discussed along with the specific functional limitations and caregiving concerns. The chapter concluded with a description of the stress process model and review of the specific variables (background characteristics, stressors, mediators and outcomes) used in this study. The following chapter will describe the research methodology to include the research questions and hypotheses, research design, sample, data collection, measures and statistical procedures.

## CHAPTER 3

### RESEARCH METHODOLOGY

Chapter 3 begins by describing the research design, which includes the research questions and hypotheses, sampling design, data collection procedures, and ethical considerations. Then the chapter will describe the variables used, explore how the data will be presented and conclude with the proposed data analysis plan.

#### Research Design

The design of this study is correlational with non probability sampling. A cross-sectional design was used to assess the impact that caregivers' background characteristics, caregivers' primary and secondary stressors, and mediating factors (coping and social support) have on the health outcomes (mental and physical health) experienced by caregivers. This research design was chosen because it allowed the researcher to survey caregivers' perceptions as they occur at one point in time while they are currently providing care. Additionally, this type of design allows the researcher to test and refine the conceptual framework. The researcher is interested in generating new insight about the stress process experienced by African American caregivers of chronically ill older adults. Due to limited research conducted in this area the cross-sectional design is appropriate. Rubin and Babbie (2005) further indicate this type of design allows the researcher the ability to record and report the perceptions, situations, and events. In addition, this researcher and others would be able to develop additional questions to be studied in future investigations regarding this population.

The units of analyses for this study are African American caregivers who provide care to African American care recipients with a chronic illness. For the purposes of this study, an African American caregiver is defined as any male or female who self-reports being born of African descent, over the age of 18, who provides assistance to an African American care recipient. The African American caregiver must report caring for someone who reports being born of African descent, over the age of 55, who has been diagnosed with cardiovascular disease (includes all heart diseases, hypertension, and stroke), and/or diabetes.

Due to the numerous variables in the full Pearlin model discussed in Chapter 2 and the limited sample size in this study (n=152), a modified version of the model was used in this study to accommodate research efficacy (Figure 3.1).

According to Concato, Feinstein and Holford (1993), "When numerous variables are included in an attempt to 'control' or 'adjust' the data, accuracy of results can be threatened by overfitting or by other mechanisms. The number of variables selected for analysis should therefore be parsimonious, based on clinical sensibility and suitable data quality" (p.207). Therefore, these authors recommend 10 subjects per variable in order to eliminate risk in multivariate models (Concato et al., 1993). In this study, the independent variables are caregivers' background and context (socioeconomic, caregiving history, and caregiving justifications), primary stressors (cognitive status, behavior problems, ADLS, IADLS, role overload, loss of relationship), and secondary stressors (family and work conflict). Additionally, coping (religious/spiritual) and social support (informal and formal) served as mediating variables to the dependant health outcome variables (physical and mental health).

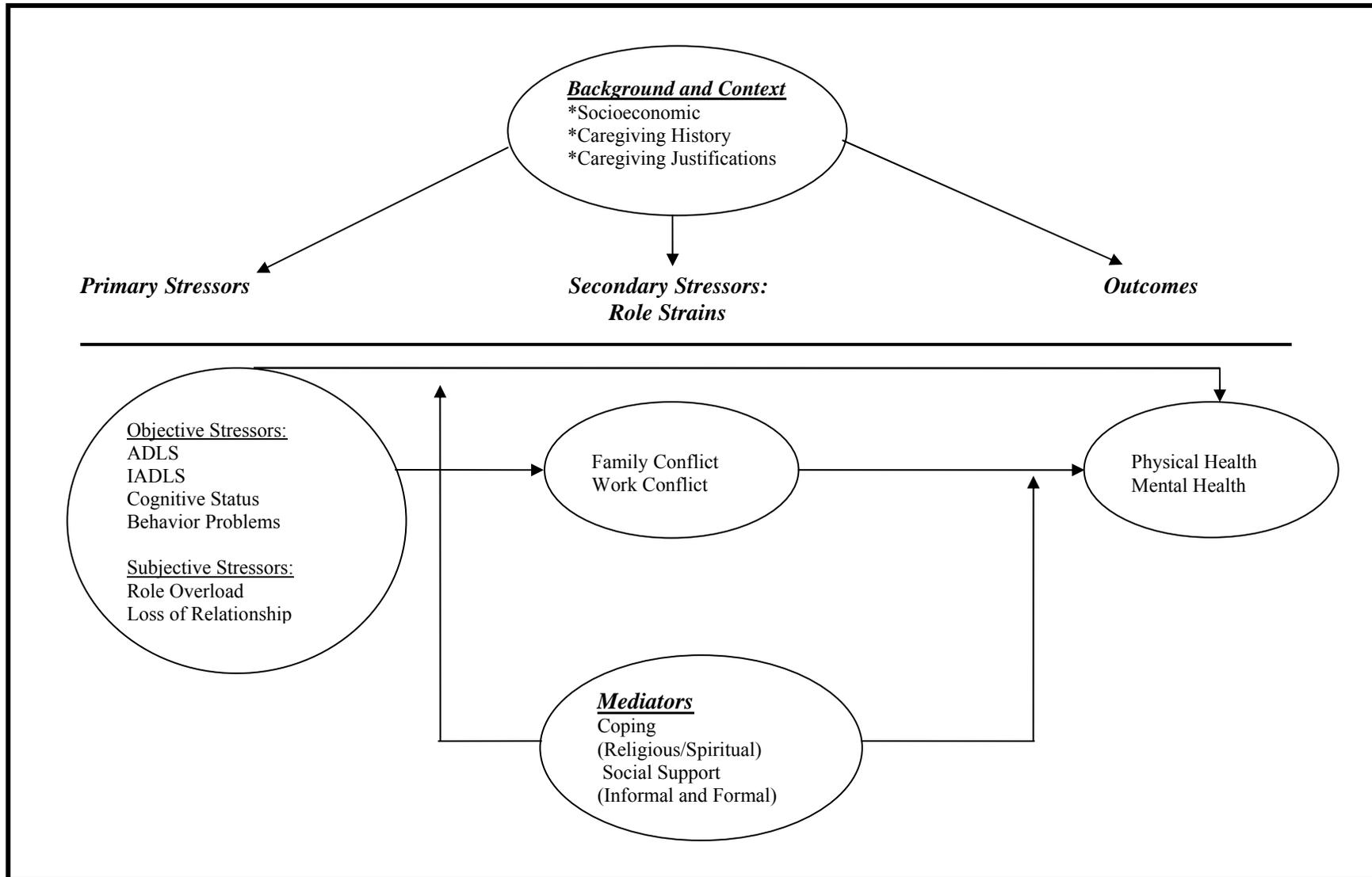


Figure 3.1. Proposed conceptual framework

Sources: Pearlin, et al., (1990) Aneshensel et. al., (1995)

### *Research Questions and Hypotheses*

Based on an adapted version of the Pearlin stress and coping model, and the previously mentioned empirical studies, the following research questions and hypotheses have been developed for this study:

*Question 1:* Which caregivers' background characteristics (socio-economic, caregiving history, caregiving justifications) might contribute to caregivers' level of mental and/or physical health?

*Question 2:* What is the strength of the relationship or association between the, primary stressors, secondary stressors, mediators and the health outcomes?

*Question 3:* Does religious/spiritual coping, informal and formal social supports mediate the relationship between primary stressors and secondary stressors?

*Hypothesis 3a:* Religious/spiritual coping mediates the association between primary and secondary stressors.

*Hypothesis 3b:* Informal social support mediates the association between primary and secondary stressors.

*Hypothesis 3c:* Formal social support mediates the association between primary and secondary stressors.

*Question 4:* Does religious/spiritual coping, informal and formal social supports mediate the relationship between secondary stressors and health outcomes (physical and mental health)?

*Hypothesis 4a:* Religious/spiritual coping mediates the association between secondary stressors and physical health outcome.

*Hypothesis 4b:* Religious/spiritual coping mediates the association between secondary stressors and mental health outcome.

*Hypothesis 4c:* Informal social supports mediate the association between secondary stressors and physical health outcomes.

*Hypothesis 4d:* Informal social supports mediate the association between secondary stressors and mental health outcomes.

*Hypothesis 4e:* Formal social supports mediate the association between secondary stressors and physical health outcomes.

*Hypothesis 4f:* Formal social supports mediate the association between secondary stressors and mental health outcomes.

*Question 5:* Does religious/spiritual coping, informal and formal social supports mediate the relationship between primary stressors and health outcomes (physical and mental)?

*Hypothesis 5a:* Religious/spiritual coping mediates the association between primary stressors and physical health outcome.

*Hypothesis 5b:* Religious/spiritual coping mediates the association between primary stressors and mental health outcome.

*Hypothesis 5c:* Informal social supports mediate the association between primary stressors and physical health outcomes.

*Hypothesis 5d:* Informal social supports mediate the association between primary stressors and mental health outcomes.

*Hypothesis 5e:* Formal social supports mediate the association between primary stressors and physical health outcomes.

*Hypothesis 5f:* Formal social supports mediate the association between primary stressors and mental health outcomes.

*Question 6:* Does family conflict and work conflict mediate the relationship between primary stressors and health outcomes (physical and mental)?

*Hypothesis 6a:* Family conflict mediates the association between primary stressors and physical health outcome.

*Hypothesis 6b:* Family conflict mediates the association between primary stressors and mental health outcome.

*Hypothesis 6c:* Work conflict mediates the association between primary stressors and physical health outcomes.

*Hypothesis 6d:* Work conflict mediates the association between primary stressors and mental health outcomes.

In the hypotheses testing phase of the study, the variables were analyzed to explore if any (or all) act as predictors or mediators of perceived emotional and/or physical distress in African American caregivers over the age of 18.

#### *Sampling Method and Procedure*

African American caregivers were defined as informal family caregivers (unpaid), over the age of 18, who provide care to a family member, friend, relative, and/or significant other. The person they were caring for had to be African American, over the age of 55, and diagnosed with cardiovascular disease (includes all diseases of the heart, hypertension and stroke), and/or diabetes. This study considered all diseases of the heart to represent cardiovascular diseases. The U.S. Department of Health and Human Services (1990) report considered cardiovascular disease to include all diseases of the heart and blood vessels. More specifically, this included

specific diseases of the heart, hypertension, cerebrovascular disease (includes stroke), arteriosclerosis, and other diseases of the arteries. The other chronic illness category was diabetes. Although cancer is the second leading cause of death among African American older adults, this study focused on all diseases of the heart and diabetes because they are considered chronic diseases that shorten the lifespan. The cancers that are primarily diagnosed in African American older adults tend to be fatal chronic illnesses (Biegel et al., 1991). Therefore, caregivers must be providing care to care recipients with at least cardiovascular disease and/or diabetes.

Jackson and Gibson (1985) suggest that age 55 is a more appropriate old age indicator for African American adults because of socioeconomic deficits, chronic illnesses, and early retirement. Due to the exploratory nature of this study, and the assumption that African Americans may be reluctant to participate in research due to cultural and systematic reasons (Giuliano et al., 2000), as well as a mistrust towards researchers and research studies (Connell, Shaw, Holmes, & Foster, 2001), a snowball technique and purposive sampling design of caregivers of older adults were utilized.

In this study, in order to determine the sampling size effect, a statistical power analysis was conducted. This analysis included (1) obtaining statistical significance, and (2) power and effect size between variables was measured. According to Rubie and Babbie (2005), significance testing indicates the probability of committing a Type I error, which is rejecting the null hypothesis when it is true. Sample size was determined by the researcher choosing a significance level of .05, indicating there is a .05 chance of the null hypothesis being true. This level of significance ( $p < .05$ ) is not only common in social work research, but it has also been shown to be dependable in reducing the likelihood of Type I error (Rubin & Babbie, 2005).

Next, a statistical power analysis was conducted to avoid a Type II error, which is failing to reject a false hypothesis (Rubin & Babbie, 2005). Cohen's (1988) power tables were used to estimate the risk of a Type II error. According to Cohen (1988), in order for the probability to commit a Type I error remains equal to the likelihood of committing a Type II error, then the statistical power would have to be .95. This level of power would require a medium effect size ( $r=.30$ ), and the minimum sample size required for would be 140 participants (Cohen, 1988). This researcher utilized a sample size of 152 African American caregivers for this study to meet this requirement, which exceeds the minimum requirement for sample size as recommended by Cohen (1988).

#### *Recruitment and Data Collection Procedures*

Recruiting African Americans in research has historically been challenging. In this study, recruitment strategies were aided by previous and current literature in recruiting older adults and their caregivers of color. Areas of particular concern for the researcher were obtaining and maintaining an adequate sample of caregivers, financial issues regarding recruitment, and obtaining trust within several communities and organizations with a higher number of African American caregivers.

Several suggestions were made regarding recruitment strategies that were employed for this study. Areal & Gallagher-Thompson (1996) suggested building partnerships with African American communities, providing transportation, educating participants about the research to increase awareness and interest in the study, and being flexible and willing to devote time and effort in recruitment efforts. In order to overcome the recruitment barriers, the researcher established partnerships with organizations where African American caregivers may have high memberships and/or employment. The researcher advertised via flier, listserves, and/or word of

mouth via personal acquaintances and professional colleagues and others who work with or knew African American caregivers to recruit. Although this may not have been a "traditional" method of recruitment, it may have alleviated any of the caregivers concerns about completing the survey since they received the survey, from someone that they knew.

Several studies recommended a multi-method or mixed mode approach for minority elderly (Areal, Alvidrez, Nery, Estes, & Linkins, 2003) African American caregivers (Chadiha et al., 2004; Dilworth-Anderson & Williams, 2004) in order to obtain a larger sample size based on the participants' preference. In an effort to increase response rates, this researcher utilized a multi-method approach to include face-to-face interviews, independent completion of the survey via pen and paper, and the option of a survey monkey (internet) for professional organization listserves and caregivers who preferred to complete the survey at work or home via the internet.

Prior to beginning data collection, the researcher obtained approval through the Institutional Review Board for research with human subjects. The purpose of the study was explained during the recruitment phase and prior to receiving the survey. A consent form was presented and reviewed, and an actual signature and/or electronic signature was obtained from each participant prior to beginning the survey. Each participant was given a prepared, pre-numbered packet including the research instruments, a letter of explanation, and a consent form. The survey took approximately 45 minutes to complete.

## Research Measurements

### *Independent Variables*

#### *Background Characteristics*

*Social and economic characteristics.* Caregiver socio-economic variables include age, employment status, employment hours per week, health conditions, and living arrangements.

*Caregiving history.* Caregiver history was measured by several items. These items provide the following information about the caregiver: number of care recipients/roles, length of time caregiving, and duration of caregiving activities every week.

*Caregiving justifications.* The relationship of the caregiver to care recipient was used as one item in this context. A cultural justification for the caregiving instrument was used as the other context. This instrument was developed by Dilworth-Anderson (Dilworth-Anderson et al., 2005; Dilworth-Anderson et al., 2004). The 10-item scale includes items that measure the caregivers' cultural values and beliefs (e.g. reciprocity, sense of duty and God's will). Each item is rated on a four point scale (4=strongly agree, 3= somewhat agree, 2=somewhat disagree, and 1=strongly disagree). Scores range from 10 to 40, with higher scores indicating strong cultural reasons for providing care based on norms, beliefs, and expectations. A previous study involving African American caregivers reported a Cronbach alpha of .84 (Dilworth-Anderson et al., 2004). The Cronbach alpha for this study was .85.

#### *Primary Stressors*

*Objective - functional disabilities.* Functional disabilities were measured by activities of daily living (ADLS) and instrumental activities of daily living (IADLS). This study employed the Katz Index of ADLS (Katz et al., 1963), while the IADL scale developed by Lawton and Brody (1969) was utilized as well. The ADL index was originally designed to assess five activities by trained observers: eating, bathing, dressing, toileting, transferring and continence (Katz, Down, Cash, & Grotz, 1970; Spector, 1990). The responses range from 0 = “totally dependent” to 2 = “independent”. Higher scores indicate that the care recipient needs less assistance with ADLS, hence more independent, while lower scores indicate the care recipient needs more assistance with ADLS and they are more dependent on the caregiver. The scores on

ADLS scale range from 0 - 10. Previous studies have demonstrated coefficients of reliability for this scale to be from .94 to .97 (Person, 2000). The reliability for this study was .91.

The Lawton IADL included nine items that assessed watching television, using the telephone, shopping (groceries/clothing), walking (outside), preparing own meals, doing own housework, taking own medication, and handling own money. The caregivers will rate the scores: 2= “independent”, 1 = “needs some assistance to complete task”, and 0 = “totally dependent.” Similar to the ADLS scale, the IADLS higher scores indicate higher levels of independence, and lower scores signify lower levels of independence. The scores range from 0-18, and previous studies have reported over .90 alpha score for the IADLs (Person, 2000). The Cronbach alpha for this sample was .89.

*Objective-cognitive status and behavioral problems.* Cognitive status and problematic behaviors will be operationalized by the Revised Memory and Behavioral Problems Checklist (RMBPC) (Teri, Traux, Logsdon, Uomoto, Zarit, & Vitaliano, 1992). The RMBPC was originally designed to be completed by dementia family caregivers to assess the care demands of the care recipient, as well as the caregiver's emotional reaction to those demands (Teri et al., 1992). This instrument includes 24 items about memory (7 items) and problematic behaviors (17 items), such as depression and disruptive behaviors. The items were rated on a five-point scale (1 = “never occurred”, 2 = “occurred infrequently and not in the last week”, 3 = “occurred 1 or 2 times in the past week”, 4 = “occurred 3 to 6 times in the past week”, 5 = “occurs daily or more often”). Total scores for the memory impairments are from 7 to 35, with higher scores indicating more severe cognitive impairments, and lower scores indicating care recipients with fewer memory problems. Behavior problem scores range from 17 to 85 with higher scores suggesting more behavior problems, and lower scores suggesting fewer behavior problems. Previous

studies have shown the scale to have high internal consistency for both areas care demands of care recipient and caregivers reaction to those demands ( $\alpha=0.75$ ;  $\alpha=0.87$  respectively) (Teri et al., 1992). The Cronbach alpha for this study was .93 for both memory and behavior problems.

*Subjective-role overload/burnout.* This measure assesses the caregivers care demands and feelings of exhaustion and fatigue. The 4-question scale responses ranges from (1) completely agree to (4) not at all. Scores range from 4 to 16 with higher scores indicating limited role overload and lower scores indicating high levels of role overload perceived by the caregiver. This scale was developed by Pearlin et al. (1990) for use with Alzheimer caregivers. The instrument yielded an alpha of .80. However, the Cronbach alpha for this study was .85.

*Subjective-loss of relationship.* Caregivers' feelings of loss of a previous relationship with the care recipient were measured by the five question relational deprivation scale developed by Pearlin et al. (1990). This scale asked caregivers how they felt about two categories (deprivation of intimate exchange, and deprivation of goals and activities). The response categories are (1) completely, (2) quite a bit, (3) somewhat, and (4) not at all. Scores range from 5 to 20. Low scores indicate care recipients elevated feelings of a loss of a relationship with care recipient. Higher scores signify limited feelings of a loss of relationship. The instrument yielded alpha of .77 (deprivation of intimate exchange) and .67 (deprivation of goals and activities) in the sample of dementia caregivers (Pearlin et al., 1990). The overall Cronbach alpha for this study was .91.

#### *Secondary Stressors: Role Strains*

*Work conflict.* The five item work-caregiving conflict scale was also developed by Pearlin et al., (1990) for use with Alzheimer caregivers. The alpha was .75. This scale measured the degree of job-caregiving conflict the caregiver experienced due to care responsibilities. Item

response categories were (1) strongly agree, (2) agree, (3) disagree, and (4) strongly disagree with a range from 5 to 20. Lower scores define high amounts of work conflict for the caregiver and higher scores define less work conflict.

*Family conflict.* The 12-item family conflict-caregiving scale was developed to examine the amount of interpersonal tension experienced by caregivers in relation to their families. The scale is divided into three sections: issues of seriousness/safety of Alzheimer disease patients, attitudes and actions toward patient and attitudes and actions toward caregiver. Response categories ranges from (1) often disagree, (2) some disagreement, (3) little disagreement, and (4) no disagreement. The alpha level for this scale yielded .86 with Alzheimer caregivers (Pearlin et al., 1990). For this study the scores range from 12 to 48 with lower scores indicating more family conflict, and higher scores indicating less family conflict.

#### *Mediating Variables*

##### *Social Support*

*Informal social support.* Social support networks were measured by the Lubben Social Network Size (LSNS) (Lubben, 1988). The LSNS includes ten items about the nature of the relationship with relatives and friends, such as living arrangement, reciprocal support, social contact with friends, number of friends the respondent feels close to, number of friends seen monthly, frequency of social contact with a relative, number of relatives the respondent feels close to, number of relatives seen monthly, and existence of a confidant relationship (Levin, 2000; Lubben, 1988). A total score for the LSNS was conducted by adding each of the eleven equally weighted items ranging from 0 to 5. Scores range from 0 to 55, with lower scores indicating low amounts of informal social support used by the caregiver, and higher scores indicating high amounts of informal social support. According to Lubben (1988), fewer than 30

out of 50 indicate that the respondent may be at risk of social isolation. Regarding the reliability of this scale, Levin (2000) confirmed that the scale had good internal consistency. Also previous research with ethnic/racial diverse caregivers reported a Cronbach alpha of .70 (Radina & Barber, 2004). The Cronbach alpha for this study with African American caregivers was .68.

*Formal social support.* A scale devised by Ho, Weizman, Cui, & Levkoff (2000) was used to measure caregiver current formal program utilization. This 11 question scale asked the caregiver if they used any of the following services during the past six months for the care recipient: nursing home, hospital (inpatient and outpatient) paid home-care, adult day care, respite care, as well as family and individual counseling/consultation. Scores range from 1 to 99, with higher scores indicating elevated use of formal social support, and lower scores indicating limited use of formal social support.

### *Coping*

The Brief Religious/Spiritual Coping (RCOPE) scale was used to measure coping in African American caregivers. Researchers have found this 11-item scale to be a good indicator for measuring potential positive and negative effects of religious/spiritual coping (Pergament & Koenig, 1998). Items can be measured in terms of how an individual manages a particular stressor (Pergament & Koenig, 1998). The scale is divided into three subscales positive religious/spiritual coping subscale (factor loadings  $>.60$ ), negative religious/spiritual coping subscale (factor loadings  $>.53$ ), and overall religious/spiritual coping. (Pergament & Koenig, 1998). On the positive and negative subscales (3 questions each) the response categories are (1) not at all, (2) somewhat, (3) quite a bit, and (4) a great deal. Responses range from (1) not involved at all to (4) very involved. The overall scoring range was from 11 to 44, with higher scores indicating high levels of religious/spiritual coping, and lower scores indicating low levels

of religious/spiritual coping. The Cronbach alpha for this study of African American caregivers was .75.

### *Dependant Variables*

#### *Mental and Physical Health Outcomes*

Emotional and physical health outcomes experienced by caregivers are measured by utilizing the Medical Outcomes Study 36 Item Short Form Health Survey (MOS SF-36). This scale was developed as a multipurpose scale to assess general perceived health (Ware & Sherbourne, 1992). The authors report eight health concepts in this scale, and they are as follows: (1) physical functioning, (2) role limitations due to physical problems, (3) social functioning, (4) bodily pain, (5) general mental health, (6) role limitations due to emotional problems, (7) vitality, and (8) general health perceptions (Ware & Sherbourne, 1992).

The scale measures both physical and mental health dimensions. Factor Analysis has been conducted on the scale to determine the physical health component to consist of items such as physical functioning, role limitations due to physical functioning, bodily pain, and general health. Higher scores on the physical health component indicate no physical limitations, disabilities or decrements in well being, as well as high energy levels and overall excellent physical health. Lower physical health scores; indicate substantial limitation in self care, physical, social and role activities, severe bodily pain, frequent tiredness and poor physical health. General mental health, role limitations due to emotional problems, social functioning, and vitality comprise the mental health component. Higher scores for mental health suggest frequent positive affect, absence of psychological distress and limitations in unusual social/role activities due to emotional problems, and overall mental health is rated as excellent. Lower mental health scores portray frequent psychological distress substantial social and role disability

due to emotional problems, and mental health in general is rated poor. Computerized scoring was administered for both the physical and mental health component. Raw scores were transformed into total scores from 0 to 100 via the computerized scoring provided by the developer QualityMetric Incorporated and funded through a University of Georgia School of Social Work Dissertation Grant.

The scale has been widely used in caregiving studies to measure emotional and physical distress experienced by caregivers. Internal consistencies of the eight scales are reported to exceed .75 and .80, with summary scores reporting higher consistencies (Ware & Sherbourne, 1992). Corcoran and Fischer (2000) indicate excellent internal reliability with alpha coefficients of .93 for physical health and .88 for mental health. This sample yielded good internal reliability with alpha coefficients of .72 for physical health and .84 from mental health.

#### Data Analysis and Statistical Procedure

In order to address the abovementioned six research questions, the analytic approach of this study involves three stages.

##### *Descriptive Analyses*

Descriptive statistics were conducted to describe the population of African American caregivers for older adults with the sample interviewed. The statistical method provided the means and frequencies for background and context characteristics of the caregivers. Caregivers' socio-economic characteristics included age, gender, marital status, education, income, employment status, number of hours employed per week, health conditions, and living arrangements. Caregiving history also included the number of care recipients/roles, length of time caregiving, and duration of weekly caregiving activities. In order to provide the demographics of the care recipients', descriptive statistics were provided regarding their age,

gender, education, income, health conditions, number of health conditions, and living arrangements.

### *Univariate Analyses*

An independent t-test for independent groups and an analysis of variance (ANOVA) for three or more independent groups were employed to answer research question 1 . The two statistical approaches presented the effects of caregivers' background characteristics (socio-economic, caregiving history, and family cultural context) variables on caregivers' level of mental and physical distress. Furthermore, when variables with three or more group divisions show statistical differences in ANOVA tests, the follow-up tests such as post hoc multiple comparisons are needed to find significant comparisons between pairs of group means. Thus, this analytic step provided specific directions of significance regarding the emotional and physical distress risk factors based on the background characteristics of caregivers'.

### *Bivariate Analyses*

Bivariate correlation analyses (*Question 2*) were used to estimate the amount of variance between each independent variable and the outcome variables (i.e., primary stressors-mental and physical health; secondary stressors-mental and physical health; mediators-mental and physical health). This section of the analyses is vital in order to determine whether or not a relationship exists between the scores on the dependant variables (emotional and physical distress) and the data on each independent variable (Huck, 2004). A Pearson Product Moment correlation coefficient was used to determine if any relationship existed between the variables, as well as the nature (strong or weak) of the relationship. This analysis is appropriate in order to demonstrate if the variables in the study are highly correlated. If the correlation is greater than .50, then multicollinearity exists. In regression, this must be assessed in order to determine if the

independent variables are networks of intercorrelations. If multicollinearity exists, then the researcher will make a decision regarding the variable(s) (Huck, 2004). Bivariate analyses were relevant in order to provide preliminary analyses for mediation analyses.

### *Mediation Analyses*

According to Fiske, Kenny & Taylor (1982) the ANOVA test does not provide an adequate test for mediational hypothesis. Therefore, this study conducted mediation analyses to determine if religious/spiritual support, informal social support, and/or formal social support individually provided mediation between primary stressors and secondary stressors (*Question 3*), between secondary stressors and health outcomes (*Question 4*), between primary stressors and health outcomes (*Question 5*). Lastly, mediation analyses were conducted to determine if family conflict and work conflict provided mediation between primary stressors and health outcomes (physical and mental health) (*Question 6*).

In order to determine mediation, a significant bivariate correlation must exist between the predictor variable and the mediation variable. If the relationships are significant, according to Baron and Kenny (1986), the test for mediation would involve three regression equations. "First, regressing the mediator on the independent variable; second regressing the dependent variable on the independent variable, and third, regressing the dependent variable on both the independent variable and on the mediator" (p.1177). Standard regression coefficients are reported for relevant variables in models tested for mediating effects.

### Summary

The purpose of this investigation was to provide an exploration of the factors that potentially contribute to the physical and emotional health of African American caregivers of older adults with chronic illness. This chapter provided a summary of the research design,

research questions, sample, data collection procedure, measurements to be used, as well as the proposed data analyses plan for the study. The next chapter will provide a description of the findings in the study, which will include the sample's demographic characteristics, univariate, bivariate and mediation analyses related to the six research questions.

## CHAPTER 4

### RESULTS

The previous chapter examined the methodology of the study, describing the research design and data collection procedures. In addition, the variables and instruments of measure were also described. This chapter presents the findings of the study which sought to answer the following research questions and hypotheses:

*Question 1:* Which caregivers' background characteristics (socio-economic, caregiving history, caregiving justifications) might contribute to caregivers' level of mental and/or physical health?

*Question 2:* What is the strength of the relationship or association between the, primary stressors, secondary stressors, mediators and the health outcomes?

*Question 3:* Does religious/spiritual coping, informal and formal social supports mediate the relationship between primary stressors and secondary stressors?

*Hypothesis 3a:* Religious/spiritual coping mediates the association between primary and secondary stressors.

*Hypothesis 3b:* Informal social support mediates the association between primary and secondary stressors.

*Hypothesis 3c:* Formal social support mediates the association between primary and secondary stressors.

*Question 4:* Does religious/spiritual coping, informal and formal social supports mediate the relationship between secondary stressors and health outcomes (physical and mental health)?

*Hypothesis 4a:* Religious/spiritual coping mediates the association between secondary stressors and physical health outcome.

*Hypothesis 4b:* Religious/spiritual coping mediates the association between secondary stressors and mental health outcome.

*Hypothesis 4c:* Informal social supports mediate the association between secondary stressors and physical health outcomes.

*Hypothesis 4d:* Informal social supports mediate the association between secondary stressors and mental health outcomes.

*Hypothesis 4e:* Formal social supports mediate the association between secondary stressors and physical health outcomes.

*Hypothesis 4f:* Formal social supports mediate the association between secondary stressors and mental health outcomes.

*Question 5:* Does religious/spiritual coping, informal and formal social supports mediate the relationship between primary stressors and health outcomes (physical and mental)?

*Hypothesis 5a:* Religious/spiritual coping mediates the association between primary stressors and physical health outcome.

*Hypothesis 5b:* Religious/spiritual coping mediates the association between primary stressors and mental health outcome.

*Hypothesis 5c:* Informal social supports mediate the association between primary stressors and physical health outcomes.

*Hypothesis 5d:* Informal social supports mediate the association between primary stressors and mental health outcomes.

*Hypothesis 5e:* Formal social supports mediate the association between primary stressors and physical health outcomes.

*Hypothesis 5f:* Formal social supports mediate the association between primary stressors and mental health outcomes.

*Question 6:* Does family conflict and work conflict mediate the relationship between primary stressors and health outcomes (physical and mental)?

*Hypothesis 6a:* Family conflict mediates the association between primary stressors and physical health outcome.

*Hypothesis 6b:* Family conflict mediates the association between primary stressors and mental health outcome.

*Hypothesis 6c:* Work conflict mediates the association between primary stressors and physical health outcomes.

*Hypothesis 6d:* Work conflict mediates the association between primary stressors and mental health outcomes.

There are five sections in chapter 4. The first section presents descriptive analysis (sample demographic characteristics) for background characteristics of the African American caregivers and their care-recipients. The second section reports the results of Univariate Analyses and answers research question 1 on effects of caregivers' background characteristics variables (socio-economic, caregiving history, and caregiving justifications), contribution on

physical and mental health outcomes (*Question 1*). The third section reports Bivariate Analyses to determine the strength of the relationship between the primary stressors (ADL, IADL, cognitive impairment, behavioral problems, role overload and loss of relationship), secondary stressors (family conflict and work conflict), mediators (religious/spiritual coping, informal and social support) and health outcomes (physical and mental health) (*Question 2*).

The fourth section will report the results of mediation analyses and answer research questions 3 thru 6. The first mediation analyses reports if the mediating variables (religious/spiritual coping, informal and formal support) provide mediation between primary stressors (ADL, IADL, cognitive impairment, behavioral problems, role overload and loss of relationship) and secondary stressors (family conflict and work conflict) (*Question 3*). The second mediation analyses reports if the mediating variables (religious/spiritual coping, informal and formal support) provide mediation between secondary stressors (family conflict and work conflict) and health outcomes (physical and mental health) (*Question 4*). The third mediation analyses reports if the mediating variables (religious/spiritual coping, informal and formal support) provide mediation between primary stressors (ADL, IADL, cognitive impairment, behavioral problems, role overload and loss of relationship) and health outcomes (physical and mental health) (*Question 5*). The fourth mediation analyses reports if secondary stressors (family and work conflict) provide mediation between primary stressors (ADL, IADL, cognitive impairment, behavioral problems, role overload and loss of relationship) and health outcomes (physical and mental health) (*Question 6*). Finally, a summary of the research findings was presented in the fifth section. The overall statistical analysis in the study was conducted with SPSS 13.0.

## Descriptive Analysis

### *Sample Characteristics*

According to proposed conceptual framework (Figure 3.1) used in this study, it is important to describe the background and context characteristics (socioeconomic and caregiving history) of the sample as they are independent variables in the study. Table 4.1 presents socioeconomic characteristics of the African American caregivers in the study. The majority (80.9%) of the caregivers for older adults with chronic illness were women. The average age of the respondents was 50.68 (SD = 13.88) with a range of 25 to 87. Almost 85% of the sample completed some college, received a college, graduate or professional degree. Most of the caregivers in this study were married (41.4%), 30.3% were single, and the remaining 28.3% were separated, divorced, or widowed.

As summarized in Table 4.1, 43.4% of the family caregivers were their children, sons (19.7%) and daughters (80.3%). Spouses were 10.5% of the caregivers (wives = 81.3% and husbands = 18.8%), 10.5% were nieces/nephews, 9.9% were grandchildren, 6.6% were in-laws, 8.1% were neighbors, 9% were friends and 2% were other relationships such as siblings and cousins. More than 67.8% of the respondents were currently employed as either full-time (57.9%) or part-time (9.9%). Other caregiver respondents (32.2%) were retired, unemployed/disabled, unemployed/looking for work, or homemakers. The employed caregivers worked on the average 25.96 hours per week (SD 19.55) with a range of 0 to 70 hours per week. Nearly 46% of the yearly household income of the sample was \$20,000 - \$49,999, 34.2% earn \$50,000 - \$99,999, 13.2% earn \$19,999 and below, and 7.2% more than \$100,000. The caregivers have 0 to 4 health conditions and on the average .9359 (SD = .9923) health conditions.

Table 4.1

*Caregivers' Characteristics (n = 152)*

Variable	Value	Number (%)	Mean (SD)
Gender	Male	29 (19.1%)	
	Female	123 (80.9%)	
Age (Yrs)	Range 25-87		50.68 (13.88)
Education	Partial HS or less	7 ( 4.6%)	
	HS diploma/equiv	16 (10.5%)	
	Some College	31 (20.4%)	
	2 yr College Degree	15 ( 9.9%)	
	4 yr College Degree	33 (21.7%)	
	Graduate/Professional	50 (32.9%)	
Marital status	Single	46 (30.3%)	
	Married/Living as	63 (41.4%)	
	Married	11 ( 7.2%)	
	Separated	21 (13.8%)	
	Divorced	11 ( 7.2%)	
	Widowed		

*Table 4.1 continued*

Variable	Value	Number (%)	Mean (SD)
Relationship with care-recipient	Spouse	16 (10.5%)	
	Son/Daughter	66 (43.4%)	
	In-law	10 ( 6.6%)	
	Grandchild	15 ( 9.9%)	
	Niece/Nephew	16 (10.5%)	
	Other	29 (19.1%)	
Employment status	Full-time	88 (57.9%)	
	Part-time	15 ( 9.9%)	
	Retired	28 (18.4%)	
	Others	21 (13.8%)	
Yearly income (\$)	\$19,999 and below	20 (13.2%)	
	\$20,000-\$49,999	69 (45.4%)	
	\$50,000-\$99,999	52 (34.2%)	
	More than \$100,000	11 ( 7.2 %)	
Hours worked	Range 0 - 70		25.96 (19.55)
Number of health conditions	Range 0 - 4		.9359 (.9923)

Although the care recipient characteristics were not analyzed in this research it is important to caregiver research to provide demographic characteristics of the care recipients in order to inform research as to the characteristics of care recipients the caregivers are providing care too. Table 4.2 summarizes the characteristics of care-recipients. Men comprised 33.6% of the care-recipients and women comprised 66.4%. The mean age of the care-recipients was 75.64 (SD = 10.56) with a range of 55 to 102. Care-recipients educational background represented 30.9% with partial high school or less, 20.4% high school graduate/equivalent, and 48.6% completed some college/technical school, completed a college degree, and/or graduate/professional degree. Care-recipients suffered from on the average 2.64 (SD = 1.24) health conditions with a range of 1 to 7 health conditions. The results showed that 29.6% of the care recipients suffered from Dementia/Alzheimer's, 44.8% have diabetes, 33.6% have heart disease, 73.0% have high blood pressure, 35.5% have high cholesterol, 21.7% suffered the effects of stroke and 25.7% had other diseases or disabilities. More than 40.1% of the care-recipients lived with the caregivers who participated in the survey and 23.7% of the care-recipients live alone.

#### Univariate Analyses

Univariate analyses answered research question 1, which determined if the caregivers' background characteristics (*socioeconomic, caregiving history and caregiving justifications*) contributed to caregiver's feelings of perceived physical and mental health outcomes in this study. In order to address the effects the researcher used the independent t-test for variables with two groups and analysis of variance (ANOVA) for variables with three or more groups. This analysis was conducted for the effects of caregivers' *socioeconomic characteristics* on both physical and mental health outcomes as well as *caregiving history* on both health outcomes

Table 4.2

*Care-recipients' Characteristics (n = 152)*

Variable	Value	Number (%)	Mean (SD)
Gender	Male	51 (33.6%)	
	Female	101 (66.4%)	
Age (Yrs)	Range 55-102		75.64 (10.56)
Education	Partial HS or less	47 (30.9%)	
	HS Graduate/Equiv	31 (20.4%)	
	Some College	35 (23.0%)	
	2 yr college degree	9 ( 5.9%)	
	4 yr college degree	16 (10.5%)	
	Graduate/Professional	14 ( 9.2%)	
Health Conditions	Dementia/Alzheimer	45 (29.6%)	
	Diabetes	68 (44.8%)	
	Heart Disease	51 (33.6%)	
	High Blood Pressure	111 (73.0%)	
	High Cholesterol	54 (35.5%)	
	Stroke	33 (21.7%)	
	Others	39 (25.7%)	
Number of Health Conditions	Range 1 - 7		2.64 (1.24)
Living arrangements	Live Alone	36 (23.7%)	
	Live with Caregiver	61 (40.1%)	

(physical and mental). Although *caregiving justifications* is a part of the background characteristics, in order to determine *caregiving justifications* contribution to physical and mental health a bivariate analyses was used due to the type of scale used.

*Socioeconomic characteristics effect on physical health and mental health.* In order to determine if the caregivers' socioeconomic characteristics contribute to the caregivers' physical health outcome, the mean differences of the caregivers' socioeconomic characteristics were analyzed via t-test or ANOVA in order to answer part of research questions 1 (*Which caregivers' background characteristics (socio-economic, caregiving history, caregiving justifications) might contribute to caregivers' level of mental and/or physical health?*).

The perception of caregivers' physical health and mental health based on socioeconomic characteristics of the sample is presented in Table 4.3. Although there was no significant difference by caregivers' gender, the results showed female caregivers ( $M = 48.30$ ) experienced higher mean scores in physical health than male caregivers ( $M = 47.58$ ). There was a significant relationship between caregivers' age and physical health ( $F = 8.44$ ,  $\eta^2 = .102$ ). The results revealed that the 25-39 aged caregiver group ( $M = 49.79$ ) showed the highest level of physical health outcomes, followed by the 40-59 ( $M = 49.04$ ) aged group and 60-87 aged group ( $M = 43.46$ ). Based on the Tukey HSD post hoc test of significant difference, caregivers over 60 reported significantly poorer physical health than the other two groups.

Regarding relationship with care-recipients, there was a significant positive relationship with physical health ( $F = 4.345$ ;  $\eta^2 = .130$ ). Grandchildren caregivers reported the highest level of physical health ( $M = 52.94$ ), followed by in-laws ( $M = 49.36$ ), son/daughters ( $M = 48.73$ ), spouse ( $M = 48.68$ ), niece/nephew ( $M = 45.78$ ) and others (friend, neighbor, sibling, cousin) caregivers ( $M = 42.68$ ). The Tukey HSD post hoc test showed pairwise difference among the

means and verified that there was a significant difference in the means between other caregivers (friend, neighbor, sibling, cousin) and son/daughter caregivers ( $p = .006$ ) as well as between other caregivers (friend, neighbor, sibling, cousin) and grandchildren caregivers ( $p = .000$ ).

Employment status of African American caregivers in this study was statistically significant ( $F=3.746$ ,  $\eta^2 = .072$ ) with levels of physical health. Caregivers who were employed full-time ( $M = 49.54$ ) reported better physical health than those who had part-time ( $M = 46.10$ ), retired ( $M = 45.14$ ) or other ( $M = 44.65$ ) employment (unemployed or homemaker). However, the Tukey HSD post hoc test, did not show a pairwise difference among the group means.

ANOVA test showed that there was a statistically significant relationship between yearly income status and the level of physical health experienced by the African American caregivers ( $F = 2.990$ ;  $\eta^2 = .057$ ). Caregivers whose income was \$20,000 - \$49,999 ( $M = 49.01$ ) reported higher levels (better) of physical health followed by caregivers who reported more than \$100,000 ( $M = 48.69$ ), \$50,000 - \$99,999 ( $M = 47.62$ ), and \$19,999 and below ( $M = 42.96$ ). The Tukey HSD post hoc test showed a significant pairwise difference in the means between caregivers income \$19,999 and below and \$20,000 - \$49,999 ( $p = .016$ ).

In addition, African American caregivers number of weekly hours worked did significantly predict the caregivers level of physical health ( $F = 5.038$ ;  $\eta^2 = .093$ ). Caregivers who worked 31-41 hours per week ( $M = 50.24$ ) experienced the highest level of physical health followed by caregivers who worked 42+ hours per week ( $M = 48.13$ ), 6-30 hours per week ( $M = 46.85$ ), and 5 hours or less per week ( $M = 44.53$ ). Based on the Tukey HSD post hoc test of significant difference, caregivers in the 5 hours or less group reported significantly lower levels of physical health than caregivers who worked 31- 41 hours ( $p < .05$ ).

Table 4.3

*T-test or ANOVA for Effects of Caregivers' Socioeconomic Characteristics on Physical and Mental Health*

Variable	Physical Health	Physical Health	Mental Health	Mental Health
	F or t value	$\eta^2$	F or t value	$\eta^2$
Gender	t = -.420	p = .684	t = 1.849	p = .066
Age (Yrs)	<b>F = 8.44*</b>	<b>.102</b>	F = 6.209	.006
Education	F = .784	.026	F = .925	.031
Marital Status	F = 1.96	.051	F = .942	.025
Relationship with care- recipient	<b>F = 4.35</b>	<b>.130</b>	F = .190	.006
Employment Status	<b>F = 3.75*</b>	<b>.072</b>	F = 1.14	.023
Yearly Income	<b>F = 2.99*</b>	<b>.057</b>	F = 2.12	.041
Hours Worked	<b>F = 5.04*</b>	<b>.093</b>	F = .279	.006
Number of Health Conditions	<b>F = 10.83*</b>	<b>.228</b>	F = .661	.018

Note. \*p < .05. \*\*\* p < .001

In this study of African American caregivers the number of health conditions experienced by the caregiver showed a statistically significant relationship with the caregivers' level of physical health ( $F = 10.83$ ;  $\eta^2 = .228$ ). Caregivers who indicated 0 health problem's reported higher levels of physical health ( $M = 50.94$ ) followed by caregivers with 1 health condition ( $M = 48.23$ ), 4 health conditions ( $M = 46.17$ ), 2 health conditions ( $M = 43.54$ ), and 3 health conditions ( $M = 37.47$ ).

Based on the Tukey HSD post hoc test of significant difference, caregivers who have 3 health conditions reported significantly lower levels of physical health than those with 0 health condition ( $p=.000$ ) and caregivers with 1 health condition ( $p=.000$ ). In addition, those with 2 health conditions also reported significantly lower levels of physical health than those with 0 health conditions.

Overall in order to answer a portion of research question 1 (*Which caregivers' background characteristics (socio-economic, caregiving history, caregiving justifications) might contribute to caregivers' level of mental and/or physical health?*), based on analyzing the relationship between caregivers' background characteristics and the level of physical health, the results reported that caregivers' age, relation with care recipient, employment status, yearly income, hours worked, and number of health conditions had significant effects on the caregivers' physical health in this study. However, based on analyzing the relationship between caregivers' background characteristics and the level of mental health, the results reported that none of the caregivers' background characteristics had significant effects on the caregivers' mental health in this study.

*Caregiving history effect on physical and mental health outcomes.* Table 4.4 presents the results of a t-test or one-way analysis of variance that identified significant relationships between

*caregiving history* and physical health outcomes and *caregiving history* and mental health outcomes in the sample. This analysis was used in order to answer if caregiving history (independent variable) contributed to the caregiver's physical health (dependant variable) in order to answer the second portion of research question 1 (*Which caregivers' background characteristics (socio-economic, **caregiving history**, caregiving justifications) might contribute to caregivers' level of mental and/or physical health?*).

Table 4.4

*T-test or ANOVAs for Effects of Caregiving History on Physical and Mental Health Outcomes*

Variable	Physical Health	Physical Health	Mental Health	Mental Health
	F or t value	$\eta^2$	F or t value	$\eta^2$
Total # of people				
caring for	F = .292	.008	F = 1.27	.033
Caregiving				
Hours (Weekly)	<b>F = 2.66*</b>	<b>.051</b>	F = .449	.009
Length of Time				
(Months)	<b>F = 2.78*</b>	<b>.053</b>	F = .731	.015
Living				
Arrangements				
(Co-residence)	t = 1.62	p = .107	<b>t = -2.34*</b>	<b>p = .020</b>

*Note.* \*p < .05.

Hours spent providing care weekly had a slight significant effect on caregivers' physical health in this study (p = .051). The study showed that caregivers who spent 88 plus hours caregiving per week (M = 44.97) and those spending between 43-87 hours per week (M = 44.59) reported the

lowest physical health score, followed by caregivers who provided 25-42 hours of caregiving ( $M = 47.77$ ), and those who spent 24 or less hours caregiving per week to older adults with chronic illness ( $M = 49.07$ ). The ANOVA test was significant ( $F = 2.657$ ,  $\eta^2 = .051$ ), and according to Tukey HSD no group mean significance. However, the results of the pairwise comparison test of significant difference revealed that caregivers who spent 24 or less hours caregiving per week experienced statistically more physical health than those who provided caregiving 43-87 hours per week ( $p = .023$ ) or 88+ hours per week ( $p = .042$ ).

Length of time the caregiver provided care indicated a significant relationship with physical health for African American caregivers in this study. Caregivers who provided care for 121 + months ( $M = 44.43$ ) were more likely to report low mental health scores than those caregivers who provided care less than 121 months. Based on the Tukey HSD post hoc test of significant difference, caregivers who provided more than 121 months of care reported significantly lower levels of physical health than those who provided 61-120 months of care.

Lastly, living arrangements was significantly associated with the caregivers mental health ( $F=12.73$ ;  $t=-2.354$ ). The caregivers who lived with their care-recipients ( $M = 45.25$ ) had lower levels of mental health than those who did not live with their care recipients ( $M = 49.32$ ).

Overall, based on analyzing the relationship between caregiving history and the level of physical health, the results reported that the total number of caregivers and caregiver living arrangements did not have a significant effect on caregivers' physical health outcomes. However, the weekly number of hour's caregiving and the length of time caregiving did have an effect on the caregivers' physical health. Overall, based on analyzing the relationship between caregiving history and the level of mental health, the results reported that the total number of caregivers, the weekly number of hour's caregiving and length of time caregiving did not have a

significant effect on caregivers' mental health outcomes. However caregiver living arrangements (co residence) did have an effect on the caregivers' mental health outcomes. This analysis answered a portion of research question 2 (*Which caregivers' background characteristics (socio-economic, **caregiving history**, caregiving justifications) might contribute to caregivers' level of mental and/or physical health?*).

*Caregiving justifications effect on physical and mental health.* A bivariate correlation analyses was conducted to determine if the final background characteristic, **caregiving justification**, significantly contributed to physical and/or mental health outcomes in order to answer research question 1 (*Which caregivers' background characteristics (socio-economic, caregiving history, **caregiving justifications**) might contribute to caregivers' level of mental and/or physical health?*). Bivariate analyses revealed mental health not physical health as perceived by the caregivers in the study was positively related to caregiving justifications  $r(150) = .31, p < .31$ . Therefore, as mental health scores increased caregiving justification increased in caregivers.

### Bivariate Analyses

The third section answers research question 2 and explores the strength of the relationship between the primary stressors (ADL, IADL, cognitive impairment, behavioral problems, role overload and loss of relationship), secondary stressors (family conflict and work conflict), mediators (religious/spiritual coping, informal and social support) and health outcomes (physical and mental health).

Zero-order correlations were computed among caregiving justifications, eight stressors, three mediators and two health outcomes measures. Using the Bonferroni approach to control for Type I error across the 14 correlations, a  $p$  value of less than .004 ( $.05/14 = .004$ ) was

required for significance. As shown in Table 4.5, the results of the correlational analyses showed numerous weak and a few moderate, yet statistically significant associations in order to answer research question 2 (*What is the strength of the relationship or association between the primary stressors, secondary stressors, mediators and health outcomes?*).

Table 4.5

*Bivariate Correlations between Physical Health and Mental Health and Primary Stressors, Secondary Stressors and Mediator Variables*

Variable	Physical Health	Mental Health
Primary Stressors		
ADLS	-.01	.11
IADLS	.03	.07
Cognitive Impairment	-.16	-.04
Behavior Problems	-.15	-.07
Role Overload	.22**	.38**
Loss of Relationship	.22**	.36**
Secondary Stressors		
Family Conflict	-.12	-.28**
Work Conflict	-.28**	-.44**
Mediators		
Religious/Spiritual Coping	-.06	.26**
Informal Social Support	.02	.33**
Formal Social Support	.02	-.14

\*\* $p < 0.01$ .

Mental and physical health outcomes were both positively and negatively correlated with study variables as indicated in Table 4.5. Primary stressors of role overload and loss of relationship were both positively correlated with physical  $r(150) = .22, p < .01$ ;  $r(150) = .22, p < .01$  and mental health (moderate)  $r(150) = .38, p < .01$ ;  $r(150) = .36, p < .01$  respectively. As the caregivers in this study experienced high levels of role overload or problems dealing with the loss of their relationship with the care recipient this impacted the caregivers scoring high physical and mental health outcomes. Work conflict showed a weak inverse association with physical health  $r(150) = -.28, p < .01$  and moderate inverse association with mental health  $r(150) = -.44, p < .01$ . The higher the work conflict the lower the physical and mental health problems experienced by the African American caregivers in this study. Mental health and not physical health as perceived by the caregivers in this study was also negatively (weak) related to family conflict  $r(150) = -.28, p < .01$ , and positively related to religious and spiritual coping  $r(150) = .26, p < .01$ , and informal social support  $r(150) = .33, p < .01$ . Therefore, as mental health scores increase family conflict decreased and religious and spiritual coping, informal social support increased.

Overall, based on the bivariate correlation analyses of the primary stressors, secondary stressors, mediators and health outcomes (physical and mental) the variables tended to be weak and moderately correlated in both positive and negative direction and many were statistically significant. Table 4.5 represents those relationships in order to answer research question 2.

#### Mediation Analyses

As a result of the significant bivariate correlation, between all study variables correlations were further analyzed to explore which variables are acting as mediators in the conceptual framework and to test additional research questions (Q3, Q4, Q5, and Q6). Baron and Kenny

(1986) define mediating variables as variables that have an effect on an independent (predictor) variable and an effect or influence on the dependant variable. Mediation was important in this study because there are several bivariate correlations that have a moderate correlation  $p \geq .40$  and or close to a moderate correlation with another study variable. According to Todman and Dugard (2007) "Moderate correlations between variables suggest that a mediation hypothesis might be entertained and that multicollinearity would not be a problem" (p. 137). As a result four of the research questions for this study of African American caregivers will test the effect of any mediating variables (Q3, Q4, Q5 and Q6).

According to Baron and Kenny (1986), in order to determine if mediation analyses can be conducted, all three of the variables in question must be significantly correlated with each other. If all three variables are significantly correlated with each other then the following conditions must be met via regression approach to test the mediation hypothesis (a) the predictor must be related to proposed mediator; (b) the predictor must be related to the outcome variable; (c) and when both the predictor and mediator are entered into the equation, the effect must decline or become non-significant, and (d) the association between the mediator and the outcome must remain significant. The statistical significance of the proposed mediated relationships must be tested using the Sobel Test. The Sobel test is the follow up test used to determine the indirect effect of the independent variable on the dependant variable via the mediator (Sobel, 1982). The Sobel test determines if a mediating variable is significantly acting in mediation if the preliminary testing of the Baron and Kenny (1986) method described previously is true. The Sobel test utilizes the unstandardized coefficient and standard error coefficient of the independent variable to the dependent variable and then the unstandardized coefficient and standard error coefficient of the mediator when the independent variable is added to the equation

(Sobel, 1982). As a result of performing the Sobel test a Z score and  $p$  (probability) score is provided. If the associated  $p$ -value is  $< .05$  the established alpha value then the association between the independent variable and the dependant variable will indicate evidence of mediation. In this study the researcher tested four path models for possible mediation according to the proposed research model Figure 3.1 and the four research questions (Q 3-6) .

*Primary stressors to secondary stressors (mediating variables) (Q3).* The first path (*Question 3*) that was analyzed was between each primary stressor (ADLS, IADLS, cognitive impairments, behavior problems, role overload and loss of relationship) and each secondary stressor (family conflict and work conflict) with the each of the proposed mediators (religious/spiritual coping, informal support and social support). According to the first rule of mediation, all three equations bivariate correlations must be significant in order to proceed with mediation analyses. When religious/spiritual coping, informal social support or formal social support was used as mediators between each primary and secondary stressors there were no significant bivariate correlations for all three relationships. The lack of significant bivariate correlations between these variables did not prove mediation for research question 3. Religious/spiritual coping, informal social support and/or formal social support did not act as mediators between primary and secondary stressors.

*Secondary stressors to health outcomes (mediating variables) (Q4).* The second path for mediation was an analysis for research question 4. The research question asked if religious/spiritual coping, informal and/or formal social support mediates the relationship between each secondary stressor (family and work conflict) and each physical and mental health outcomes. Bivariate correlations indicated that there were no significant correlations between family conflict and work conflict and any of the mediators (religious/spiritual coping, informal

social support and/or formal social support). Therefore, no further mediation analyses can be conducted between secondary stressors and health outcomes. Research question 4 did not prove any significant mediation between secondary stressors and health outcomes.

*Primary to health outcomes (mediating variables) (Q5).* The path between primary stressors (ADLS, IADLS, cognitive impairments, behavior problems, role overload, and loss of relationship) and physical and mental health outcomes represented the third mediation analysis in order to answer research question 5.

Bivariate correlations were only significant between role overload (predictor) and mental health (outcome)  $r(150) = .38; p < .01$ , role overload (predictor) and informal social support as the mediator  $r(150) = .23; p < .01$ , and informal social support (mediator) and mental health (outcome)  $r(150) = .33; p < .01$ . After controlling for background and context variables (co residence and caregiver justifications), that displayed significant bivariate relationships with mental health, the analyses for mediation was further explored. This first mediation analyses explored the notion that informal social support (mediator) would account for associations between role overload (predictor) and mental health (outcome). Role overload was significantly associated with the proposed mediator (informal social support) ( $\beta = .21, p < .05$ ) and the outcome variable (mental health) ( $\beta = .32, p < .01$ ). Once the mediator (informal social support) and predictor (role overload) was entered into the equation the mediator (informal social support) became non-significant ( $\beta = .22, p < .05$ ) and the predictor (role overload) became non-significant ( $\beta = .28, p < .05$ ).

*Primary to health outcomes (secondary stress variables as mediators (Q6)).* Final mediation analyses was conducted between primary stressors (ADLS, IADLS, cognitive impairments, behavior problems, role overload and loss of relationship) and health outcomes

(physical and mental) with secondary stressors (family and work conflict) as proposed mediators to answer research question 6 (*Does family conflict and work conflict t(secondary stressors) mediate the relationship between primary stressors and health outcomes?*).

As a part of the preliminary mediation analyses, six significant bivariate correlations were found in this path between the following (see Table 4.6):

1. Role overload (predictor), work conflict (mediator), and physical health (outcome)
2. Role overload (predictor), work conflict (mediator), and mental health (outcome)
3. Loss of Relationship (predictor), work conflict (mediator), and physical health (outcome)
4. Loss of Relationship (predictor), work conflict (mediator), and mental health (outcome)
5. Loss of Relationship (predictor), family conflict (mediator), and mental health (outcome)

Table 4.6

*Significant Correlations between Primary Stressors, Secondary Stressors and Health Outcomes*

Variable	1	2	3	4	5	6
<b>Primary Stressors</b>						
1. Role Overload	-					
2. Loss of Relationship	.41**	-				
<b>Secondary Stressors</b>						
3. Work Conflict	-.44**	-.29**	-			
4. Family Conflict	-.39**	-.26**	.32**	-		

Table 4.6 continued

Variable	1	2	3	4	5	6
Health Outcomes						
5. Physical Health	.22**	.22**	-.28**	NS	-	
6. Mental Health	.38**	.36**	-.44**	-.28**	NS	-

Note: NS = Nonsignificant. \*\* $p < 0.01$

Before mediation analysis was conducted on each equation, background and context variables were controlled for physical and mental health. Controls for physical health included age, relationship to care recipient, employment status of caregiver, caregiver yearly employment, caregiver hours worked, number of health conditions of caregiver, hours per week caregiving (weekly), length of time providing care (months). Background and context controls for mental health were co-residence and caregiver justifications.

Equation 1 (Table 4.7) explored work conflict as the mediator to explain the relationship between role overload and physical health. Table 4.7 (column 1, equation 1) indicates a relationship between predictor (role overload) and mediator (work conflict) ( $\beta = -.42, p < .01$ ) and between the predictor (role overload) and the outcome (physical health) ( $\beta = .14, p < .05$ ) (Table 4.7, column 2, equation 1). Once the predictor and the mediator were entered into the equation, the relationship between the mediator and outcome remained significant ( $\beta = -.21, p < .05$ ) (Table 4.7 column 4, equation 1) and the relationship between the predictor and outcome remained significant, ( $\beta = .06, p = .48$ ) (Table 4.7, column 3, equation 1) which indicated no mediation.

Table 4.7

*Standardized Regression Coefficients for Relevant Variables in Models Testing for Mediating Effects (Research Question 6)*

Predictor → Outcome (Mediator)	Predictor to mediator	Predictor to outcome (not adjusted for mediator)	Predictor to outcome (adjusted for mediator)	Mediator to outcome (adjusted for predictor)
	$\beta$	$\beta$	$\beta$	$\beta$
1. Role Overload → PHO <sup>a</sup> (Work Conflict)	-.42**	.14*	.06*	-.21*
2. Role Overload → MHO <sup>a</sup> (Work Conflict)	-.42**	.32**	.19*	-.31**
3. Loss of Relationship → PHO <sup>a</sup> (Work Conflict)	-.27*	-.15*	.09*	-.21*
4. Loss of Relationship → MHO <sup>a</sup> (Work Conflict)	-.26*	.30*	.21**	-.33**
5. Loss of Relationship → MHO <sup>b</sup> (Family Conflict)	-.24**	.30*	.26*	.17*

*Note.* Only coefficients that were directly relevant to evaluation mediation effects are presented. MHO = Mental Health Outcome, PHO = Physical Health Outcome  
\*  $p < 0.05$ . \*\* $p < 0.01$ . <sup>a</sup> Two tailed significance. <sup>b</sup> One tail significance only.

Work conflict in equation 2 also acted as a proposed mediator between role overload and mental health. The bivariate correlations were all significant among the three variables (see Table 4.7). After controlling for background and context variables, mediation analyses was conducted and the relationship between predictor (role overload) and mediator (work conflict) was significant ( $\beta = -.42, p < .01$ ) as well as the relationship between the predictor (role overload) and outcome (mental health) ( $\beta = .32, p < .01$ ). The relationship between the mediator ( $\beta = .19, p < .05$ ) and predictor ( $\beta = -.31, p < .01$ ) remained significant when both were entered into the equation, thereby no indication of mediation.

On the third and fourth mediation analysis work conflict was also correlated with loss of relationship for both physical and mental health outcomes. The proposition in the third equation was that work conflict and the loss of relationship with the care recipient might account for the caregivers' physical health. As shown in Table 4.7, equation 3, was reliably associated with the proposed mediator ( $\beta = -.27, p < .05$ ) and physical health ( $\beta = -.15, p < .05$ ). The relationship between loss of relationship and physical health remained significant ( $\beta = .09$ ) when work conflict ( $\beta = -.21, p < .05$ ) was entered into the equation. Thereby there was no indication of mediation. Similarly, work conflict was not a significant mediator between loss of relationship and mental health outcomes. Equation 4 demonstrated the significant values between predictor (loss of relationship) and mediator (work conflict) ( $\beta = -.26, p < .05$ ), as well as the predictor to the outcome ( $\beta = .30, p < .01$ ). Once mediator and predictor were added to the equation the affect on the outcome remained significant ( $\beta = .21, p < .01$ ) which proved no mediation.

Final mediation analysis (equation 5) explored the notion that family conflict would account for associations between loss of relationship and mental health. As shown in Table 4.7 (equation 7) loss of relationship was significantly associated with the proposed mediator (family

conflict) ( $\beta = -.24, p < .01$ ) and with the outcome variable, mental health ( $\beta = .30, p < .01$ ). The association between loss of relationship and mental health outcome remained significant when family conflict was added to the equation ( $\beta = .26, p < .01$ ) and there was a decline with the mediator to outcome ( $\beta = .17, p < .01$ ), the subsequent Sobel test revealed only one tailed significance ( $z = 1.81, p = .04$ ), but not two tailed significance ( $z = 1.81, p = .06$ ). Equation 5 supported a portion of the hypothesis 6b which states family conflict mediates the association between primary stressors (loss of relationship) and mental health outcome.

Overall mediation analyses only proved family conflict mediates the loss of relationship with the caregivers mental health. In this study with African American caregivers, family conflict acted as individual mediators with loss of relationship to predict mental health outcomes.

#### Summary of Findings

The purpose of this study was to answer six research questions: 1) Which caregivers' background characteristics (socio-economic, caregiving history, caregiving justifications) might contribute to caregivers' feelings of emotional and/or physical distress? 2) What is the strength of the relationship or association between the background characteristics, primary stressors, secondary stressors, mediators and the health outcomes? 3) Does religious/spiritual coping, informal and formal social supports mediate the relationship between primary stressors and secondary stressors? 4) Does religious/spiritual coping, informal and formal social supports mediate the relationship between secondary stressors and health outcomes (physical and mental health)? 5) Does religious/spiritual coping, informal and formal social supports mediate the relationship between primary stressors and health outcomes (physical and mental)? and 6) Does family conflict and work conflict mediate the relationship between primary stressors and health outcomes (physical and mental)?

Table 4.8 presents a summary of the results of the data analyses for Question 1 and 2. In terms of caregivers' background and context characteristics, there were significant differences between the groups in age, relationship to care recipients, employment status, income, hours worked per week, and number of caregiver health problems. Older caregivers', caregivers who were friends, neighbors, siblings or cousin, caregivers who were unemployed, who received lower income, who worked less than 5 hours a week, and caregivers who had at least 3 health problems were at risk to have lower levels of physical health. Background characteristics did not have any significant impact on mental health.

In regards to caregiving history, those caregivers who provided more than forty three hours per week of care and those who have provided care for over 121 months had significantly lower physical health scores. The only significant variable for mental health was if the caregiver and care recipient lived together. If the caregiver and care recipient lived together this may significantly predict lower levels of the care recipients' mental health.

In order to address the relationship between the stressors and mediators on the caregivers perceived physical and mental health bivariate correlation analysis was conducted and the results identified several significant stressors and mediators predicting physical and mental health. Table 4.8 also provides more specific results for these relationships. Primary stressors of role overload and loss of relationships when they are reduced may have an impact in predicting lower physical and mental health scores. However, secondary stressors of work conflict when increased tend to have an association with lower mental and physical health for the caregiver. In addition when family conflict was increased the caregivers tended to experience lower mental health outcomes. Caregivers who did not use informal social support and religious/spiritual coping as a coping strategy were more likely to experience poorer mental health.

Table 4.8

*Significant Predictors of Physical and Mental Health Outcomes*

Background & Context	Lower Health Outcomes (Negative)	
	↓ Physical Health	↓ Mental Health
Socioeconomic (CG)	Age (Older)	Socioeconomic
	Relationship (Others)	variables did not
	Job status	significantly effect
	(Unemployed/Homemaker)	mental health
	Income (Lower)	
	Hrs per Week (Fewer)	
Caregiving History	# of Health Problems (3)	
	# Hrs per Week (43+)	Co residence (Yes)
	Length of Time (121+months)	
Caregiving Justifications		↓ Justifications
Primary Stressors	↑ Role Overload	↑ Role Overload
	↑ Loss of Relationship	↑ Loss of Relationship
Secondary Stressors	↑ Work Conflict	↑ Work Conflict
		↑ Family Conflict
Mediators		↓ R/S Coping
		↓ Informal SS

Mediation analysis was also conducted to determine if the mediators and/or secondary stressors acted in mediation to predict health outcomes. Results from the study concluded that family conflict was the only significant mediator in predicting mental health.

## CHAPTER V

### DISCUSSION

Chapter 5 of this investigation provides interpretations of expected and unexpected data results presented in Chapter 4. This chapter also reports implications for caregiving systems of African American caregivers, addresses several limitations in the study, and finally, proposes future studies and recommendations that will contribute to African American caregivers of older adults with chronic illness.

The two major aims of this investigation were to identify significant risk factors for physical and mental health outcomes experienced by African American caregivers, and to test which mediating variables provided an explanation for the caregiving stress process in order to predict the caregivers' physical and mental health outcomes. The findings in the study supported previous research that examined predictors of physical and mental health outcomes for African American caregivers, but also presented different results with those of empirical studies on African American caregivers.

#### Interpretations for Data Results

##### *Care-recipients' and Caregivers' Background and Context Characteristics*

##### *Care-recipients' Demographic Information*

The results of this research reflected that the majority of the care recipients tended to be women. The majority of the care recipients were high school graduates/equivalent or less. The majority of the care recipients had at least 3 health conditions with the range being between 1 to 7 health conditions. The majority of the care recipients suffered from coexisting chronic

conditions such as high blood pressure, diabetes, high cholesterol, heart disease, and stroke. This study also supported previous research that the African American family is the primary source of support for chronically ill older adults (Dilworth-Anderson et al., 1999a; Dilworth-Anderson et al., 1999b). The data presented that 40.1% of the caregivers lived with the care-recipients.

### *Caregivers' Background Characteristics*

The mean age of the caregivers was 50.68 and almost 81% of the family caregivers were women. The sample consisted of sons and daughters (43.4%), spouses (10.5%), niece/nephew (10.5%), grandchildren (9.9%), in laws (6.6%) and other relatives or friends (19.1%). These results revealed that middle-aged women generally provided care for older adults with chronic illness, and the children of the care recipient frequently provided care. This is consistent with the literature on caregivers (e.g., Family Caregiving Alliance, 2008). In addition, the majority of the African American caregivers in this study were married/living as married (41.4 %) which is inconsistent with research on African American caregivers. Research tends to indicate the majority of African American caregivers tend to be single (Dilworth-Anderson & McAdoo, 1988). Majority of the caregivers were employed as full or part time workers and they worked an average of 25.96 hours per week, which may have contributed to the caregiver experiencing role conflicts of being an employee and a caregiver. Bullock et al., (2003) found similar results in studying effects of employment and African American caregivers.

The yearly income of the majority of caregivers in the sample ranged from \$20,000 - \$49,999 (45.4%) with the next range being \$50,000 - \$99,999 (34.2%). The yearly income in this sample tended to be higher than other studies with African American caregivers (e.g. Dilworth-Anderson et al., 2004). In addition, the African American caregivers in this study provided care to almost 3 care recipients and spend 30.35 hours weekly providing care. The mean length of

time of caregiving was 23.65 months and the maximum duration was 840 months. The caregivers in this study also reported a mean score of 35.38 out of a possible 40 as to the cultural importance (justifications) of providing care. One possible explanation for the long caregiving duration is that African American caregivers are traditionally expected to provide care to older adults.

### *Predictors for Physical Health and Mental Health*

#### *Caregivers' Background and Context*

Caregiving literature has shown that characteristics of caregivers are associated with the physical and mental health outcomes for African American caregivers (e.g., Drenta & Goldner, 2006; Dilworth & Anderson et. al., 2004). The caregiver's background and context characteristics generally included gender, age, education level, marital status, income, relationship with care-recipient, employment status, total number of people caring for, hours of care, length of time providing care, and living arrangements. This study added another component to the background characteristics which was the number of health problems of the caregiver. The study considered caregivers' background characteristics and also confirmed several significant predictors of the caregiver's physical health outcome. The study was not able to find any socioeconomic characteristics which were proven to be significant predictors for caregivers' mental health outcome. Age, relationship to the care-recipient, employment status, income, hours per week working, and number of health problems of the caregiver had significant relationships with the caregivers' physical health in the sample.

First, as the caregivers' age increased, they were more likely to have poorer physical health than the younger caregivers. Providing care to the elderly with chronic illnesses is very demanding. Older caregivers', who also might have poor mental and physical health, were more

likely to experience poor health outcomes due to the stressful nature of providing care. Second, caregivers who were friends, neighbors, other relatives, or church members showed lower levels of physical health. This result indicates that caregiving to ill older adults had more negative physical health effect to those who were not immediately related than it did to those who were closely related. Third, caregivers who were unemployed or homemakers were more likely to have lower levels of physical health than those who were employed or retired. However, those caregivers that were employed 31 to 41 hours per week experienced better physical health outcomes. Also caregivers whose income was lower and that had at least three health conditions, experienced lower levels of physical health. As caregivers had fewer work responsibilities, lower income, and their own health problems, they frequently experienced more complications with their own physical health. In regards to caregiving history and caregiving justifications they both significantly predicted caregivers' physical and mental health outcomes. Caregivers' hours per week employed and length of time caregiving significantly predicted physical health. The results proved that caregivers in this study who were employed over forty three hours per week and those who provided care over one hundred twenty-one months reported lower levels of physical health. In regards to mental health, caregivers who resided with the care-recipients tended to have lower mental health outcomes.

Overall, this study showed that none of the caregivers' socioeconomic characteristics of age, gender, education, marital status, relationship with care-recipient, employment status, income, hours worked or caregiver health conditions were associated with mental health outcomes. However, co-residence with the care-recipient significantly impacted mental health. In addition, gender, marital status, and education were not statistically associated with caregivers' physical health. However, age, relationship, and daily caregiving hours, marital status,

relationship with care-recipient, employment status, monthly income, number of hours per week providing care and length of time caregiving were significant predictors of physical health.

Caregivers who were older, not working or working few hours, had lower incomes, were not related, with three health problems, provided care at least forty three hours per week, and for over 121 months had higher levels of physical health outcomes. Caregivers' who lived with their care-recipient tended to have lower mental health outcomes yet, high levels of caregiving justifications showed an increase in mental health outcomes. Contrary to the researcher's expectation, part or full-time employed caregivers experienced lower degrees of physical health than those unemployed caregivers. Caregivers who were not immediately related to the care-recipient experienced greater physical health concerns. This reflects that providing care for a non immediate family member is more physically stressful to caregivers than those caregivers who are employed part-time or full-time.

#### *Caregiving Stressors and Mediators*

The literature on predictors for health outcomes has consistently shown that caregiving stressors and coping mediators are associated with greater likelihood of poor physical and/or mental health outcomes (e.g., Drenta & Goldner, 2006; Wallace Williams, Dilworth-Anderson & Goodwin, 2003). Considering caregivers' primary and secondary stressors the bivariate correlation model identified that only role overload, loss of relationship and work conflict were associated with the caregivers level of physical and mental health outcomes. The primary stressors of ADLS, IADLS, cognitive impairments, or behavior problems did not demonstrate a significant association with physical health or mental health. African American caregivers in this study who experienced more role overload were more likely to experience physical and mental health problems. In addition, as the caregiver experienced increased feelings of a loss in

the previous relationship they had with the care-recipient prior to providing care, the caregiver would experience more physical and mental health problems. Interestingly, when the caregivers in this study experienced high levels of work conflict their physical and mental health outcomes decreased. Yet, an increase in family conflict only showed a reduction in mental health outcomes, but did not show a significant effect with physical health outcomes. These findings are inconsistent with the literature on caregiving that indicates work conflict demonstrates a negative effect on physical and mental health outcomes (e.g. Bullock et al., 2003) and family conflict reduces mental health outcomes (e.g. Stephens et al., 2001).

Although the primary stressors cognitive impairments and behavior problems were not significant with physical and mental health, this is consistent for African American caregivers in the literature (e.g. Sorensen & Pinquart, 2005). However, the non-significant affect of the other primary stressors ADLS, IADLS, was not expected. Caregiving literature indicated that care recipients who require high amounts of assistance with ADLS and/or IADLS, tend to affect the caregivers physical and mental health (e.g. Wallace-Williams, 2003). A possible explanation for these results is that care recipients in this study tended to have chronic health conditions such as cardiovascular diseases and diabetes as opposed to caregivers who are suffering from Alzheimer's/Dementia which affect care recipients differently in regards to the demands for ADLS and/or IADLS assistance, cognitive impairments and/or behavior problems. Consequently, primary stressors with this population of caregivers providing care to chronically ill may not significantly affect the caregivers' physical and mental health outcomes.

Caregivers' resources, including informal support, formal support, and religious/spiritual coping strategies were considered as mediating variables to predict physical and mental health outcomes in this study. African American caregiving literature frequently reports that informal

social support and the use religious/spiritual coping strategies assist with the reduction of negative physical and/or mental health outcomes (e.g., Drenta & Goldner, 2006; Williams & Dilworth-Anderson, 2002; Morano & King, 2005). Bivariate correlations were conducted with the mediating coping variables of religious/spiritual coping, informal and formal social support. An increase religious/spiritual coping and informal social support showed a positive relationship with reducing the amount of mental health outcomes experienced by the African American caregivers in their caregiving role, which is consistent with the literature for African American caregivers (Dilworth-Anderson, Boswell, & Cohen, 2007; Williams, 2005). An unexpected result was that none of the mediating coping variables of religious/spiritual coping, informal and formal social support displayed a significant relationship with the caregivers' level of physical health for this sample. These results are unexpected and may be explained that in this sample religious/spiritual coping tended to have a significant impact on the mental health level as opposed to physical health due to the spiritual nature (Dilworth-Anderson et al., 2007; Williams, 2005). In regards to informal social support it was more likely to reduce mental health in this study. The caregivers in this study were consistent with the literature and demonstrated low utilization of formal supports. This low use of formal supports may demonstrate that caregivers tended to provide care independently and not receive much formal support due to the care recipients' actual physical needs. In other words, caregivers do not tend to seek or have formal social support while providing care to older adults who have chronic illness, due to the low levels of ADLS, IADLS, cognitive impairments, and behavior problems experienced by the care recipients. This study confirmed that the strongest bivariate predictor for physical and mental health was work conflict, followed by role overload and loss of relationship. The next strongest predictors for mental health were informal social support and religious/spiritual coping.

### *Effects of Mediation Analyses*

Previous literature on mediators for physical and mental health has frequently suggested that religious/spiritual coping, informal and formal support coping strategies as an explanation for mediating the relationship between stressors and negative health outcomes (e.g. Drenta & Goldner, 2006; Picot et. al., 2006; Moberg, 2005; Morano & King, 2005). In particular, several factors together or an interplay between various stressors and coping mediators may lead caregivers' positive or negative health outcomes. Thus, this study not only questioned whether religious/spiritual coping, informal social support, and formal social support acted as mediators, but also explored whether family and/or work conflict acted as mediators to affect health outcomes.

There were several unexpected findings that require further analysis. The results of mediation analyses indicated that actual the mediators of religious/spiritual coping, and formal support did not provide adequate mediation as an explanation for caregivers physical or mental health outcomes. African American caregivers in this study who reported fewer family conflicts, yet high loss of relationships tended to experience lower mental health complications as opposed to experiencing loss of relationships with an increase of family conflicts. This study confirmed for this sample of African American caregivers of older adults with chronic illness family conflict acted as significant mediators for predicting mental health with the primary stressors of loss of relationship.

### Limitations

It is necessary to note a number of limitations in this study before generalizing its findings. First, several scales were checklist, including ADLS, IADLS, cognitive impairments, problematic behaviors, role overload, caregiver justifications, religious/spiritual coping,

informal social support, formal social support, physical and mental health outcomes by the caregivers, were based on reflective responses by the caregivers. The results might not be free from caregiver memory prejudice. Therefore, conducting a study that asks about current behaviors and experiences or using another method of collecting the data through observation might rule out caregivers' introspective responses.

Second, this study employed a physical and health outcome survey that analyzed several components of the caregivers' perception of their mental and physical health. African American caregivers tend to rate their health problems worse than other caregivers who provide care to older adults. A more accurate account of the caregivers' physical and mental health may have been seen by providing an actual recorded physical and mental health evaluation over time.

Third, most of the employed scales in this study were originally developed for Caucasian caregivers of older adults who were providing care to care recipients with Alzheimer/Dementia. Though all the measurements except for work conflict in the study showed high levels of reliability, the scales were not checked with logical validity procedures. Various approaches (e.g., criterion-related, concurrent, predictive, or convergent and discriminate validity) to establishing the validities of the measurement are needed. In addition, replication studies of the measurements must be conducted on other African American caregivers who provide care to older adults with chronic illness are needed in order to address cross-validation of the scales.

Fourth, the caregivers were asked to answer their perceptions of their own physical and mental health. The measurement focused on the caregivers' viewpoint of their own health limitations. Caregiver's might respond with socially and culturally desirable answers to personal questions. Although the majority of the sample did the survey via the internet and there was anonymity, the caregivers might underrate their own physical and mental health due to

associated illness denial, and stigma. The caregivers' that did face-to-face interviews for data collection may have been at a higher risk to select socially desirable answers.

Fifth, this study explored the stressors and coping mediators predicting physical and health outcomes of African American caregivers of older adults with chronic illness. However, this study did not take into account African American non caregivers in order to determine if non caregivers have the same physical and mental health outcomes concerns.

Finally, since this study used a correlational design, the nature of the design did not provide information about changes in caregivers' physical and mental health over time. Even though the research questions in the study were theoretical based, this cross-sectional design has a limitation in confirming causal effects among variables. That is, a longitudinal design should test significant predictors' physical and mental health of the caregivers over time.

#### Directions for Future Studies

The main two purposes of this study were to identify and explore significant predictors for physical and mental health outcomes of African American caregivers who provide care to older adults with chronic illness and to test mediation analyses as an explanation for reducing physical and mental health outcomes. Based on the findings and limitations of this study, the researcher suggests several recommendations for future research on African American caregivers physical and mental health outcomes experienced during their role as caregivers for older adults with chronic illness.

First, this study discovered that the primary stressors of ADLS, IADLS, cognitive problems and behavior problems were limited in their impact on caregivers physical or mental health outcome. This may be due to the fact that caregivers were caring for individuals with chronic illness as opposed to those with more debilitating illnesses. Future research will need to

expand on the other areas of the stress process model to include financial conflict, intrapsychic strains (self-esteem, mastery or caregiver satisfaction, competency and loss of self). These are areas that may affect the caregiver's role more directly particularly as they pertain to care recipients with chronic illness needs.

Second, this study found that the typical mediators of religious/spiritual coping, informal social support, and formal social support did not act as mediators in this model. Typically in African American caregiving research, religious/spiritual coping (Dilworth-Anderson et al., 2007), informal social support and formal social support (Chadiha et al., 2003) provide significant coping strategies to reduce physical and/or mental health. Future research would need to explore if these mediators are acting in moderation (interaction) with the other study variables in this sample of African American caregivers.

Third, although this study explored predictors of health outcomes of African American caregivers at one point in time, future research will need to examine caregiving over time. Caregivers in this study were at different phases in their caregiving experiences, which could possibly decrease the external validity of the study. A longitudinal study of caregiving would allow for vital information about the caregiving experiences over time and this may project various phases of the care recipients physical and mental health outcomes.

Fourth, additional statistical analysis of the data from this study would allow the researcher to further examine multiple relationships with the study variables and model fit. For example, future study may include structural equation modeling (SEM). Indirect paths could be further explored to reflect if any partial mediation exists within the variables. SEM could help determine if the stress process model (Pearlin et al., 1990) is an appropriate conceptual framework for this study.

Finally, culturally appropriate instruments for African American caregivers should be developed and used for reporting reliable and valid results on African American caregivers. Historically, African Americans are less likely to talk about family concerns and are reluctant to express personal emotions particularly to researchers. Since most of the scales employed in this study were originally designed for Caucasian caregivers, the results with these scales may not exactly measure African American caregivers' primary stressors, secondary stressors, religious/spiritual coping, formal social support, and informal social support.

### Conclusion

Research about the experiences of African American caregivers is limited. In addition, literature about African American caregivers of older adults with chronic illness is also limited. The majority of the research compares African American caregivers to other ethnic groups (Caucasians, Latino, Asian etc.). Literature tends to focus on caregiving to those with Dementia, Alzheimer, and terminal illnesses as opposed to care recipients with chronic illness. This population is crucial since chronic illness is affecting a large population of African American elderly and their caregivers. Chronic illness can become very debilitating and require long term caregiving needs.

From the results of this correlational study African American caregivers have several stressors and mediators that affect their level of physical and/or mental health outcomes that should be considered when working with this population of caregivers. This research should be explored in more detail in order to contribute to knowledge and understanding of African American caregivers, so that appropriate interventions can be developed to assist the growing

population of African American caregivers providing assistance to older adults with chronic illness.

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APPENDICES

APPENDIX A  
QUESTIONNAIRE

## APPENDIX A-1

---

 CAREGIVER'S BACKGROUND CHARACTERISTICS
 

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**PLEASE CIRCLE YOUR ANSWER**

1. What is your Gender ? [CGGENDER]                      1. Female                      2. Male
2. What is your (Caregiver) current age? ? \_\_\_\_\_ [CGAGE]
3. How much education have you had? [CGEDUC]
- |  |                           |
|--|---------------------------|
| <input type="checkbox"/> Less than 6 <sup>th</sup> grade                         | 5. Trade/Technical School |
| <input type="checkbox"/> Junior high school (7 <sup>th</sup> - 8 <sup>th</sup> ) | 6. Some College           |
| <input type="checkbox"/> Partial High School                                     | 7. 2- year college degree |
| <input type="checkbox"/> High school graduate, GED,<br>or equivalent             | 8. 4-year college         |
|  | 9. Graduate/Professional  |
4. What is your marital status ? [CGMSTAT]
- |                      |              |
|----------------------|--------------|
| 1. Single            | 4. Separated |
| 2. Living as Married | 5. Divorced  |
| 3. Married           | 6. Widowed   |
5. If you don't mind, would you tell me you approximate annual household income? (Caregiver) [CGINCOME]
- |                       |                     |
|-----------------------|---------------------|
| 1. Less than \$18,000 | 4. 38,001 to 48,000 |
| 2. 18,001 to 28,000   | 5. 48,001 to 58,000 |
| 3. 28,001 to 38,000   | 6. More than 58,001 |
6. What is your current religious preference? [CGRELIG]
- |              |                                    |
|--------------|------------------------------------|
| 0. None      | 6. Muslim                          |
| 1. Baptist   | 7. Non Denominational              |
| 2. Catholic  | 8. Presbyterian                    |
| 3. Episcopal | 9. Roman Catholic                  |
| 4. Lutheran  | 10. Jehovah Witness                |
| 5. Methodist | 11. Others (Please specify: _____) |



## APPENDIX A-2

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**CARE-RECIPIENT'S BACKGROUND CHARACTERISTICS**

---

1. What is the Care-recipient's Gender? [CRGENDER]
  1. Female
  2. Male
  
2. What is the Care-recipient's Age? \_\_\_\_\_ [CRAGE]
  
3. What is the Care Recipient's Income? [CRINCOME]
  1. Less than \$18,000
  2. 18,001 to 28,000
  3. 28,001 to 38,000
  4. 38,001 to 48,000
  5. 48,001 to 58,000
  6. More than 58,001
  
4. What diagnosis does the Care-recipient have? (Circle ALL that apply) [CRHEALTH]
  1. Cardiovascular Disease (Any Heart Disease) \_\_\_\_\_
  2. Hypertension (High Blood Pressure)
  3. Diabetes (Sugar) (Circle: Insulin or Non Insulin)
  4. High Cholesterol
  5. Dementia
  6. Stroke
  7. Others: \_\_\_\_\_

## APPENDIX A-3

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 CAREGIVING HISTORY
 

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1. How long have you been providing care to the care recipient? [CHLTH]
  1. Less than 3 months
  2. 3 to 6 months
  3. 7 to 9 months
  4. 10 to 12 months
  5. 13 to 24 months
  6. More than 24 months (How many years ? \_\_\_\_\_)
  
2. How many hours do you provide care on weekly basis? \_\_\_\_\_ Hours [CHHOURS]
  1. 7 - 15 weekly hours
  2. 16 - 24 weekly hours
  3. 25 - 33 weekly hours
  4. 34 - 42 weekly hours
  5. 43 - 51 weekly hours
  6. Other \_\_\_\_\_ Hours
  
3. If you are absent, does your family have secondary or third caregiver and who are they? [CHABSENT]
  1. No
  2. Yes  
If yes, who are they? (i.e. sister, brother, niece, etc.)

2<sup>nd</sup> Caregiver \_\_\_\_\_

3<sup>rd</sup> Caregiver \_\_\_\_\_
  
4. How many people are you caring for over the age of 55 ? \_\_\_\_\_ [CHOD]
  - 4 a. Your Relation: (Circle as many that apply) [CHODR]
    1. Child
    2. Parent
    3. Spouse
    4. Relative
    5. Other \_\_\_\_\_

5. How many people are you caring for between 18 and 55 ? \_\_\_\_\_ [CHAD]

5 a. Your Relation: (Circle as many that apply) [CHADR]

1. Child
2. Spouse
3. Relative
4. Other \_\_\_\_\_

6. How many people are you caring for under the age of 18 ? \_\_\_\_\_ [CHCH]

6. a Your Relation: (Circle as many that apply) [CHCHR]

1. Your own Children (How many ? \_\_\_\_\_)
2. Your own Grandchildren (How many ? \_\_\_\_\_)
3. Other Relatives (How many ? \_\_\_\_\_)

## APPENDIX A-4

## CAREGIVING JUSTIFICATIONS

I give care because \_\_\_\_\_ : [CGJ]

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

Questions	Answers			
1). It is my duty to provide care to elderly dependant family members. [CGJ01]	4	3	2	1
2). It is important to set an example for the children in the family. [CGJ02]	4	3	2	1
3). I was taught by my parents to take care of elderly dependant family member. [CGJ03]	4	3	2	1
4). Of my religious and spiritual beliefs. [CGJ04]	4	3	2	1
5) By giving care to elderly dependant family members, I am giving back what has been given to me. [CGJ05]	4	3	2	1
6). It strengthens the bond between me and them. [CGJ06]	4	3	2	1
7). I was raised to believe care should be provided in the family. [CGJ07]	4	3	2	1
8). It is what my people have always done. [CGJ08]	4	3	2	1
9). I feel as though I am being useful and making a family contribution. [CGJ09]	4	3	2	1
10). My family expects me to provide care. [CGJ10]	4	3	2	1

## APPENDIX A-5

## PRIMARY STRESSORS

1. Please inform us about your **CARE RECIPIENT's** daily living skills. Does the care recipient (your relative/friend) need help with:

2 =	Independent
1 =	Needs Some Assistance
0 =	Totally Dependant

(1) Eating [CRADL01]	0	1	2
(2) Dressing [CRADL02]	0	1	2
(3) Shaving or putting on make-up [CRADL03]	0	1	2
(4) Bathing [CRADL04]	0	1	2
(5) Going to the bathroom [CRADL05]	0	1	2
(6) Walking (outdoor) [CRADL06]	0	1	2
(7) Walking (indoor) [CRADL07]	0	1	2
(8) Watching Television [CRIADL08]	0	1	2
(9) Using the Telephone [CRIADL09]	0	1	2
(10) Shopping (groceries/clothing) [CRIADL10]	0	1	2
(11) Preparing their own meals [CRIADL11]	0	1	2
(12) Doing their own housework [CRIADL12]	0	1	2
(13) Taking their own medication [CRIADL13]	0	1	2
(14) Handling their own money [CRIADL14]	0	1	2

2. These are some problems that some CARE RECIPIENT's have. Please indicate if any of these problems occurred during the past week . (MEMORY AND BEHAVIORAL)

4 =	Never occurred
3 =	Occurred infrequently and not in the last week
2 =	Occurred 1 or 2 times in the past week
1 =	Occurred 3 to 6 times in the past week
0 =	Occurs daily or more often

Statements	Your Rating
(1) Asking the same question over and over. [CRMB01]	0 1 2 3 4
(2) Trouble remembering recent events (e.g., items in the newspaper or on TV). [CRMB02]	0 1 2 3 4
(3) Trouble remembering significant past events. [CRMB03]	0 1 2 3 4
(4) Losing or misplacing things. [CRMB04]	0 1 2 3 4
(5) Forgetting what day it is. [CRMB05]	0 1 2 3 4
(6) Starting but not finishing things. [CRMB06]	0 1 2 3 4
(7) Difficulty concentrating on a task. [CRMB07]	0 1 2 3 4
(8) Destroying Property. [CRMB08]	0 1 2 3 4
(9) Doing things that embarrass you. [CRMB09]	0 1 2 3 4
(10) Waking you or other family members up at night. [CRMB10]	0 1 2 3 4
(11) Talking loudly and rapidly. [CRMB11]	0 1 2 3 4
(12) Appears anxious or worried. [CRMB12]	0 1 2 3 4
(13) Engaging in behavior that is potentially dangerous to self or others. [CRMB13]	0 1 2 3 4
(14) Threats to hurt oneself. [CRMB14]	0 1 2 3 4
(15) Threats to hurt others. [CRMB15]	0 1 2 3 4
(16) Aggressive to others verbally. [CRMB16]	0 1 2 3 4
(17) Appears sad or depressed. [CRMB17]	0 1 2 3 4
(18) Expressing feelings of hopelessness or sadness about the future (e.g., "Nothing worthwhile ever happens," "I never do anything right"). [CRMB18]	0 1 2 3 4
(19) Crying and tearfulness. [CRMB19]	0 1 2 3 4
(20) Commenting about death of self or others (e.g., "Life isn't worth living," "I'd be better of dead"). [CRMB20]	0 1 2 3 4
(21) Talking about feeling lonely. [CRMB21]	0 1 2 3 4
(22) Comments about feeling worthless or being a burden to others. [CRMB22]	0 1 2 3 4

(23) Comments about feeling like a failure or about not having any worthwhile accomplishments in life. [CRMB23]	0 1 2 3 4
(24) Arguing, irritability, and/or complaining. [CRMB24]	0 1 2 3 4

3. Here are some statements about your (CAREGIVER) energy level and the time it takes to do the things you have to do. How much does each statement describe you? (OVERLOAD).

4 = Not at All
3 = Somewhat
2 = Quite a bit
1 = Completely

Statement	Answer
(1) You are exhausted when you go to bed at night. [CGRO01]	4 3 2 1
(2) You have more things to do than you can handle. [CGRO02]	4 3 2 1
(3) You don't have time just for yourself. [CGRO03]	4 3 2 1
(4) You work hard as a caregiver but never seem to make any progress. [CGRO04]	4 3 2 1

4. Caregiver's sometimes feel that they lose important things in life because of their relative's illness. To what extent do you feel that you personally have lost the following? How much have you lost: (RELATIONSHIP)

Statement	Answer
(1) Being able to confide in your relative. [CGLR01]	4 3 2 1
(2) The person whom you used to know. [CGLR02]	4 3 2 1
(3) Having someone who really knew you well [CGLR03]	4 3 2 1
(4) The practical things (he/she) used to do for you [CGLR04]	4 3 2 1
(5) Contact with other people [CGLR05]	4 3 2 1

5. Here are some thoughts and feelings that people sometimes have themselves as caregivers. How much does each statement describe your thoughts about your caregiving? How much do you: (ROLE CAPTIVITY)

4 =	Very much
3 =	Somewhat
2 =	Just a little
1 =	Not at all

1). Wish you were able to lead a life of your own	[CGRC01]	4	3	2	1
2). Feel trapped by your relative's illness	[CGRC02]	4	3	2	1
3). Wish you could just run away	[CGRC03]	4	3	2	1

## APPENDIX A-6

## SECONDARY STRESSORS

1. Family members may differ among themselves in the way they care for a family member.  
(FAMILY CONFLICT)

4 = No Disagreement  
 3 = Just a little disagreement  
 2 = Some disagreement  
 1 = Quite a bit of disagreement

How much disagreement have you had with anyone in your family concerning any of the following issues?

Statement	Answer			
(1) The seriousness of your relative's memory problem [FC01]	4	3	2	1
(2) The need to watch out for your relative's safety, [FC02]	4	3	2	1
(3) What things your relative is able to do for himself/herself. [FC03]	4	3	2	1
(4) Whether your relative should be placed in a nursing home. [FC04]	4	3	2	1

Thinking of all your relatives, how much disagreement have you had with anyone in your family because of the following issues? (How much disagreement have you had with anyone in your family because they):

(5) Don't spend enough time with your relative [FC05]	4	3	2	1
(6) Don't do their share in caring for your relative [FC06]	4	3	2	1
(7) Don't show enough respect for your relative [FC07]	4	3	2	1
(8) Lack patience with your relative [FC08]	4	3	2	1
(9) Don't visit or telephone you enough [FC09]	4	3	2	1
(10) Don't give you enough help [FC10]	4	3	2	1
(11) Don't show you enough appreciation for your work as a caregiver [FC11]	4	3	2	1
(12) Give you unwanted advice [FC12]	4	3	2	1

2. From your personal experience, how much do you agree or disagree with the following statements about your present work situation ? In the last 2 months or so : ? (WORK CONFLICT)

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

1. You have less energy for your work [WC01]	4	3	2	1
2. You have missed too many days [WC02]	4	3	2	1
3. You have been dissatisfied with the quality of your work [WC03]	4	3	2	1
4. You worry about your relative (friend) while you are at work [WC04]	4	3	2	1
5. Phone calls about or from your relative (friend) interrupt your work [WC05]	4	3	2	1

3. Think back to your financial situation as it was just before you began taking care of your relative. Compared with just before you began to take care of your relative (friend) answer the following: (FINANCIAL STRAIN)

5 =	Much more now
4 =	Somewhat more now
3 =	About the same
2 =	Somewhat less now
1 =	Much less now

1. Compared to that time, how would you describe your total household income from all sources? [FS01]	5	4	3	2	1
2. Compared to that time, how would you describe your monthly expenses ? [FS02]	5	4	3	2	1

3 =	Some money left over
2 =	Just enough to make ends meet
1 =	Not enough to make ends meet

3. In general, how do your family finances work out at the end of the month ? [FS03]	3	2	1
--	---	---	---

## 4. How do you feel about your ability to care for your relative? (MASTERY)

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

1. I can fit in most of the things I need to do in spite of the time taken by caring for my relative. [CGM01]	4	3	2	1
2. I feel uncertain about what to do about my relative [CGM02]	4	3	2	1
3. I feel reassured knowing that as long as I am helping my relative, he/she is getting proper care ? [CGM03]	4	3	2	1
4. You should be doing more for your relative. [CGM04]	4	3	2	1
5. You could be doing a better job in caring for your relative. [CGM05]	4	3	2	1
6. In general, I feel I am able to handle most problems in the care of my relative [CGM06]	4	3	2	1
7. I am pretty good at figuring out what my relative needs [CGM07]	4	3	2	1
8. Nothing I do seems to please my relative. [CGM08]	4	3	2	1
9. Taking responsibility for my relative giver my self-esteem a boost. [CGM09]	4	3	2	1
10. My relative is beyond being helped by most things I do for him/her [CGM10]	4	3	2	1
11. The things I do for my relative keeps him/her from getting worse. [CGM11]	4	3	2	1
12. I can take care of my relative with no help, or I could ---if I had to. [CGM12]	4	3	2	1

## 5. Caregiver's sometimes feel they lose important things in life because of their relative's illness. To what extent do you feel that you personally have lost the following? (LOSS OF SELF)

4 =	Completely
3 =	Quite a Bit
2 =	Somewhat
1 =	Not at all

1). A sense of who you are [LS01]	4	3	2	1
2). An important part of yourself [LS02]	4	3	2	1

6. Here are some thoughts and feelings that people sometime have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving? How much do you: (COMPETENCE)

4 =	Very much
3 =	Somewhat
2 =	Just a little
1 =	Not at all

1). Believe that you've learned how to deal with a very difficult situation [CP01]	4	3	2	1
2). Feel that all in all, you're a good caregiver [CP02]	4	3	2	1

4 =	Very
3 =	Fairly
2 =	Just a little
1 =	Not at all

Think now of all the things we've been talking about: the daily ups and downs that you face as a caregiver; the job you are doing; and the ways you deal with the difficulties. Putting all these things together:

3). How competent do you feel ? [CP03]	4	3	2	1
4). How self-confident do you feel ? [CP04]	4	3	2	1

7. Sometimes people can also learn things about themselves from taking care of a close relative. What about you? How much have you: (GAIN)

4 =	Very much
3 =	Somewhat
2 =	Just a little
1 =	Not at all

1). Become more aware of your inner strength. [GN01]	4	3	2	1
2). Become more self-confident [GN02]	4	3	2	1
3). Grown as a person [GN03]	4	3	2	1
4). Learned to do things you didn't do before [GN04]	4	3	2	1

## APPENDIX A-7

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 CAREGIVER SOCIAL SUPPORT SYSTEMS
 

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1. Please inform us about formal service you have used in the last 6months? Did you use the following services and programs for caring your care-recipient? (FORMAL)

- |                                    |                         |        |
|------------------------------------|-------------------------|--------|
| (1) Nursing home care              | (How long _____ Months) | [FS01] |
| (2) Hospital – inpatients          | (How long _____ Months) | [FS02] |
| (3) Hospital – outpatients         | (How long _____ Months) | [FS03] |
| (4) Adult day care                 | (How long _____ Months) | [FS04] |
| (5) Respite care                   | (How long _____ Months) | [FS05] |
| (6) Home care                      | (How long _____ Months) | [FS06] |
| (7) Support groups                 | (How long _____ Months) | [FS07] |
| (8) Individual counseling          | (How long _____ Months) | [FS08] |
| (9) Family consultation            | (How long _____ Months) | [FS09] |
| (10) Information & Referral        | (How long _____ Months) | [FS10] |
| (11) Others (Please Specify _____) |                         | [FS11] |

2. Please CIRCLE the number that best reflects your answer. (INFORMAL)

(1) How many relatives (including in-laws) do you see or hear from at least once a month?  
[IS01]

- |                   |                  |
|-------------------|------------------|
| 0. Zero relatives | 3. 3-4 relatives |
| 1. 1 relative     | 4. 5-8 relatives |
| 2. 2 relative     | 5. 9+ relatives  |

(2) Tell me about the relative with whom you have the most contact? How often do you see or hear from that person? [IS02]

- |                        |                       |
|------------------------|-----------------------|
| 0. < Monthly           | 3. Weekly             |
| 1. Monthly             | 4. A few times a week |
| 2. A few times a month | 5. Daily              |

(3) How many relatives do you feel close to? That is, how many of them do you feel at ease with, can talk to about private matters, or can call on for help? [IS03]

- |                   |                  |
|-------------------|------------------|
| 0. Zero relatives | 3. 3-4 relatives |
| 1. 1 relative     | 4. 5-8 relatives |
| 2. 2 relative     | 5. 9+ relatives  |

(4) Do you have any close friends? That is, do you have any friends with whom you feel at ease, can talk to about private matters, or can call on for help? [IS04]

- |                   |                  |
|-------------------|------------------|
| 0. Zero relatives | 3. 3-4 relatives |
| 1. 1 relative     | 4. 5-8 relatives |
| 2. 2 relative     | 5. 9+ relatives  |

(5) How many of these friends do you see or hear from at least once a month? [IS05]

- |                   |                  |
|-------------------|------------------|
| 0. Zero relatives | 3. 3-4 relatives |
| 1. 1 relative     | 4. 5-8 relatives |
| 2. 2 relative     | 5. 9+ relatives  |

(6) Tell me about the friend with whom you have the most contact. How often do you see or hear from that person? [IS06]

- |                        |                       |
|------------------------|-----------------------|
| 0. < Monthly           | 3. Weekly             |
| 1. Monthly             | 4. A few times a week |
| 2. A few times a month | 5. Daily              |

(7) When you have an important decision to make, do you have someone you can talk to about it? [IS07]

- |              |               |
|--------------|---------------|
| 0. Never     | 3. Often      |
| 1. Seldom    | 4. Very often |
| 2. Sometimes | 5. Always     |

(8) When other people you know have an important decision to make, do they talk to you about it? [IS08]

- |              |               |
|--------------|---------------|
| 0. Never     | 3. Often      |
| 1. Seldom    | 4. Very often |
| 2. Sometimes | 5. Always     |

(9) Do you help anybody with things like shopping, filling out forms, doing repair, providing child care, etc.? [IS09]

- |              |               |
|--------------|---------------|
| 0. Never     | 3. Often      |
| 1. Seldom    | 4. Very often |
| 2. Sometimes | 5. Always     |

(10) Do you live alone or with other people? [IS10]

lives alone (0)

lives with other unrelated individuals (1)

lives with other relatives or friends (4)

lives with spouse (5)

## APPENDIX A-8

## RELIGIOUS/SPIRITUAL COPING

4 =	A Great Deal
3 =	Quite a Bit
2 =	Somewhat
1 =	Not at all

1). I think about how my life is a part of a larger spiritual force [PC01]	4	3	2	1
2). I work together with God as partners to get through hard times [PC02]	4	3	2	1
3). I look to God for strength, support and guidance in crises. [PC03]	4	3	2	1
4). I try to find the lesson from God in crises [PC04]	4	3	2	1
5). I confess my sins and ask for God's forgiveness [PC05]	4	3	2	1
6). I feel that stressful situations are God's way of punishing me for my sins or lack of spirituality. [NC01]	4	3	2	1
7). I wonder whether God has abandoned me. [NC02]	4	3	2	1
8). I try to make sense of the situation and decide what to do without relying on God. [NC03]	4	3	2	1
9). I question whether God really exist. [NC04]	4	3	2	1
10). I express anger at God for letting terrible things happen. [NC05]	4	3	2	1
11). To what extent is your religion involved in understanding or dealing with stressful situations in any way? [OC01]	(Check One)			
	Very Involved			(4)
	Somewhat Involved			(3)
	Not very involved			(2)
	Not involved at all			(1)

## APPENDIX A-9

## HEALTH OUTCOMES

These questions ask for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

For each of the following questions, please select the one response best describes your answer.

1. In general, would you say your health is: [GH01]

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/>				

2. Compared to one year ago, how would you rate your health in general now? [HT]

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
	▼	▼	▼
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports [PF01]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf [PF02]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Lifting or carrying groceries [PF03]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- |  |                          |                          |                          |
|--|--------------------------|--------------------------|--------------------------|
| d. Climbing several flights of stairs [PF04] | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Climbing one flight of stairs [PF05]      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Bending, kneeling, or stooping [PF06]     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Walking more than a mile [PF07]           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Walking several hundred yards [PF08]      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Walking one hundred yards [PF09]          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Bathing or dressing yourself [PF10]       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- |  | All of the time          | Most of the time         | Some of the time         | A little of the time     | None of the time         |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
|  | ▼                        | ▼                        | ▼                        | ▼                        | ▼                        |
| a. Cut down on the amount of time you spent on work or other activities [RPO1]                       | <input type="checkbox"/> |
| b. Accomplished less than you would like [RP02]  | <input type="checkbox"/> |
| c. Were limited in the kind of work or other activities [RP03]                                       | <input type="checkbox"/> |
| d. Had difficulty performing the work or other activities (for example, it took extra effort) [RP04] | <input type="checkbox"/> |

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- |  | All of the time          | Most of the time         | Some of the time         | A little of the time     | None of the time         |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
|  | ▼                        | ▼                        | ▼                        | ▼                        | ▼                        |
| a. Cut down on the amount of time you spent on work or other activities [RE01] | <input type="checkbox"/> |
| b. Accomplished less than you would like [RE02]                                | <input type="checkbox"/> |
| c. Did work or other activities less carefully than usual [RE03]               | <input type="checkbox"/> |

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? [SF01]

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="radio"/>				

7. How much bodily pain have you had during the past 4 weeks? [BP01]

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="radio"/>					

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? [BP02]

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="radio"/>				

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a. Did you feel full of life? [VT01]	<input type="radio"/>				
b. Have you been very nervous? [MH01]	<input type="radio"/>				
c. Have you felt so down in the dumps that nothing could cheer you up? [MH02]	<input type="radio"/>				
d. Have you felt calm and peaceful? [MH03]	<input type="radio"/>				
e. Did you have a lot of energy? [VT02]	<input type="radio"/>				
f. Have you felt downhearted and depressed? [MH05]	<input type="radio"/>				
g. Did you feel worn out? [VT03]	<input type="radio"/>				

- h. Have you been happy? [MH05]
- i. Did you feel tired? [VT04]

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)? [SF02]

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
<input type="checkbox"/>				

11. How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
	▼	▼	▼	▼	▼
a. I seem to get sick a little easier than other people [GH02]	<input type="checkbox"/>				
b. I am as healthy as anybody I know [GH03]	<input type="checkbox"/>				
c. I expect my health to get worse [GH04]	<input type="checkbox"/>				
d. My health is excellent [GH05]	<input type="checkbox"/>				

## APPENDIX A-10

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**FINAL QUESTIONS**

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1. Where do you live?  
  
City:  
  
State:  
  
Zip code:
  
2. What was your relationship like with the care recipient before he/she became ill?
  
3. What do you find *most stressful* about being a caregiver?
  
4. What do you find *most rewarding* about being a caregiver?
  
5. Since you have started caring for your family member/friend, have your physical health changed? If so, how (i.e. Is it better, worse, more medications, less medications, new medical diagnosis, weight gain, weight loss, and/or frequently missed doctor appointments for yourself)
  
6. How many of your African American friends, family members and/or coworkers providing care to older adults 55 + ?

7. Do you know if any of these caregivers would be willing to participate in this survey? If so, do you feel comfortable providing their name, phone number and/or email address.

**NAME**

**CONTACT INFORMATION**

**THANK YOU FOR PARTICIPATING IN MY RESEARCH!!!!**