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Caregiver Burden and Racial Discrimination in African Americans:

A Mixed Methods Study of Chronic Stress

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Doctor of Philosophy

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Abstract

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Background: Caregiver burden is a multidimensional response to the physical, emotional, and financial stressors of caring for chronically ill adults. It has been repeatedly linked with negative health outcomes. Despite enduring multiple challenges as caregivers, African Americans have long been described as being less burdened by their caregiving responsibilities, compared to their White counterparts. In contrast to what has been previously depicted in the literature, caregiver burden in African Americans is becoming a significant concern for a widening group of social scientists. This dissertation examined the diverse ways African Americans are specifically affected by the ongoing stress of caring for a loved one.

Purpose: The purpose of the study was to examine the psychological and biological effects of chronic stress, specifically caregiver burden and racial discrimination, on the health of African American caregivers of dementia patients.

Methods: To unpack the stress and coping process and explore burden comprehensively, we utilized a mixed methods design with both quantitative and qualitative components.

Sample: The data came from a program project grant that included a study of African American caregivers of patients diagnosed with Alzheimer's dementia. The current study used data from 100 African American informal family caregivers, 90% being women. From this sample, nine caregivers were selected for follow up in-depth interviews.

Findings: This study was able to illuminate multiple challenges African American family caregivers face. Consistent with previous findings, we discovered that caregiver burden and discrimination have independent relationships with both depression and anxiety. We also discovered discrepancies between the survey data and narrative accounts of caregiver burden. The sense of obligation and disruption emerged as two prominent components of the burden experience for these caregivers.

Discussion: We concluded that discrimination was an added stressor for African American caregivers, significantly predicting both depression and anxiety. Although some caregivers were more resilient and perceived low levels of burden, the caregivers were on average highly burdened by their caregiving responsibilities. By accounting for discrimination and using mixed methods, our findings extend the current understanding of the impact of caregiving in African Americans and will hopefully influence future research, clinical practice and health policy.

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I would like to start with recognizing the John A. Hartford, Building Capacity for Geriatric Nursing Research and the Substance Abuse and Mental Health Service Administration Minority Fellowship Program for their generous dissertation research funding support.

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To the four most important people in my life – my husband Bruce David and three children, Madison, Dylan-Nicole, and Jude – it is because of you that I kept going every day. You are my inspiration.

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Dedication

I would like to dedicate this dissertation to my grandmother, Ms. Effie Mae Frances Albright, who suffered from dementia for many years prior to her passing during my doctoral program. She was a strong woman who always taught me that education was something no one could take from me. To my courageous brother, Vernon Markham, who “stepped up" and with the help of his wife, took great care of grandma. Thank you for your sacrifice. Your love and commitment to our family was a source of inspiration for this important work.

TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

Statement of the Problem

Over the next 40 years, the United States (US) population is projected to grow to approximately 439 million, an increase of 42% (US Census, 2010). In addition to the growing population, there is also an expected rise in the number of older adults. By the year 2030, nearly one in five United States residents will be aged 65 and older. This rapid change in age structure is largely due to aging baby boomers, causing a shift from the older population (aged 65 and up) making up 13% to a projected 19% of the total United States population (US Census, 2010). US residents are also living longer. The number of people 85 and older is projected to grow from 5.8 million in 2010 to 8.7 in 2030 and to 19 million in 2050 (US Census, 2010).

As individuals age, there is a greater likelihood for chronic illnesses such as diabetes, heart disease, and dementia (Institute of Medicine [IOM], 2007). Chronic illnesses account for 70% of the deaths that occur in the United States each year (IOM, 2012). Chronic illnesses are the leading cause of disease and death in our country, and due to increases in life expectancies in the United States, these conditions are also rapidly increasing (Harris & Wallace, 2012). For example, there are currently 5.2 million people diagnosed with Alzheimer's disease (AD) in the United States; however, projections indicate that by 2050, the incidence of AD will most likely equal one million people annually, bringing a total estimated prevalence to nearly 16 million people with AD (Alzheimer's Association [AA], 2012).

Alzheimer's is the most common form of dementia (AA, 2012). Characterized by a loss of brain function that occurs with various diseases, dementia can affect cognitive functioning including memory, thinking, language, judgment, and behavior (National Library of Medicine, 2012). Individuals suffering from Alzheimer's and other dementing illnesses experience sharp declines in their level of functioning, requiring them to rely on others to assist them in their activities of daily living. The direct costs of caring for those with Alzheimer's or other dementias to American society are an annual estimate of over $200 billion (AA, 2014).

Diagnoses such as dementia require extended and ongoing management, and family members who provide care assume taxing responsibilities that include symptom assessment, evaluation, and decision-making. Many patients with chronic illnesses rely on family members for assistance with various duties such as medication administration, meal preparation, transportation, bathing, and toileting. Because the symptoms associated with dementia (i.e., progressive cognitive decline and behavioral changes) gradually result in reduced functional status, maintaining independent living can become nearly impossible.

Informal family caregivers have been described as the backbone of the healthcare system. There are currently more than 65 million caregivers currently in the United States (National Alliance for Caregiving [NAC] & American Association of Retired Persons [AARP], 2009). Approximately 15 million caregivers are specifically caring for individuals with AD (AA, 2012). The annual economic value of family caregiving is estimated to be over $450 billion (AA, 2012), a contribution made at a considerable cost to caregivers. There is compelling evidence that caring for older adults with chronic illnesses, particularly dementia, can be taxing and harmful to the health of the caregiver (Schulz & Sherwood, 2008). For several decades, research has repeatedly demonstrated that dementia caregivers have experienced higher levels of burden than other caregivers (NAC & AARP, 2009). It has been consistently shown that these caregivers have higher rates of disease, lower rates of healthcare use, and are less likely to engage in self-care activities than non-caregivers (Pinquart & Sorensen, 2006; Schulz & Martire, 2004). Schulz and Beach (1999) found that dementia caregivers had a 63% increased risk of death compared to non-caregivers.

Providing extensive informal care to adult family members can produce increased levels of stress for the caregiver. Exposure to chronic stress has been theorized to disrupt both neuroendocrine and immune systems (McEwen & Stellar, 1993; McEwen, 1998; McEwen & Seeman, 1999). Caregivers have been noted to have poorer immune status and more negative cardiovascular outcomes than their non-caregiving counterparts (Kiecolt-Glaser et al., 2003; Pinquart & Sorensen, 2007; Schultz & Sherwood, 2008; Aneshensel, Pearlin, & Schuler, 1993). In fact, earlier studies examining immune response in caregivers have shown that the stress of caring for a family member adversely affects immune markers responsible for controlling latent herpes viruses and antibody titers to latent Epstein-Barr virus (Kiecolt-Glaser, Dura, Speiche, Trask, & Glaser, 1991). Additionally, several inflammatory biomarkers have been associated with accelerated aging (Gouin, Hantsoo, & Kiecolt-Glaser, 2008).

Inflammation is an adaptive response necessary to promote health and healing in the body (Corwin, 2000). Chronic low levels of inflammation, however, have been shown to have negative health outcomes (Blackburn, 2001; Pace et al., 2006). Individuals experiencing chronic stress over time are at increased risk for the health consequences associated with chronic inflammation. For example, C-Reactive Protein (CRP) is considered an acute-phase reactant that is traditionally used as a marker of systemic inflammation or tissue injury (Du Clos & Mold, 2004). Synthesized by the liver, this globular protein is stimulated by circulating inflammatory cytokines and is responsible for activating the complement system (Clyne & Olshaker, 1999). An expanding body of research has indicated CRP as a risk predictor for future cardiovascular events, including myocardial infarctions in men and women (Lee, Colditz, Berkman, & Kawachi, 2003; Ridker, Hennekens, Buring, & Rifai, 2000).

Enduring chronic stress not only results in chronic inflammation and accelerated aging, but there is also growing evidence that the cumulative stress process can lead to the development of psychological conditions (Mausbach, Rabinowitz, Patterson, & Grant, 2007b). Researchers have discovered significant associations between increased cytokine activity with psychological stress and symptoms of depression (Raison, Capuron, & Miller, 2006; Tiemeier et al., 2003). The suggestion that the immune system plays a key role in the development of psychiatric disorders is not a new one; it was first suggested by Wagner-Jauregg in late 1800’s (Corwin, 2000). Recent discoveries of the relationship between cytokines and the central nervous system, however, have revitalized older theories (Corwin, 2000).

The negative health consequences of caregiving are of particular concern for African Americans. Along with the aging population, the United States is also becoming more diverse. As the Asian and Hispanic populations continue to soar in the United States, the African American population is also steadily growing. In 2010, African Americans made up 13.6%, or 42 million, of the total United States population (US Census, 2010). By 2050, however, the Census Bureau projects that African Americans will comprise approximately 15% (more than 65.7 million) of the total United States population. These growth projections are particularly alarming because of the existing health disparities in the African American community (United States Department of Health & Human Services [DHHS], 2010). Given this increase of diversity among the elderly, the US can expect not only a higher incidence of chronic illnesses among African Americans but also a higher prevalence of family caregiving for this population, as well. For example, in a recent special report on race, ethnicity, and AD, the Alzheimer's Association (2010) reported that African Americans are twice as likely to develop AD in their lifetime. With African Americans experiencing a disproportionate share of illnesses such as cardiovascular disease, hypertension, stroke, and dementia, we can expect a corresponding increased number of individuals requiring dependence on informal family caregivers.

African American caregivers may be at an even greater risk for negative health consequences because of additional psychosocial adversities minorities commonly face, such as race- and social status-related stressors. There is a pressing need for caregiving research to account for the cultural/historical context that can contribute to increased risk in minority populations. For example, minorities are much more likely to experience racism and discrimination than their White counterparts (Kessler, Mickelson, & Williams, 1999). One study found that when assessing perceived experiences of discrimination within the past 12 months, 70% of African Americans reported discrimination compared to 36% of Whites (Forman, Williams, & Jackson, 1997).

Research studies have overwhelmingly documented that discrimination is predictive of negative health outcomes (Williams & Mohammed, 2009), though little is known about its compounding effect on caregiver burden in African Americans. The concept of caregiver burden has long provided the field with a prevailing metaphor that captures the range of adverse impacts on caregivers. Dating back to very early studies on African American and White caregivers, African American caregivers have reported lower levels of caregiver burden than White caregivers (Lawton, Rajagopal, Brody, & Kleban, 1992; Mui, 1992; Hinrichsen & Ramirez, 1992). In light of more recent findings that appear to modify and even contradict this notion (Kingsberry, Saunders, & Richardson, 2010), there is a growing need to examine whether there might be a more nuanced and/or a changing set of results regarding caregiver burden, particularly among African American caregivers.

Purpose of the Study

The overall goal of this study is to improve our understanding of how the caregiving experience affects the health and wellbeing of African American caregivers. **The purpose of the study is to examine the psychological and biological effects of chronic stress, specifically caregiver burden and racial discrimination, on the health of African American caregivers of patients diagnosed with dementia.** Since the role of perceived discrimination on caregiver burden and health has been largely unexplored in African American caregivers of adults with chronic illnesses, the aims of this project are not only to examine the effects of caregiver burden but also to elucidate the role of perceived racial discrimination as an added burden on African American caregivers. The first two aims address both psychological (depression/anxiety) and biological (CRP) consequences of stress. The third specific aim of this study explores the essence of the relationships identified in the quantitative phase of the study. The research questions for the qualitative component are framed by a phenomenological approach and add richness by obtaining more details from the individual caregiver's life experiences. The specific aims (A), research questions (RQ), and hypotheses (H) for this study are as follows:

Specific Aims of the Study

A1. To examine the association between caregiver burden, perceived discrimination, and psychological distress measures (depression and anxiety) in African American caregivers.

H1. Participants with higher levels of caregiver burden and perceived discrimination will have increased levels of psychological distress, including significantly higher levels of depression and/or anxiety.

H2. Perceived discrimination will be a significant predictor of depression and anxiety in African American caregivers above and beyond caregiver burden.

A2. To assess the relationship between caregiver burden, discrimination, and C-Reactive Protein (CRP) in African American caregivers.

H1. Participants with higher levels of caregiver burden and discrimination will have significantly higher levels of C-Reactive Protein.

A3. To determine whether the narrative experiences of caregiving and burden are consistent with how African American family caregivers scored on the Zarit Burden instrument.

RQ 1: What is the meaning of burden in this sample of African American caregivers?

RQ 2: What is the meaning of race and racism for these African American caregivers?

This study consisted of a sample of 100 African American informal family caregivers of adults with dementia. The quantitative data were made available from a larger parent study, a program project (P01) grant titled: *Caregiver Stress: Interventions to Promote Health and Well-being*. The P01 had two nearly identical studies; the study that served as the parent study for this project was *Promoting Health and Wellbeing in African American Dementia Family Caregivers.* The current study involved both quantitative and qualitative research; however, the primary focus was on predictive quantitative research, followed by qualitative interviews of a smaller sample group of caregivers. There was an interest in first identifying whether a significant correlation existed between the independent variables (caregiver burden, perceived discrimination) and the dependent variables (CRP, psychological distress). Correlational statistics were conducted to describe the strength and direction of the relationships between the variables of interest.

Regression analysis procedures were employed to determine the predictive value of both caregiver burden and discrimination on caregiver health, measured by both physiological and psychological indicators.

The phenomenon of caregiver burden has not been adequately explored in African American caregivers (Kingsberry et al., 2010; Williams, Dilworth-Anderson, & Goodwin, 2003). By examining caregiver burden within a mixed method design, this project seeks to illuminate the nuances of the complex relationships identified by the variables selected for this study. The significance of this line of inquiry is that it might provide an enhanced understanding of caregiver burden and how perceived discrimination can be an added stressor for African American caregivers who are already experiencing increased levels of stress. This study will potentially generate new knowledge by exploring the relationship between perceived discrimination, caregiver burden, and physiological inflammatory biomarkers of stress in African American caregivers. Findings from this research could also be used to design future studies that investigate how perceived discrimination experienced by minority caregivers can negatively impact their ability to effectively care for their loved ones.

Theoretical Framework

With the US population aging and the minority population growing, it is becoming more relevant to understand how minority caregivers are uniquely affected by their caregiving responsibilities. Understanding how African Americans perceive, process, and are consequently affected by various stressors can possibly help explain specific health outcomes in this population. In fact, the examination of the relationship of stress and health and the role stress plays in producing health disparities in African Americans has become a significant topic of research (Sternthal, Slopen, & Williams, 2011). Theoretical frameworks are a valued component of a research project, as they serve to highlight key concepts and how these concepts relate to one another (Fawcett, 2005). In order to adequately investigate these complex relationships, it was essential to have an appropriate framework that could address this diverse set of variables comprehensively.

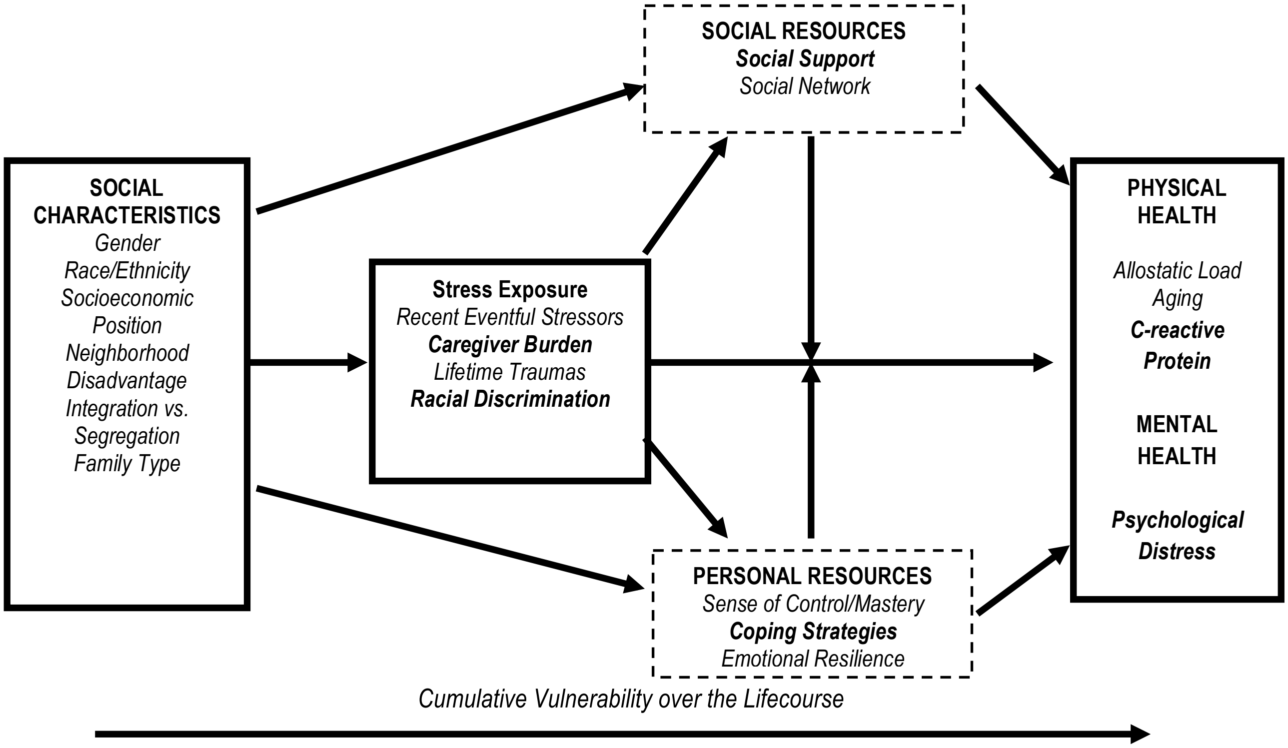

Figure 1.1. Expanded Stress Process Model, (Turner, 2010)
Note. Bolded variables were included and tested in the current study.

Pearlin Stress Process Model

The Pearlin Stress Process Model (SPM) has had a tremendous impact on multiple disciplines including psychology, sociology, gerontology, public health, and nursing. The original theoretical framework and the expanded model describes how contextual factors, including fixed and dynamic characteristics that individuals bring to the experience of caring for someone with dementia, provide a larger backdrop for understanding the stress process (Pearlin, Lieberman, Menaghan, & Mullan, 1981). The expanded Pearlin SPM (see Figure 1.1) includes complex relationships of race/ethnicity, socioeconomic position, and other social characteristics that can make one vulnerable to exposure to psychosocial adversities such as racism (Turner, 2010).

Social characteristics. There is an elaborate connection between the exposures of stress and status locations within various social arrangements and institutions (Turner, 2010; Pearlin et al., 1981). Three main components—stressors, moderators/mediators, and outcomes—are depicted in the model.

Unlike other models of stress (Kim, Knight, & Longmire, 2007), one of the distinct features of the SPM is the emphasis on social structures and contexts that can determine how individuals are exposed to stress (Pearlin, 1989). Pearlin states that “structural contexts of people’s lives are not extraneous to the stress process but are fundamental to that process” (1989, pg. 242). Stress researchers have historically examined the stress process from a psychological framework; however, growing evidence highlighting the role of social determinants of health have required a greater sociological perspective on how individuals are affected by stress (Pearlin, 1989).

One of the primary assumptions underlying this framework is that one’s social position can indirectly influence the process of stress exposure. Depending on the placement in stratified social structures, one can either be advantaged or disadvantaged in the stress process. Individuals of a lower social status might have limited access to psychosocial resources that might otherwise protect or ameliorate the negative impact of the exposure to stress (Pearlin, 1989). The amount of stress individuals are exposed to can have an additive and interactive effect, creating cumulative vulnerabilities in predicting health status over the lifespan (Ferraro & Shippee, 2009; Priestly, 2000; Myers, 2009). Pearlin (2005) argues that not only does social status affect the intricate and nuanced ways that a person is exposed to and copes with stress and consequently determines the health outcomes of the individual, but the placement itself can act as a stressor directly leading to health outcomes.

Stress exposure*.* Stressors can be described as the problems or hardships that challenge the adaptive capacities of people (Pearlin et al., 2005). In order to effectively trace the relationship between stress and health, Pearlin and colleagues are careful to distinguish types of stressors. For example, they differentiate acute (or event) stressors and chronic stressors. Pearlin encourages researchers to consider how acute stressors, such as a foreclosure on a home, could be more of an indication of the enduring stress of economic hardship. Pearlin also underscores the point that events need to be unambiguously distinguished from other types of stressors. This is an important distinction because recent reviews have shown that chronic stress in the form of perceived discrimination has been particularly deleterious for the emotional and physical health of minorities (Paradies, 2006; Pascoe & Richman, 2009; Williams & Mohammed, 2009). Chronic stressors are deemed serious because of their tendency to persist, as they are built into people's daily existence (Pearlin et al., 2005). Clarifying these constructs both conceptually and empirically advances our understanding of stress and its effect on health. Additional assumptions of the expanded SPM are that (1) the process of stress involves much more than the simple number and severity of stressors, (2) the exposure to stress and the resources to mitigate the stress directly come from the conditions of the individual's life, and 3) the stressors may be rooted in earlier circumstances and continue over the life course (Pearlin et al., 2005; Turner, 2010).

Mediating and moderating influences*.* There is a strong emphasis on both mediating and moderating influence on the relationship between stress and health. For example, various types of interpersonal and intrapersonal resources are highlighted in the model to demonstrate how individual- and community-level characteristics can alter and mitigate the effects of stress on health outcomes. In the expanded SPM, mediators and moderators have been divided into two categories: social and personal resources (Pearlin et al., 2005; Turner, 2010). Social resources in the model include caregivers' social networks and social support, whereas personal resources refer to individual coping strategies, emotional resilience, and mastery.

Coping*.* It is important to briefly note that root concepts and propositions in Lazarus' original stress and coping theory were also incorporated into the expanded stress process model. Lazarus and Folkman (1984) identified three concepts central to their theory: cognitive appraisal, emotion, and coping. Coping consists of cognitive and behavioral efforts to manage specific external and internal demands that are appraised as exceeding the resources of the person (Lazarus, 1993). Lazarus posited the theory of coping as a complex process with two major functions: problem-focused and emotion-focused. The function of problem-focused coping is to change the person-environment relationship by acting on the environment or oneself. The function of emotion-focused coping is to either change the stressful relationship with the environment or the meaning of what is happening (Lazarus, 1993). Aranda and Knight (1997) proposed that members of certain ethnic groups select specific coping strategies due to distinct cultural beliefs and values. For instance, they highlighted how African Americans are less likely to use effective coping strategies such as active (or problem-focused) coping and more likely to engage in emotion-focused (avoidance) coping strategies that could predispose them to more emotional distress (Knight, Silverstein, McCallum, & Fox, 2000). Because of the central role coping plays in the stress process and particular strategies found in studies with African Americans, avoidance coping was added to the theoretical model and selected as a control variable in the current study.

Social support. In addition to coping mechanisms and strategies, social support was also included as a mediating variable in our study. There is substantial evidence to support that the health and wellbeing of individuals are positively affected by the structure of their informal social networks, as well as by the quality and nature of the supportive activities of those networks (Pinquart & Sorensen, 2000; Yang, 2006). The findings are mixed in terms of how minority caregivers use and benefit from social support. In their 20-year review of caregiving studies, Dilworth-Anderson, Williams, & Gibson (2002) discovered that minority caregivers used formal services less than their White counterparts and that African American had more diverse informal social support systems. Janevic and Connell (2001) reported mixed findings in their review of the literature, with regard to size of support systems between African American and White caregivers. Despite the differences in social support systems across diverse groups, social support is generally seen as a dynamic, multidimensional construct that strongly influences how humans behave and how individuals perform in their social roles (Cohen & Syme, 1985). Personal resources such as emotional resilience and mastery can also be activated to mitigate the effects of the stressors (Pearlin, 2005). Studies have found that mastery—a sense of personal control—is a strong predictor of both psychological and physical outcomes (Mausbach et al., 2012; Pearlin et al., 1981; Pudrovska et al., 2005). Longitudinal studies have found that personal mastery can reduce the effects of stress on depression and cardiovascular health outcomes over time (Mausbach et al., 2007). Considering the evidence that demonstrates that social support is a critical variable that can strongly influence the relationship between appraised stress and health outcomes, it was included in the analysis. Resilience and mastery, however, were not accounted for in this study.

Outcomes. Stressful experiences have been empirically linked to diverse psychological, behavioral, and physiological outcomes. Taking the moderating and mediating variables into account, a wide variety of mental and physical states have been identified as potential outcomes of the stress process. Examples of the physiological effects of caregiver stress include increased stress hormones (Von Känel et al., 2012), suppression of the immune system (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey & Sheridan, 1996), increased incidence of hypertension (Shaw et al., 1996), and coronary heart disease (Vitaliano et al., 2002). Geronimus (1992) originally proposed the “weathering” hypothesis to account for the early deterioration of health in African Americans, particularly in Black women (with regard to childbearing). This hypothesis is relevant to research with African American caregivers, many of who are women. In fact, national studies have found that an estimated 70% of family caregivers of adults with dementia are women (Alzheimer’s Association, 2012). Geronimus’ hypothesis has been useful in explaining how the inherent stress of living in a race-conscious society that often marginalizes and disadvantages African Americans can disproportionately cause accelerated aging, such that African Americans show the morbidity and mortality typical of a White individual who is significantly older (Geronimus, 2006).

Given our understanding of how stress causes dysregulation of multiple biological processes, allostatic load appears to be conceptually well suited for the studying of “weathering” or the cumulative effects of chronic stress in minority caregivers (Geronimus, 2006). Developed by McEwen and colleagues, the concept of allostatic load has been defined as “the cumulative wear and tear on the body’s systems owing to repeated adaptation to stressors” (Geronimus, 2006, p. 826). Allostatic load provides a meaningful description of the biological consequences of the cumulative effects of the individual's response to chronic stress exposure (McEwen & Seeman, 1999). It has been operationalized with algorithms measuring biomarkers of stress. Although not explicitly stated in the model, the "weathering" hypothesis is implied by the inclusion of allostatic load as one of the outcomes of the expanded SPM.

Although more detailed than other caregiving stress models, the relationship between stress and health is less linear than what is portrayed in the SPM. The relationships that shape stress exposure and help create psychosocial adversities occur reciprocally through cognitive-emotional, behavioral, and biological pathways (Myers et al., 2009). The multiple pathways by which these complex interactions of race/ethnicity and other variables predict health over the lifespan are not highly emphasized. Despite not having these relationships explicitly outlined in the model, there is recognition of various theories that helped inform the development of the expanded SPM. In addition to cumulative disadvantage, inequality, and lifecourse theories, there is also an acknowledgement of a critical race perspective (Delagado & Stefancic, 2012) that emphasizes an awareness of how racism operates in our society. Remaining conscious of these mechanisms is key to explaining how racial differences in health exist (Thrasher, Clay, Ford & Stewart, 2012). The following section of this chapter includes a discussion of each of these theories and the relevance of their inclusion in this project.

Additional Theoretical Perspectives

Critical Race Theory

Originating from legal studies, critical race theory (CRT) is a perspective that is rooted in social justice and has been described as a methodology to assist researchers to remain conscious of race and equity (Ford & Airhihenbuwa, 2010). Transcending various disciplines, critical race theory integrates methodologies with the purpose of illuminating the root causes of social injustices, injustices that are known to create racial disparities in health. Critical race theorists—scholars who are interested in transforming the relationship among race, racism, and power—have been successful in generating a movement toward racial equity that “distinguishes contemporary racial mechanisms from older ones (e.g. Jim Crow)” (Ford & Airhihenbuwa, 2010, p. S31).

Researchers have been criticized for neglecting to acknowledge structural forces and for overemphasizing individual and interpersonal mechanisms (Ford & Airhihenbuwa, 2010). By retaining a critical race perspective in this project, we can begin to understand how societal structures and power differentials can set up a cascade of complex pathways that create negative outcomes for African Americans in the United States, while systematically advantaging others (Jones, 2000). These key insights can be useful in helping researchers focus less on individual behaviors and patterns and more on the larger systems that unfairly place minorities in positions of vulnerability and higher risk for poor health outcomes. Instead of focusing simply on “race,” the sample in this study has been limited to African American caregivers, thereby shifting the focus from how race shapes behavior to how racialized experiences, such as perceptions of discrimination, might influence health. The within-group design of this study allows the opportunity to explore the diverse experiences and perceptions among African Americans.

Another key concept in the CRT is *ordinariness* (Ford & Arihihenbuwa, 2010). Ordinariness describes how racism has become a societal norm and how consequently African Americans, along with other minorities, develop polarizing responses and either begin to ignore everyday racism or become hypervigilant about it (Ford & Arihehenbuwa, 2010). During the era of legalized discrimination and segregation by race, acts and notions of racism were known to be overt and aberrational, whereas acts of racism in the post-civil rights era are subtler in nature. Understanding that the ordinariness of racism can be experienced through constant and chronic exposures to daily insults and unfair treatment, the everyday discrimination scale has been selected as the study instrument to capture individuals’ perceptions of discrimination.

Central to the critical race perspective is the awareness of power differentials. As researchers affiliated with a predominately White institution, it is crucial that we are aware of the potential distrust we may face that might supersede the notion of racial concordance. In light of the qualitative interviews conducted with the selected participants, practicing reflexivity and maintaining critical self-consciousness was a particularly useful technique. Remaining attentive to intra-racial power imbalances throughout the study helped in attempts to alleviate a priori assumptions held regarding this particular population and maintaining trustworthiness of data interpretation.

Feminist Perspective

Knowing that women make up an estimated 59-75% of informal family caregivers (AARP, 2006), there was an expectation that the majority of the respondents in this study would also most likely be female. Although this project was not limited to only African American women, 90% of the participants in the study consisted of female caregivers. Like many other racial/ethnic groups, caregiving has been perceived as primarily a female role in the African American community (Sterritt & Porkorny, 1998). Given that the responsibilities and therefore consequences fall predominately on women, there was a need to also consider how feminist theory could enhance our understanding of how women in particular may be affected by providing long-term care.

Feminist theorists criticize how the firm stereotype of caregiving being primarily a domain of women silences women and perpetuates rigid family structures that socialize women into specific roles that ultimately hinder their pursuit of equality in society (Mackinnon, 2009). Women may feel as though they are unable to object to assumed responsibilities and subsequently suppress their feelings of anger or resentment, making them even more vulnerable to stress and strain. Scholars who have taken a feminist approach to unpacking *women as caregivers* have explored various aspects how women, particularly minority women, could be at increased risk for marginalization, and oppression (Mackinnon, 2009).

A feminist perspective also provides the researcher an opportunity to further explore the notion of intersectionality. This is particularly the case when the research involves African American women. Originally coined by an African American feminist scholar (Crenshaw, 1991), intersectionality was used to describe how African American women were excluded from both feminist and antiracist discourses—each respectively associating with either White women or African American men (Bowleg, 2012). Intersectionality, however, addresses how social identities are not independent, but multiple and intersecting. The experiences of women are strongly influenced and shaped by the positions they occupy in society and the intersections of multiple classifications such as gender, race, and class. These multiple social identities that are at the micro level actually intersect with structural factors at the macro level and ultimately produce disparities in health (Bowleg, 2012). For example, because of their social placements, African American women uniquely face social challenges such as poverty, lack of education, and vulnerability to disease—all of which can negatively affect health outcomes (Collins, 2000).

Intersectionality research investigating the health of minority groups, such as African American women, should do so within their contexts and vantage points, in contrast to using the White dominant culture as a referent (Weber & Parra-Medina, 2003). This becomes relevant when exploring phenomena that are rooted in cultural norms and experiences. In order to fully appreciate the complex ways African American women are affected by their roles as caregivers, it is imperative to explore the dynamic mechanisms of stress with this particular lens. Keeping the principles of feminism and intersectionality in mind will be helpful in developing probing questions for the in-depth qualitative interviews. Questions crafted with this perspective could aid in revealing the subtle complexities of how racism and sexism intersect to powerfully shape the experiences of African American women.

Lifecourse Perspective

Although it has not been formalized as a theory, the *lifecourse perspective* can be described as an approach for understanding the lives of people, but within the structural, cultural, and historical contexts of their life experiences. The lifecourse perspective recognizes that historical changes can significantly influence human behavior, and it also emphasizes the interdependence that humans have with others, primarily family members. Because of the particular attention on historical, cultural, and structural contexts of individuals' lives, the lifecourse perspective is relevant in this specific study in that it provides an understanding of the dynamic ways that experiences in adulthood can be traced back to earlier life experiences and anchor the current caregiving situation into the context of other experiences over the course of the caregiver's life (Hutchinson, 1997). If an African American caregiver has endured a lifetime of hardship, these experiences can shape their ability to cope with current stressors. Likewise, the lifecourse perspective also places special emphasis on how the various journeys of life can be extremely diverse. This appreciation of diversity and how these varying experiences can influence one's lifecourse brings fuller meaning and relevance of Pearlin's SPM and its applicability to the African American caregiver.

The idea of diverse trajectories is one of the most relevant themes in the lifecourse perspective that applies to this project. Ferraro and Kelley-Moore (2003) note that lifecourse studies suggest permanent effects on health or status attainment resulting from early inequalities. Some persons are advantaged in their early years, and this advantage may compound over time. Others are disadvantaged because of various factors, including both genetic and environmental; these disadvantages also accumulate over time (Priestley 2000). Preston and colleagues describe these disadvantages as "scarring" or inhibiting the individual's potential in life (Preston, Hill, and Drevenstedt, 1998, p. 1232). The more advantaged are set on promising trajectories leading to further advantage. Those who are disadvantaged early subsequently face additional risks to their health and wellbeing (Ferraro & Kelley-Moore, 2003). Early advantage or disadvantage is critical to how cohorts become differentiated. Early risk factors are instrumental in not only shaping short-term trajectories but long-term outcomes as well (Ferraro & Kelley-Moore, 2003). Although long-term change is expected, due to the cumulative effects of persistent disadvantage, the nature of the change is naturally linked with earlier experiences, abilities, and resources (Elder, 1995).

Cumulative disadvantage shapes an individual's risk for future vulnerability. Sternthal et al. (2011) found that when compared to other racial groups, African Americans have a higher prevalence of stress exposure. In this same study, the researchers also discovered that numerous stressors have an additive effect on health. If individuals are exposed to conditions and stressors earlier in life, these experiences can negatively predict health outcomes. This key point of the lifecourse perspective was essential in developing the specific aims of this study. Exposure to racism and discrimination can occur at various stages of the lifecourse, and measuring how they combine with other risk factors and stressors to ultimately affect health can be a powerful explanation of outcomes.

Chapter Summary

Studying complex variables such as race, racism, chronic stress, and biological measures can be challenging. The expanded SPM, however, is one of the most comprehensive theoretical frameworks in the stress literature. The emphasis on the contextual approach to understanding the stress and coping process in the expanded SPM has far-reaching implications. In order to retain the historical perspective that is necessary for understanding racial differences in health, it is critical to include societal factors in the theoretical framework. Additional theoretical perspectives provide salient underpinnings to this dissertation. The lifecourse and feminist perspectives, along with critical race theory, have enhanced the theoretical framework and guided the development of the interview questions. Incorporating these theories into the project provides the vocabulary that is necessary for revealing the potential interactions of the complex relationships within the stress and coping process. Research studies have overwhelmingly documented the negative health outcomes associated with discrimination; however, little is known about its compounding effect in minority caregivers. The purpose of the study is to examine the psychological and biological effects of chronic stress, specifically caregiver burden and racial discrimination, on the health of African American caregivers of adults with chronic illnesses. The specific aim exploring the additive effect of discrimination in the stress process of caregivers, coupled with the inclusion of CRP, makes the expanded Pearlin's SPM most fitting for guiding this study. The next chapter presents a review of the literature and not only summarizes how caregiving burden has been examined but also includes a discussion of how perceived experiences of discrimination have impacted the health of African Americans.

CHAPTER 2

LITERATURE REVIEW

Enduring stress over long periods of time can result in permanent changes in the physiological and psychological responses that influence vulnerability to and course of disease, making chronic stress toxic to one's health. (Cohen, Janicki-Deverts, & Miller, 2007). This conclusion has particular relevance for African American caregivers. Although caregiver burden has been widely studied, it is not fully understood in minority populations where a myriad of factors can influence how burden is experienced, perceived, and managed. Less is known about how other psychosocial stressors, including stress related to racialized experiences, can intensify the stress of caregiving responsibilities for African American caregivers. Understanding how discrimination correlates with existing stressors and outcomes can lead to discovering ways in which various psychosocial stressors interact, accumulate, and adversely affect caregivers' health. This study explored the relationship between perceived discrimination and caregiver burden in African American caregivers. The impact of discrimination and burden was assessed by measures of psychological distress (depression and anxiety) along with the inflammatory biomarker, CRP, to assess the physiological stress response.

The first chapter outlined how the growing number of individuals living longer is significantly contributing to the increased number of chronic illnesses in the United States. It also described how this phenomenon has placed a growing dependence on informal family caregivers. The evidence regarding the negative impact caregiving has on the health of the caregiver is quite compelling. This study specifically seeks to explore how African Americans are uniquely affected by the caregiving experience, particularly in light of the persisting inequities in society, health and health care. This chapter will include an overview of caregiver burden with particular attention to African American caregivers. It will also discuss how racial discrimination affects health. Finally, the chapter will conclude with a review of the topic of chronic stress and physiological biomarkers.

Impact of Dementia Caregiving

Family members provide care to over 80% of adults with AD who receive their care in the community (Zhu et al., 2008). More than 65% of the care given to these patients is from women (Family Caregiving Alliance [FCA], 2011). In 2010, 14.9 million families and other unpaid caregivers of people with Alzheimer's disease and other dementias provided about 17 billion hours of unpaid care (FCA, 2011). There is substantial evidence throughout the caregiving literature that shows that increased levels of stress negatively affect caregivers. The adverse effects of caregiving are particularly harsh on women, who assume more taxing responsibilities.

Researchers have found that women caregivers handle the most difficult caregiving tasks (i.e., bathing, toileting and dressing), whereas their male counterparts, are more likely to help with finances, arranging care, and other less burdensome tasks (NAC & AARP, 2009). A number of studies have also found that female caregivers are more likely than males to suffer from high stress due to caregiving (FCA, 2011). Research has shown that when compared to their non-caregiving counterparts, caregivers are more likely to have financial difficulties, endorse feelings of depression and psychological distress and are less likely to care for themselves (Janevic & Connell, 2004; Pinquart & Sorsesen, 2006; Schulz & Martie, 2004).

It has long been established that caregiving can have detrimental psychological effects for caregivers, however research has also demonstrated that caregiving can have serious physiological consequences as well. When asked about general health, 17% of caregivers feel their health has gotten worse as a result of their caregiving responsibilities (FCA, 2011). Family caregivers are also at risk for poor immune and cardiovascular health and mortality outcomes (Aneshensel et al., 1993; Gouin et al., 2008; Lee, Colditz, Berkman, & Kawachi, 2003; Schulz & Beach, 1999). Researchers interested in the adverse effects of caregiving have found that caregiver burden has been significantly linked with illness and poor health outcomes, including: mortality, depression, and decreased quality of life (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006).

Caregiver Burden

Caregiver burden is generally understood as a multidimensional response to the physical, emotional, and financial stressors of caring for an adult with a disabling condition (George & Gwyther, 1986; Zarit, 1980). It has also been defined as a strain or load carried by those caring for these elderly individuals (Montgomery, Gonyea & Hooyman, 1985; Pearlin, Mullan, Semple & Skaff, 1990) or as the negative repercussion of informal care (Gaugler, Kane, & Langlois, 2000). Others operationalize burden as reported stress associated with the provision of caregiving assistance (McGinnis, Schulz, Stone, Klinger, Mercurio, 2006; Sayegh & Knight, 2011). The concept has sometimes been divided into "subjective burden" (a caregiver's emotional response to the caregiving situation) and "objective burden" (the extent of disruption the caregiving has caused the caregiver's family and household) (Platt, 1985; Montgomery et al., 1985).

Gerontology researchers have defined burden in various ways. Some researchers use classic definitions that are more fitting to subjective burden, which describes the caregiver's attitude and response to the care recipient (McGinnis et al., 2006; Sayegh & Knight, 2011). Others use a combination of both subjective and objective interpretations (Elliott, Burgio, & DeCoster, 2010; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999). Still others attempt to broaden the concept by defining burden not only as a consequence of the care of the needed by an individual, but a multidimensional construct that influences both mental and physical health, work and finances, and other family relations (Allen-Kelsey, 1998; Kosberg, Kaufman, Burgio, Leeper, & Sun., 2007). For example, Kim et al. (2011) assessed caregiver burden by amount of physical strain, emotional stress and financial hardship. The distinction between subjective and objective burden is not consistently used in the literature (Chou, 2000). Although burden is a concept that has been recognized for more than thirty years, it has primarily been applied to caregivers of older adults with dementia.

Racial differences. Compared to White dementia caregivers, African American caregivers are generally younger, unmarried, and have greater financial hardship (Haley et al., 1996; Hinrichsen & Ramirez, 1992). They care for older adults with greater functional limitations, keep their elders at home longer, and perceive greater unmet needs (Pinquart & Sorensen, 2005). African American dementia caregivers, however, have been noted to perceive greater rewards with caregiving (Picot, 1995). Culturally embedded values, extended informal social networks, and the use of various types of religious coping have been suggested as elements of the African American experience that might mediate the negative influence of burden on caregiver health (Picot, Debanne, Namazi, & Wykle, 1997; Stevens et al., 2004; Wykle & Segal, 1991). Dilworth-Anderson and colleagues (2005) demonstrated in a study of 167 participants, that when compared to their White counterparts, African Americans are more likely to report cultural reasons for caregiving. Specific reasons tested in this study included: reciprocity or giving back, setting an example for children, being raised that care is provided by family members, and being expected to care for other family members.

There is a robust conversation contrasting the experience of African American dementia caregivers with that of White caregivers (Pinquart & Sorsen, 2005). For example, African American and White family caregivers differ in the use of health care services. White caregivers tend to have a better understanding of Alzheimer’s and other dementias (Ayalon & Arean, 2004). Studies have found that African American caregivers also believe many of the symptoms of Alzheimer’s disease are a part of the normal process of aging and tend to minimize behavior problems (Burns, Nichols, Graney, Martindale-Adams, Lummus, 2006; Gonzales, Gitlin, & Lyons, 1995).

Historically, African American dementia caregivers are reported to experience less depression and burden and greater satisfaction and fulfillment in their caregiving responsibilities than White caregivers (Lawton et al., 1992; Picot, 1995). Other findings suggest that, while African Americans are burdened by caregiving responsibilities, they might experience and/or express it differently (Calderon & Tennstedt, 1998;

Fox, Hinton, & Levkoff, 1999). More recently, researchers have described contemporary African American dementia caregivers as possibly becoming more burdened than Whites by their role. It has been suggested that key stressors, including limited economic resources, multiple caregiving roles, and reduced social support, have increased among African Americans (Hargrave, 2006; Kingsberry et al., 2010). Differences in how African Americans define burden and their distrust to disclose to White researchers have also been suggested as possible explanations of the discrepancies found in the literature (Hargrave, 2006).

The view that African Americans report lower levels of caregiver burden than Whites has a strong foundation in research history. Early studies consistently found that African Americans not only perceived lower levels of burden, role strain, and role demand, but also had less desire to institutionalize their relatives (Lawton et al., 1992; Mui, 1992; Hinrichsen & Ramirez, 1992). Trends of findings of lower burden among African Americans in the early to mid 1990's continued into the 2000's. Investigators consistently found that African Americans perceived lower levels of burden (Allen-Kelsey, 1998; Hughes et al., 1999; Knight et al., 2000; Spurlock, 2005). For example, Knight and colleagues (2000) concluded that although African American caregivers were younger and in poorer health (both tending to increase burden and emotional distress outcomes), they reported lower levels of burden. Similarly, Burns et al. (2006) found that African American caregivers were less likely to rate the behavior of the person they were caring for as "bothersome," even though, when compared to Whites, African American caregivers were more likely to have less education and lower annual income. Kosberg and colleagues (2007) also found fewer reports of burden among African American caregivers, despite finding that African American caregivers provided more hours of care and used denial to cope with the caregiving situation.

The picture, however, has always been more complicated. One of the earlier studies found that among African American caregivers, those with higher income and lower educational status did report higher levels of burden, suggesting that factors other than race or ethnicity could influence the experience of burden (Lawton et al., 1992). Likewise, Cox (1995) and colleagues' examination of caregiver stress among African American and White caregivers found no significant difference in stress between the two groups, as a whole, but found that African American caregivers who perceived a lack of informal support and incompetency had higher levels of stress, pointing to the important role of other mediators in caregiver burden.

Quantitative vs. Qualitative. Although most of the caregiver burden studies published find African American caregivers typically appraise lower levels of burden than do White caregivers, these conclusions are primarily from quantitative studies. Findings from qualitative studies yield considerably different results. An especially striking finding among these studies is the frequency and consistency with which African Americans caregivers described their situation in negative terms. In many qualitative studies exploring caregiving in African Americans, caregivers specifically use the words “anger” and “frustration” when describing their caregiving experience (Calderon & Tennstedt, 1998; Fox et al., 1999; Jones-Cannon & Davis, 2005; Kelley, 1994; Lampley-Dallas, Mold, & Flori, 2001; Loukiss, Farran & Graham, 1999; Sterritt & Pokorny, 1998).

Caregivers’ qualitative reports portray a more nuanced experience of stress and burden, an experience not necessarily captured in standard quantitative instruments designed to measure these concepts. These feelings are typically focused on the broader support systems, not just on the dyadic caregiving experience. Caregivers repeatedly report that they often felt frustrated by not receiving sufficient support from other family members, particularly from siblings (Jones-Cannon & Davis, 2005; Sterritt & Pokorny, 1998). Levy, Hillygus, Lui, and Levkoff (2000) found that African American caregivers discussed lack of support significantly more than other caregivers. Healthcare providers were identified as adding to the sense of frustration; this was often because providers were perceived as culturally insensitive to caregivers’ needs (Kelley 1994; Lampley-Dallas et al., 2001; Loukissa, Farran, & Graham, 1999).

Caregivers also point to larger social structures that place them in conditions they identify as “disadvantaged” and that tend to increase their overall feelings of frustration. For example, Lampley-Dallas and colleagues (2001) reported that African American caregivers perceived the lack of support groups in their neighborhoods as a service disparity that embodied their sense of perceived racism. Stereotypes formed by a socio-historical context might also shape and give meaning to unique sources of burden for the African American caregiver. For example, Fox et al. (1999) noted that all of the African American caregivers in their study commented on how their loved ones accused them of stealing. Although persecutory claims are not uncommon among dementia patients, these accusations were particularly painful to the caregivers. Fox and colleagues concluded that the meaning of these exchanges may derive from "local contexts of economic inequalities and vulnerability" and that this dimension of burden for African American caregivers has been largely ignored (Fox et al., 1999, pg. 518).

Despite the significant amount of research focused on caregiver burden, especially in dementia family caregivers, there remains a need to clarify the concept of burden in a manner that takes the historical and cultural aspects of diverse populations into account. When caregivers are allowed to share their stories freely, African American caregivers report struggles they face as caregivers. Although African American caregivers do, more frequently than White caregivers, cast their role positively and express satisfaction in support received from family and community, they also consistently verbalize feelings of anger and frustration (Jones-Cannon & Davis, 2005; Kelley, 1994; Lampley-Dallas et al., 2001).

Conceptualizing Racism

Racism has been defined as "a system of structuring opportunity and assigning value based on phenotype ("race") that unfairly disadvantages some individuals and communities (while) unfairly advantages other individuals and communities…" (Jones, 2003, p.10). Jones (2003) has conceptualized racism as operating on three levels: institutionalized, personally-mediated (interpersonal), and internalized. Institutionalized racism in the US began with the initial historical insult of oppression and legalized segregation based on race. At the institutional level, structural barriers are created for some individuals while unearned privilege is given to others.

Personally-mediated racism is exhibited in both prejudice (assumptions and beliefs about groups of people based on race) and discrimination (differential treatment based on race). Krieger has also described this type of racism as interpersonal discrimination. Krieger defines it as “directly perceived discriminatory interactions between individuals whether in their institutional roles or as public and private’’ (Krieger 1999, p. 301). Similarly, Clark defines racism as “beliefs, attitudes, institutional arrangements, and acts that tend to denigrate individuals or groups because of phenotypic characteristics or ethnic group affiliation” (Clark, Anderson, Clark, & Williams, 1999, p. 805). Internalized racism occurs when the members of the stigmatized races begin to accept the negative messages about their own abilities and worth from the majority. It can manifest as embracing the values and beliefs of the dominant group while also rejecting one’s own culture and ancestry (Jones, 2000).

Societal values and norms at both the macro- and micro-level exert influences that drive or determine groups’ exposure to either hazards or resources (Nguyen & Peschard, 2003). These values are instrumental in determining how the society is structured and the inequalities that are created within it. Inequality typically occurs when one group controls critical goods and practices social closure to secure its own advantage or power within the society (Tilly, 1999). Scholars have argued that oppressed groups are typically deprived of material goods and experiences that would otherwise enable them to take advantage of greater opportunities (Jones, 1972; Tilly 1999). Consequently, these societal inequalities lead to socioeconomic exclusion from necessary resources and may result in poorer health for those excluded (Nguyen & Peschard, 2003). Because political power is a key concept in maintaining societal inequalities, legal practices and policies can extend inequalities across multiple spheres of influence or *domains* (Anderson, 2010). These domains consist of, but are not limited to, critical areas such as education, housing, and healthcare, all of which strongly influence the health of individuals. Given this perspective, it is understandable how racism affects the health of African Americans through multiple and recursive pathways (Myers, 2009).

When examining overall social determinants in the African American community, there have been dramatic improvements since the early 1960's compared to Whites. Racial/ethnic health disparities, however, have been resistant to the positive outcomes of the civil rights movement. For example, there has been no change in mortality rates in nearly four decades (Satcher et al., 2005). De jure segregation is no longer legal; however, African Americans are still experiencing subtle forms of discrimination on a daily basis. Jones argues "the elimination of disparities – the magnificently democratic goal of Healthy People 2010 cannot be achieved without first undoing racism" (Jones, 2008, pg. S16).

Discrimination and Health

Racism and discrimination are often used interchangeably. They differ, however, in that racism can be defined as the systematic and structural means by which societies allocate status and privilege by race (Delgado & Stafanic, 2012). Discrimination, by contrast, is the differential treatment one might encounter as a result of racist attitudes and beliefs. Although discrimination is not limited to a single group of people, discrimination is most prevalent among racial/ethnic minorities and highly stigmatized groups (Williams & Mohammed, 2009). Due to the pervasive and persistent nature of health disparities within communities of color, particularly in the African American and American Indian communities, racial discrimination is one of the most widely studied aspects of discrimination in the literature of discrimination and health. Irrespective of other seminal determinants, the experiences of discrimination and distrust tend to operate independently to produce disparities in health (Dunlop, Manheim, Song, & Chang, 2002; Pathman, Fowler-Brown, & Corbie-Smith, 2006); ultimately increasing mortality risk among African Americans (Barnes, DeLeon, & Lewis, 2008).

Studies examining the linkage between discrimination and mental health outcomes have found almost without exception that higher levels of discrimination correlate with poorer mental health status (Ahmed, Mohammed, & Williams, 2007). Perceptions of discrimination have been associated with depression, anxiety, PTSD, and psychosis (Banks, Kohn-Wood, & Spencer, 2006; Lincoln, Chatters, Taylor, & Jackson, 2007; Pole, Best, Metsler, & Marmar, 2005; Veling et al., 2007). Although the majority of these studies have been cross sectional, several prospective studies have also found positive associations between discrimination and negative health (Brody et al., 2006; Green et al., 2006; Simons et al., 2006; Schulz et al., 2006b). Additionally, recent systematic reviews and meta-analysis have found that discrimination not only increases the risk of psychological consequences, but physiological problems, as well (Paradies, 2006; Pascoe & Richman, 2009; Williams & Mohammed, 2009). Researchers have found self-reported discrimination related to poor sexual functions, hemoglobin A1c, uterine myomas and coronary artery calcification (Zamboni & Crawford, 2007; Piette, Bibbins-Domingo & Schillinger, 2006; Wise et al. 2007; Lewis et al. 2006).

Inflammatory Biomarkers of Stress

Researchers have suggested that racial discrimination influences the regulation of biological systems that are activated in the stress response (Harrell, Hall, & Taliaferro, 2003). Due to its association with cardiovascular reactivity, increased blood pressure, and biomarkers of stress, discrimination can produce increased vulnerability to disease (Harrell et al., 2003). The stress literature can serve as a foundation for understanding the relationship between perceived discrimination, caregiving, and health. Developed by Dr. Hans Selye, the stress theory describes a physiological phenomenon that occurs when an individual experiences stress at a particular level. Selye posited that the body responds to stress of any kind with a unified defense mechanism, characterized by specific structural and chemical changes. When this reaction is prolonged or faulty, it can produce disease (Selye, 1976). An important sign of the stress defense mechanism is an increase of a spectrum of specified hormone secretion, but this is not the body's only defense against stress. The body also produces a variety of other chemical compounds.

C-Reactive Protein

C-reactive Protein (CRP), the stress biomarker selected for this study, has been identified as a reliable indicator of increased stress and consequently, when elevated, a risk factor for cardiovascular disease (Celik, Iyisoy, Celik, Yuksel & Kardesoglu, 2009). CRP has been suggested in the literature as a biomarker that integrates several cardiovascular processes that are responsive to changes in caregiving burden, making it a promising candidate for the longitudinal investigation of the impact of atherothrombotic process in chronic caregivers (Von Känel et al., 2012). A sensitive marker of inflammation, but not specific for any one condition, CRP has a median normal concentration of 0.8mg/L (Ridker, 2003). When an individual is exposed to an illness or injury, CRP levels can immediately rise in an acute inflammatory response. Chronic elevation of CRP, rather, is a marker of systemic inflammation and has been associated with increased risk of coronary artery disease (Pearson et al., 2003; Ridker et al., 2000).

More recently, studies in the caregiving literature have started to incorporate biomarkers of stress. Gouin and colleagues found in their review of studies of chronic stress in older adults that caregivers had significantly higher levels of biomarkers of stress (Gouin et al., 2008). In their study investigating biological and psychosocial predictors of depression, Clark, Nicholas, Wassira, and Gutiérrez (2013) found that caregiver burden not only predicted levels of depression, but it was also a significant predictor of higher levels of both IL-6 and CRP. Interleukin (IL)-6, a pro-inflammatory cytokine that has been identified as a key player in the stress response as well as in the pathophysiology of depression, (Corwin, 2000; Raison et al., 2006) is responsible for activating CRP and initiating the complement cascade. Von Känel and colleagues (2012) recently discovered in their longitudinal study of 118 elderly AD caregivers and 51 non-caregiving controls that longer duration of caregiving was associated with elevated CRP levels. Compared to the controls in the study, caregivers also had greater tumor necrosis factor alpha (TNF-α) levels and showed a significant decrease in CRP levels three months after the death of the AD spouse.

Stress and Coping in African Americans

Recent studies have also indicated a significant correlation between perceived discrimination and markers of inflammation that are known correlates of cardiovascular disease and other negative health outcomes. One of the first studies exploring perceived discrimination and CRP (Lewis, Aiello, Leurgans, Kelly, & Barnes, 2010) found a significant dose dependent relationship between experiences with discrimination and CRP levels in a sample of 296 older African Americans. This relationship remained significant after adjusting for smoking, blood pressure, and diabetes (Lewis et al., 2010). Stress researchers interested in race and caregiver stress are beginning to investigate how other psychosocial stressors can come into play and affect health outcomes.

John Henryism, “a behavioral predisposition to cope in an active, effortful manner with the psychosocial stressors of everyday life” (James et al. 1992, p. 59) has been included in studies to explain intra-group differences (James & Thomas, 2000). Merritt, McCallum, and Fritsch (2011) conducted a study examining how John Henryism predicts cardiovascular risk in African Americans with scarce coping resources. They found that African American female caregivers with higher caregiver strain and high coping effort had significantly flatter – or more dysregulated – cortisol slopes than the White female caregivers in the study. The finding that African American caregivers have flatter slope scores highlights that these caregivers experience higher levels of psychosocial stress in society (neighborhood stress, financial hardship, and perceived discrimination) than Whites and that the adverse health effects of these experiences can be amplified for African American caregivers. The finding suggests that the process of striving against adversity can produce chronic stress and subsequently increases the risk for hypertension and other cardiovascular diseases.

Although there is substantial evidence about the detrimental effects of discrimination and the deleterious impact of caregiving, there has not been any research examining the effects of discrimination and how these experiences may compound the cumulative stress process of being a minority caregiver of an adult with dementia. The findings from this research study potentially have application for others in the caregiver role who might also experience perceived discrimination. For example, a qualitative study examining caregivers of gay/lesbian elders, found that because of the added burden of exposure to discrimination, caregivers experienced challenges of providing care in the context of reduced support and rejection by family and society (Brotman et al, 2007). Findings from this research could be useful in designing future studies investigating how perceived discrimination can negatively impact minority caregivers' ability to effectively care for their loved ones.

Chapter Summary

In order to gain a deeper understanding of how African American caregivers are affected by their caregiving responsibilities, it is important to consider and account for other stressors. Other moderating stressors that could potentially add to the burden of caregiving have not been fully explored in this population. Specifically, there is a need to determine how large-scale sociopolitical forces, including racism and perceived discrimination might exacerbate stress for African American caregivers. Additionally, the findings regarding how African Americans report feelings of caregiver burden depend largely on research methodology. It appears that when burden is examined quantitatively, African Americans generally report lower levels of burden than their White counterparts. When burden is explored using qualitative approaches, however, African Americans tend to disclose burdensome experiences similar to that of White caregivers. These conflicting results could also be addressed through mixed methods; though, studies designed to examine these specific questions have not been conducted. Instead of taking a purely traditional quantitative or qualitative approach, researchers could benefit by blending methodologies. The research design and methodology for this current project are discussed in the following chapter.

CHAPTER 3

METHODOLOGY

This chapter describes the design of the research study and includes management and analytic strategies for both qualitative and quantitative components. Each stage of the study is described separately and then the steps to integrate findings are discussed. Following the description of the research design and methods, there is a discussion of strategies used to address issues of research integrity of this project.

Campbell and Fisk (1959), who originally introduced the idea of triangulation, called on social scientists to consider using multiple operations or methods to ensure that the explanation of variation was due to the underlying phenomenon of interest and not of the method. Conflicting results from the literature suggest that the previously held picture of African American caregivers as less burdened than their White counterparts should be reexamined. The difference in findings between the quantitative and qualitative studies also calls into question the meaning and salience of the concept of burden for African American caregivers and raises, as well, an issue about whether standard measures of burden account sufficiently for the socio-historical and cultural context of African American caregiving. Given these findings, a pure quantitative or qualitative method alone was deemed to be inadequate to fully explore these relationships, making mixed research, the third major research paradigm (Johnson, Onwuegbuzie, & Turner, 2007), an attractive alternative.

Research Study Design

Mixed Methods

Using a combination of methods that has complementary strengths and non-overlapping weaknesses allows the researcher to benefit from the best of both methods while simultaneously addressing many of the limitations of each approach (Creswell & Plano-Clark, 2011; Teddlie & Tashakkori, 2009). This type of approach increases the reliability and accuracy of each method (Risjord, Dunbar, & Moloney, 2002).

The goal of using mixed methods was to obtain a general picture of stress, burden and health in African American caregivers with the quantitative data and uncover richer meaning of these concepts through qualitative data analysis. Because discrimination and forms of racism have been noted in the literature as pertinent contextual factors, using both methods to further explore these concepts will considerably add to the current understanding of these complex relationships (Bastawrous, 2013). Nurse scientists have long supported the idea of conducting mixed methods research. Morse (1991) states *sequential triangulation* is best adopted when the planning of one method depends on the results of the first method. Sandelowski (2000) states one purpose of triangulation is to corroborate results from one method with the findings from another, further validating the relationships or meanings of the concepts being studied.

Using the sequential mixed design (see Appendix A), this study was conducted in two phases QUAN → qual (Creswell & Plano-Clark, 2011; Teddlie & Tasakkori, 2009). This notation is widely used in mixed research literature to denote that the quantitative study will have greater priority and will be followed by the qualitative study, a smaller component of the overall design. The first phase used a cross-sectional survey design to collect quantitative data from baseline measures through the parent study. The qualitative component followed the quantitative analysis. The data collected from the in-depth interviews were used to explain and/or corroborate findings from the initial quantitative phase.

Parent study. The parent study, a NINR funded program project titled “Caregiver Stress: Interventions to Promote Health and Well-being,” is a randomized controlled trial of caregivers of patients with dementia and heart failure. The program project has two individual studies and has a goal of enrolling 384 participants through both convenience and snowball sampling techniques. The data for this dissertation study were gathered by the parent project. A dataset of 100 African American caregivers from the parent study was available at the time of analysis. Participants who met the inclusion criteria (at least 21 years old, English speaking, self-identify as African American, and providing care for adult with AD) for the parent study were eligible for inclusion into the quantitative component of the study. Additionally, in order to participate in the qualitative phase of this project, the study participants had to have expressed willingness to be re-contacted for future study procedures and activities. In some cases if the care recipient was institutionalized or had expired, study participants who had completed their baseline measures were excluded from completing the rest of the parent study. The baseline data from these individuals were still appropriate for analysis in this study, and they also remained eligible to participate in the in-depth interviews for the qualitative phase of this project. One caregiver who participated in the qualitative portion of the study lost her husband a few weeks prior to her scheduled interview. His passing, though, occurred after she completed the entire interventional study. The remaining eight caregivers who were interviewed were actively providing care of their loved one in their home.

Qualitative sampling strategy. In order to address the research aims of this project, caregivers were selected purposively to not only have a sample that represents a broader group of cases, but to also set up comparisons among different types of cases. Caregivers were identified based on their experiences of burden, as reported on the Zarit Burden Interview (ZBI). Also referred to as ‘‘qualitative’’ or “criterion sampling” (Creswell & Plano-Clark, 2011), this particular strategy helped to generate a list of eligible caregivers determined by how they responded to the ZBI during baseline data collection in the parent study. Selected participants were stratified by typical and intense cases (low, moderate and high burden scores). More than half of the sample had ZBI scores over 40, ranking them as highly burdened. About a third of the group scored as moderately burdened and only 13% of the caregivers were categorized in the low burdened group (see Table 3.1).

From the stratification strategy, I began to select caregivers to participate in the qualitative component. The goal of this specific technique was to ensure a sample of caregivers with a range of experience. This sampling technique was useful because it helped me to draw specific conclusions about particular caregivers based on how they responded on the ZBI. For example, I was also able to assess for similar or dissimilar experiences as I compared the caregivers within each burden group (low, moderate, and high) and then across all cases.

Table 3.1. Qualitative Sampling Strategy Results

Low Burden ZBI Score <21	Moderate Burden ZBI Score 21-40	High Burden ZBI Score >40
12 Caregivers (13%)	30 Caregiver (32.6%)	51 Caregiver (55.4%)

Note. N=93 (7 cases had missing items)

Institutional Review Board (IRB) Approval

Prior to analyzing data from the parent study and approaching potential participants to interview, I completed all regulatory processes and acquired approval for initiating the sub-study from the Institutional Review Board (IRB) of Emory University. IRB approval was obtained on 6/6/2013 by submitting Amendment #22 to the existing IRB approved parent study protocol #IRB00026244 (see Appendix B for Informed Consent and Health Insurance Portability and Accountability Act (HIPAA) Authorization Forms).

Quantitative Phase

Instruments

The following is a list of measures used in the current study (see Appendices D-I for study instruments). Table 3.2 contains all of the instruments used to operationalize key variables in this study along with internal consistency reliabilities conducted via SPSS v.21 (IBM, 2012).

Table 3.2. Study Instrument Internal Reliability Consistencies

Instrument	Alpha	N	Number of Items
Zarit Burden Interview	.92	95	22
Everday Discrimination Scale	.88	97	9
Vigilance Scale	.78	98	4
Revised Ways of Coping Checklist	.93	82	66
Avoidance Coping Subscale	.68	96	8
EnrichD Social Support Instrument	.89	100	7
PROMIS: Depression	.93	99	8
PROMIS: Anxiety	.91	100	7

Zarit Burden Interview. The Zarit Burden Interview (ZBI) is one of the most widely used instruments used to measure subjective burden in the Alzheimer's dementia caregiver population (Zarit et al, 1980). The original scale had 29 items, but many researchers modify it and use shorter versions (22, 18, and 12 items). The 22-item instrument was the burden measure used in these analyses. Each question is scored on a 5 point Likert scale ranging from "never" to "nearly always" present. Total scores range from 0 to 88. Summed scores are interpreted with higher scores indicating higher levels of perceived burden and lower scores indicating lower perceptions of burden. Translated in multiple languages and tested in various cultures, the ZBI has demonstrated good internal consistency, with reliability as high as .92 (Bédard et al., 2001). Validity for this instrument has also been established in African American participants (Knight et al., 2000; Longmire & Knight, 2011).

Everyday Discrimination Scale. The everyday discrimination scale is a 9-item, Likert-type questionnaire with scores ranging from 0 (almost everyday) to 6 (never) - lower scores reflect higher levels of perceived discrimination. Developed by Williams and colleagues (1997), this instrument is one of the most commonly used tools to measure perceptions of everyday discrimination (Bastos, Celeste, Faerstein, & Barros, 2010; Paradies, 2006). Reliability has been well established in multiple studies. Internal consistency scores range from 0.87-0.90. The questions on this scale ask participants: How often on a day-to-day basis do you experience each of the following types of discrimination? The nine items included responses such as *"you are treated with less courtesy than other people"* and *"you are treated with less respect than other people."* Other items asked about others' perceptions like *"people acted as if you're not smart" "dishonest"* or *"that you're not as good as they are."*

Vigilance. To measure vigilance, we used a racism-related vigilance measure created from ethnographic research that described how individuals anticipate and prepare for racial discrimination (Essed, 1991). The 4-item scale ask responses to the following questions: In your day-to-day life, how often do you do the following things: *"try to prepare for possible insults from other people before leaving home?"*

"feel that you always have to be very careful about your appearance to get good service or avoid being harassed?" "carefully watch what you say and how you say it" and "try to avoid certain social situations and places?" Responses were on a 6-point Likert scale ranging, from "almost everyday" to "never". Both discrimination measures, the everyday discrimination and vigilance scale, were reverse coded and then summed, with higher values representing higher levels of perceived discrimination and vigilance.

Revised Ways of Coping Checklist. Social support was operationalized with the Revised Ways of Coping Checklist (WCCL-R). Participants completed the WCCL-R (Vitaliano, Russo, Carr, Maiuro, & Becker, 1985) to assess various coping processes. It is a 66 item scale with multiple subscales that measure problem-focused coping, seeking social support, blaming one's self, wishful thinking, and avoidance coping. The instrument is on a four-point scale and caregivers were asked to rate the degree to which they used the various types of coping strategies in dealing with stressful situations (0 = never used, 1 = used somewhat, 2 = used quite a bit, 3 = used a great deal). Given African Americans' tendency to utilize more emotion-focused strategies (Aranda & Knight, 1997; Knight et al., 2000), the avoidance coping subscale was selected to operationalize this particular coping strategy. Typical avoidance coping items include: *"I sleep more than usual," "I hope for a miracle,"* and *"I took it out on other people".*

PROMIS measures*.* Patient Reported Outcomes Measurement Information System (PROMIS) is a National Institute of Health (NIH) funded initiative to produce highly reliable and precise instruments that reflect the patient health status for physical, mental and social wellbeing (Reeve et al., 2007). The short depression and anxiety measures were originally included in the parent study and were used to operationalize psychological distress in this project. The PROMIS instruments are scored using item-level calibrations. The most accurate way to score a PROMIS instrument is to utilize scoring tools (PROMIS Assessment Center/NIH, 2013) that look at responses to each item for each participant, also referred to as response pattern scoring. All of the total raw scores were converted into a T-score for each participant. The T-score rescales the raw score into a standardized score with a mean of 50 and a standard deviation (SD) of 10. Therefore a person with a T-score of 40 is one SD below the mean. For most PROMIS instruments, a score of 50 is the average for the United States general population with a standard deviation of 10 because calibration testing was performed on a large sample of the general population. In this current study, we used both PROMIS depression and anxiety instruments. The depression scale is an 8-item measure, whereas the anxiety instrument has 7 items (PROMIS Assessment Center/NIH, 2013).

EnrichD Social Support Instrument (ESSI). The EnrichD social support measure was selected as the instrument to operationalize social support in the current study. The ESSI is a seven-item, self-report measure originally used in the ENRICHD trial (Mitchell et al., 2003). Participants were asked questions like: *"Is there someone there to help you with daily chores?" "Can you count on anyone to provide you with emotional support?"* and *"Is there someone available to you who shows you love and affection?"* The instrument is a 5-point Likert scale where respondents chose from a range of answers from "none of the time" to "all of the time". Individual items were then summed for a total score, with higher scores indicating greater social support.

***C-Reactive protein**.* Conventional CRP assays have been useful in assessing the dramatic increases (sometimes up to 3000 fold) of CRP in response to an acute infection or injury, but are less sensitive in detecting the relatively small increases of CRP due to subtle, chronic inflammation. High sensitivity CRP (hsCRP) has been recommended in determining lower levels of CRP elevation. A statement from the Centers for Disease Control and Prevention and the American Heart Association suggested the following interpretation of hsCRP results: <1mg/L =low risk, 1-3mg/L=average risk, and >3mg/L=high risk (Ridker, 2003). Using test/retest to measure the analytical precision of CRP, both variability and reliability have been deemed adequate (Riese, Vrijkotte, Meijer, Kluft & de Geus, 2002).

Hs-CRP was collected via venous samples during baseline data collection in the parent study. Plasma was aliquoted into pre-cooled siliconized polypropylene tubes and stored at -80C until assayed for hormones and cytokines. Once the samples were analyzed, a senior biostatistician on the parent project uploaded lab results into SPSS version 21 and added the CRP values to the dataset for analysis with other study variables.

Quantitative Data Analysis

Analysis of the data from both quantitative and qualitative approaches was conducted independently. All of the quantitative data were examined for completeness and consistency prior to data entry with verification and correction of discrepancies. Descriptive statistics were used to characterize the sample on demographic, psychosocial, behavioral and biological variables via SPSS. Since several of the variables were deemed to have non-normal distributions, Spearman Rho's correlations were used to examine unadjusted associations between predictors, outcomes and covariates of interest. Due to its extreme non-normal distribution, CRP was transformed into a different variable, using the natural log transformation. After investigating residuals, skewness statistics, and sample size, it was determined that it was appropriate to use the other variables in regression analyses without transforming them into different variables.

Regression diagnostics were implemented to determine the extent to which the independent variables are correlated with one another and whether or not significant multicollinearity exists. In the event of significant multicollinearity, variable selection methods (such as forward backward and stepwise approaches) and theoretically based decisions were used to retain the final predictors. For example, significant multicollinearity existed between the Zarit total score, personal strain and role strain; therefore only the Zarit total score was used in the analyses.

To examine the multivariate association between discrimination, caregiver burden and C-reactive protein (CRP) and psychological distress measures (depression/anxiety), a series of hierarchal multivariate linear regression models were created to assess the predictive power of both caregiver burden and perceived discrimination for each outcome measure. The crude models tested the association between discrimination and CRP, after adjusting for control variables. The final model contained additional variables to control for BMI and other potential confounders. Other exploratory models were created with interaction terms to rule out associations between discrimination and other covariates (not shown). All non-significant interaction terms were dropped from the final models. Logistic regression models were conducted with dichotomized dependent variables to determine predictive value of burden and both everyday discrimination and vigilance. The Power Analysis and Sample Size (PASS) Software (Hintze, 2011) was used for sample size calculation. It was calculated that a sample size of 100 was needed to achieve 80% power to detect an R-square of 0.10 attributed to 6 independent variables in the theoretical framework, using an F-Test with a significance level (alpha) of 0.05.

Qualitative Phase

Phenomenology

The second phase of this study was a series of in-depth interviews co/nducted to explore the meaning of burden and the experiences of discrimination from a qualitative perspective. Phenomenology was the specific qualitative approach selected to guide this phase of the study. Van Manen eloquently describes phenomenology as a project in which the phenomenologist “directs the gaze toward the regions where meaning originates, wells up, percolates through the porous membranes of past sedimentations – and then infuses us, permeates us, infects us, touches us, stirs us, exercises a formative affect” (Van Manen, 2007, pg.11). Phenomenology strives to illuminate – through a rich description – the lived experience of a particular phenomenon (Sokolowshi, 2000) and rediscover the actuality of that experience. Phenomenology has also been described as a way of unfolding the dimensions of human experience; how we exist in, live in, our world (Hein & Austin, 2001). The assumptions of a phenomenologist are that the experiences of another can be made known and our job, as researchers, is to make those experiences visible to others (Hein & Austin, 2001). It examines both the distinct essence of an experience and what is common.

The goal of the qualitative component of this project was to gain insight into individual experiences as well as shared experiences of a group of caregivers. Complex constructs like burden, racism, and culture can best be understood through an iterative process of examining and re-examining propositions. Heidegger (1962) believed as researchers we are integral parts of an external reality that causes us to be in a state of *being-in-the-world*. That said, this project aligned more closely with the interpretive approach. The interpretive approach is distinct from other approaches in phenomenology in that the researcher is a central part of making sense of the participant's experiences (Smith, 2009).

Rooted in psychology, this interpretive strategy involves a two-stage interpretation process that explores the individual's perceptions and experiences. Researchers using this approach go beyond what is obvious and typically search for richer meanings (Smith, 2009). Another distinct feature of interpretative phenomenological analysis is that there is not a goal to seek one single answer or truth, rather coherent accounts with a particular attention to the words of the participants (Pringle, Drummond, McLafferty, & Hendry, 2011). In order to have in-depth and rigorous analysis of the individual accounts, it is not uncommon for these types of studies to have smaller sample sizes (Pringle et al. 2011).

Qualitative Data Collection

Sample. A purposive sample of nine caregivers was identified from the quantitative analysis. These caregivers ranged from being low, average and highly burdened. The sample size estimation was fitting for phenomenology studies and is based on other qualitative work with similar populations (Fox et al., 1999; Calderon & Tennestedt, 1998). Once I determined the caregivers had completed the study and consented for re-contact by research staff members, I made phone calls to explain the study procedures and obtain consent. Once caregivers agreed to participate, formal consent procedures were conducted during face-to-face interviews.

Interviews. All of the caregivers were given several meeting options. I offered to meet caregivers at a reserved meeting space on campus, in their homes, or a location of their choice. Out of the ten interviews (1 caregiver was interviewed twice), six interviews took place in personal residences, three in local coffee shops, and one in a private conference room on the campus of Emory University. Prior to starting the interview, I read the entire informed consent and Health Insurance Portability and Accountability Act (HIPAA) Authorization Form and obtained appropriate signatures. I ensured participants understood that the informed consent was more than a mere document but that it was also a process. I wanted to be clear that they knew and understood their rights as research participants and that at anytime they could terminate the interview or withdraw from the study. I explained that all of the interviews would be recorded and that I would be simultaneously taking notes during the interview. All of the caregivers originally contacted agreed to participate in the study. One caregiver failed to show for a scheduled appointment. I left a message with the caregiver and was able to reschedule for different day. The interviews took place between August and October 2013.

The interviews were conducted using a semi-structured interview guide (see Appendix B). The interview guide was developed from the literature and study research questions (Mason, 1996). The focus of the interviews was on the individual caregiving experiences, meaning of burden and how race and racism mattered in their role as informal family caregivers. The average interview lasted approximately 45 minutes. All of the interviews were conducted with the primary caregiver. In three instances the care recipients were either nearby or present: (1) niece caring for her aunt (2) daughter caring for her mother and (3) husband caring for his wife. At times it did appear that the caregiver who was caring for her aunt was concerned about her hearing what we were discussing (although she was in another room). The proximity of her aunt did not influence her transparency. When we would touch on sensitive subjects, the caregiver would lower her voice. I made sure to take careful notes during this time of the interview, in case the recording was affected by the changes in her volume. The second caregiver that had a family member nearby did not have any concerns of her mother hearing our conversation. She was in a different part of the house and at the conclusion of the interview she brought her mother out to meet me. The last caregiver that had a family member nearby was one of the male caregivers caring for his wife. His wife was actually present throughout the interview.

I started the interviews with an open question; “Tell me about yourself and how you became a caregiver.” This opening question encouraged the caregiver to talk about themselves, their relationship with their loved one, and how the family member originally got diagnosed with dementia. At times, I took the liberty to ask follow up questions regarding details they shared in their response. Using this technique, I found I was able to establish rapport rather quickly with the caregivers. Once we talked for a few minutes, I proceeded to follow the interview guide. Other questions on the guide included, *“What aspects of caregiving are particularly challenging or difficult for you?”, “Tell me more about other family members and friends and how they assist you in your role as a caregiver”, “In what ways have race or racism affected your roles as a caregiver?”, “How would you define burden?”* The final question or towards the end of the interview, I asked caregivers if they believed they were burdened.

All of the caregivers appeared to be warm, receptive and engaged throughout the entire interview process. I did not have to deviate from the study protocol during any of the interviews. At the end of each appointment, I concluded by asking if they had any additional concerns. At times, many of the caregivers had much more to share. I also asked them if necessary, could I possibly contact them for a second interview. Each of the caregivers was interviewed at least once. All of the caregivers agreed to future contact. One caregiver was interviewed a second time due to her providing such a rich account of her caregiving experience in the first interview. A $25 VISA gift card was given to each research participant.

Data storage and management. All of the interviews were taped and audio-files were de-identified and immediately uploaded to a transcriptionist. Transcripts were then uploaded into MAXQDA v.11 (Verbi Software, 2013), a qualitative research software program for data management necessary for analysis. The interview guide was adapted for future interviews with subsequent participants, based on crucial ideas generated from the previous interviewees. For example, after hearing several caregivers’ state they felt that they were not able to discuss feelings of stress and burden, this was included as a follow up question for subsequent interviews. Field notes and memos were used to document thought processes regarding codes, themes, and the steps taken to obtain the findings. Bracketing and reflexivity were additional strategies utilized to set aside any personal reaction or preconceived notions as they surface.

A file for each participant was created and kept in a secured location. Each file included a demographic form, transcript copies and a copy of the informed consent and HIPAA form. Additional notes regarding interactions with the participant before, during, or after the interview was kept in a separate notebook. Digital copies of transcripts and memos were filed in MAXQDA. These files along with audio recordings were stored on a password-protected laptop.

Qualitative Data Analysis

After each interview, I documented my first impressions and reviewed notes taken during the interviews. The notes captured the caregivers' key concerns as possible codes. For example, after the first couple of interviews, I noticed that caregivers talked about work (having to quit working, having to give up travel opportunities associated with work, and not being able to go back to work). Initially I did not know if these concerns were related to value of working or loss of freedom, but I flagged "work" as an idea for a code. By reflecting on the interviews, listening to audio files, and writing memos about the interviews, I started the initial phase of analysis that would prepare me for the next round of interviews.

The goal of the qualitative component was to conduct an in-depth phenomenological analysis of caregiver burden. The phenomenological research design was to reveal essential perceptions that constituted the meaning of the experience of being an African American caregiver (Sandelowski, 2000). In order to distinguish the essence of burden, the analytical approach was descriptive, using constant comparative analysis (Boeije, 2002; Strauss & Corbin, 1998). A preliminary list of open codes was made to index the data. Codes such as *"faith in God"*, *"social support"*, and *"burden"* were anticipated given the interview guide and current literature. Written memos were developed both for codes that were generated deductively from my familiarity with the burden and racism literature, as well as ideas inductively generated from the openly coded data.

According to the mixed methods design, the qualitative stage of this project was a smaller component and therefore we focused on the themes that were most relevant to the research questions. Caregivers talked extensively about various topics and concerns producing rich, descriptive accounts of their caregiving experience. Written memos were used to document ongoing interpretation as the codes formed themes of the African American caregiving experience. A code descriptor list was simultaneously created and refined with subsequent interviews and corroboration from involved faculty. All direct quotes that supported specific themes or identified clusters were highlighted for potential empirical evidence to illustrate the findings during the level of data analysis. Analysis of the qualitative data was an iterative and ongoing process throughout this phase of the study.

After the codes were identified in each case, higher-level codes and categories were developed in an attempt to classify and group coded segments together. This classification allowed within case and across case comparisons. For example, codes such as *"disadvantage", "values",* and *"resilience"* emerged from the data as preliminary themes. By using the constant comparison method, I was able to start looking for similarities and differences between the different caregivers. Because I categorized caregivers as low, moderate, and highly burdened, I was also able to specifically look for emerging themes by level of burden.

Once the transcripts had been exhaustively coded, an interpretive reading of the interviews was performed to infer meaning from the data (Mason, 1996). After I thoroughly indexed data for each individual caregiver, I was able to group all of the low caregivers together and identify commonalities and differences within this group and then compare themes against the other caregivers that scored moderate to high on the ZBI. Moving back and forth between the various accounts and groups facilitated the development of analytic lines that contributed to the construction of the meaning of burden in African American caregivers. Qualitative researchers were consulted throughout this process for insight and expertise.

Data Integration

There are multiple analytic strategies for incorporating findings from both qualitative and quantitative components of a mixed methods study. Most importantly, I had to determine the best way to integrate the findings. For example, some researchers convert qualitative data into numbers or convert quantitative data to narrative codes. The integration of data in this study occurred at two different time points. The first point of integration took place when the individuals were stratified based on responses to the burden instrument. This initial analysis helped to inform the second stage by influencing sample selection. Quantitative and qualitative data were collected and analyzed individually.

The second point of integration occurred once quantitative analysis was complete and qualitative themes were finalized. Once data collection and analysis phases of these two stages were concluded, the data were compared to determine how the qualitative results explained the quantitative findings. Findings from each component of the study were then compared to determine how the results from one stage could support and/or explain the other. Originally, we only planned for the qualitative data to explain the quantitative results. However, after identifying themes derived from the interviews and reviewing the significant findings in the statistical analysis, we found evidence in the quantitative portion of the study to support narrative accounts as well.

Multiple strategies were employed in order to maintain the integrity of this research project. Gathering and analyzing data in an unbiased manner was as equally important to the informed consent process. Data were stored in a secure and confidential manner. Standard practices for handling missing data and outliers was conducted to reveal, not distort, the relationships between variables of interest. To ensure conclusions drawn were honest and trustworthy, a senior biostatistician was also consulted on this project. The biostatistician had opportunities to review SPSS output and had access to dataset. Independent analysis was completed and findings from statistical analyses were replicated.

Research Integrity

Various techniques were employed to optimize the descriptive, interpretive, and theoretical validity in the qualitative data analysis (Morse, Barrett, Mayan, Olson & Spiers, 2002). Descriptive validity is the attempt to obtain an accurate rendering of the facts from the cases (Maxwell, 1992). Fidelity checks on random segments of the audio-files were conducted to ensure that transcriptions matched the recordings. Interpretive validity was achieved through skillful probing and clarifying interviewing during data collection. Summarizing periodically throughout the interview helped to improve the accuracy of obtaining the participant's point of view. Finally, consulting with experienced qualitative researchers optimized the theoretical validity of the interpretations. To verify the trustworthiness of results and conclusions drawn from these analyses, an expert qualitative researcher conducted independent reviews of the transcripts at various stages of the analysis. Weekly conference calls were held to review theoretical conclusions. Caregiving and gerontology experts were also consulted to review written analyses. This collaboration enhanced the credibility of this component of the project.

Chapter Summary

This study utilized sequential triangulation methods to explore the meaning and the biological impact of stress, caregiver burden, and discrimination on the health of African American caregivers of patients diagnosed with chronic illnesses. The primary rationale for using a mixed method design is to expand the scope or breadth of research to offset the weaknesses of either approach alone (Driscoll, Appiah-Yeboah, Salib, & Rupert, 2007). The design chosen for this study provided a richer elucidation of the relationships of the complex concepts in the study than any one particular approach could offer. Integrating both quantitative and qualitative findings was particularly useful in addressing the conflicting results regarding African Americans and caregiver burden found in the literature.

CHAPTER 4

RESULTS

Several variables and concepts were examined in this study. Primarily, we sought to investigate the various ways African American caregivers' health and wellbeing are being affected by their caregiving responsibilities. In order to examine chronic stress and how it affects the African American caregivers in this study, we selected caregiver burden and measures of discrimination (everyday discrimination and vigilance), along with covariates of interest such as coping styles and social support, to determine how these factors might influence or predict levels of CRP as well as experiences of depression and anxiety.

The purpose of this chapter is to present the results of the statistical analyses conducted for this quantitative portion of the study and an analysis of the meaning of burden from the qualitative interviews conducted with a smaller selection of participants from the sample. The quantitative analyses include initial descriptive statistics, followed by a series of correlations, and hierarchical linear regressions and logistic regression models. Overall, these results indicate significant associations between the independent predictors included in this study and the focused outcome measures. A summary of the qualitative analysis, using a phenomenological approach, follows the quantitative results section of this chapter. Our findings suggest that narrative accounts from caregivers differ from what is reported on survey data. We summarize both quantitative and qualitative findings and introduce possible explanations for the inconsistencies found between the two data collection methods.

Quantitative Results

Descriptive Statistics

The first table summarizes descriptive statistics conducted on the categorical measures included in this study. The vast majority of participants in this study were women with 90% of the participants being female and 10% being male. With regard to marital status, 44% of respondents were found to be married (including 1 caregiver identified as living with a domestic partner), 33% were divorced, separated, or widowed, and finally 23% identified as being single.

Table 4.1. *Descriptive Statistics: Categorical Measures*

Measure	N	%
Marital Status		
Single	23	23%
Divorced/Sep/Widow	33	33%
Married/Partner (1)	44	44%
Gender		
Male	10	10%
Female	90	90%
Education		
8th grade or less	1	1%
HS Diploma	15	15%
Tech/Vocation	9	9%
College	47	47%
Post-Graduate	28	28%
Employment Status		
Retired	32	32%
Not Working/Unemployed/Homemaker	13	13%
Caregiver	4	4%
Working	47	47%
Self-Employed	3	3%
Full-Time Student	1	1%
Care Recipient (CR) Relationship		
Spouse	17	17%
Mother	59	59%
Father	11	11%
Aunt/Uncle	11	11%
Other	2	2%
	Total: 100	100%

The average level of education in this sample was college level with 75% of the respondents reporting some college education; 28% of these individuals had some graduate level of education. An additional 25% of participants had at least a high school diploma with 9% of these individuals having some technical or vocational training. Only 1% had an education level of 8th grade or less. When asked about employment status, half of the sample is still actively working with 47% of the caregivers employed and 3% self-employed. The second largest response was 32% noting that they were retired. An additional 17% stated that they were unemployed, not working, or listed “caregiver” as their occupation. There was 1 full-time student in this sample.

With regard to the relationship of the respondent with the person that they are caring for, 70% of the caregivers were providing care for an elderly parent (59% of the respondents caring for their mother and 11% for their father). An additional 17% of the caregivers were providing care for their spouses. The remaining 13% of the caregivers were providing care for either an aunt/uncle (11%) or some other individual (2%). In addition to caring for their loved one with dementia, many of these caregivers were also providing care for others in their home. In fact, 38% noted that they were caring for others, with 13% of those individuals they were caring for also chronically ill. Given that social support is an identified covariate in this study, we also inquired about family support and strife. The majority of the caregivers (55%) in this study reported at least occasional strife in the family, with 13% of this group noting serious difficulties and an additional 8% stating their problems with the family are the main source of difficulties in caregiving.

The most common chronic illness mentioned in this sample was hypertension (HTN) with 38% of caregivers responding that they had been diagnosed. An additional 10% of the sample stated they had been diagnosed with diabetes mellitus (DM), six of these also had HTN. Over a fifth of the sample (22%) had been diagnosed with arthritis. Hyperlipidemia was indicated by 9% of the sample. Twenty-four percent of the caregivers indicated other chronic illnesses. Some of the disorders listed included: HIV (5), thyroid disease (4), gastric reflux (4), anemia (3), multiple sclerosis (1) and fibromyalgia (1). Although the majority of the sample acknowledged suffering from at least one chronic condition, 40% of the sample reported “none” for this set of questions. The BMI was found to have a mean close to 31, indicating obesity, with average blood pressure being approximately 125/76.

Table 4.2 summarizes the descriptive statistics associated with the continuous measures included in this study. The mean respondent was slightly over 56 years of age. The average age of the care recipient was nearly 79 years of age. The individuals being cared for in this study had been diagnosed with Alzheimer’s disease for nearly 4 years and the average caregiver has been providing care for them nearly the entire time since their diagnoses. The majority of these caregivers and their loved ones live together with approximately 79% of them reporting co-residence. The average respondent indicated that they provided close to 43 hours of care per week.

With regard to the independent and dependent variables, Zarit total score had a mean close to 42, with the personal strain subscale having a mean of 21 and the role strain subscale having a mean close to 12. These averages indicate moderate to high levels of caregiver burden. The everyday discrimination total score was found to have a mean of 16, with the vigilance subscale having a mean of 10. This sample’s level of perceived discrimination was relatively low. When asked what the participants believed the unfair treatment was attributed to, 21% reported age, 23% checked gender, whereas 27% of the respondents stated they did not know the main reason why they were being treated unfairly. Over half of the sample felt that they were being discriminated against due to their race (42%) and/or national origin (10%). Caregivers were allowed to check multiple responses to this question.

CRP was found to have a value close to 2.5; values less than 3 indicate lower risk for an adverse cardiovascular event. Caregivers overall appeared to have elevated risk for both depression and anxiety, with PROMIS measures averaging above 50 in both indicators for this sample group. Depression T-Scores had a mean close to 52 and anxiety scores were on average close to 56. There are two covariates or control measures included in this study, social support and avoidance coping. Social support, operationalized by the EnrichD Social Support measure (ESSI), was found to have a mean of 18.4, indicating moderately low levels of perceived social support, while ways of coping (escape/avoidance subscale) was found to have a mean of 7.8. Items on the escape and avoidance subscale suggest detachment and measures behavioral efforts to escape or avoid the problem.

This sample of African American dementia caregivers was majority women, overall highly educated, and mostly retired or unemployed. These caregivers were providing extensive care for their loved ones and on average highly burdened. They reported experiencing slightly above average levels of depression and anxiety and did not perceive adequate social support from family and friends.

Table 4.2. Descriptive Statistics: Continuous Measures

Measure	Mean	Median	Min	Max	Standard Deviation
Demographics					
Caregiver Age	56.32	56	30	78	9.26
Care Recipient Age	79.18	80	55	102	8.66
BMI	30.80	30.33	21.1	46.8	5.34
Independent/Dependent					
Zarit: Total	41.483	42	7	74	15.93
Everyday Discrimination	16.111	16	9	30	6.068
Discrimination: Vigilance	10.142	9	4	24	5.462
CRP	2.4718	1.790	.05	8.73	2.043
PROMIS: Depression	51.851	52.40	37.1	69.3	8.749
PROMIS Anxiety	55.679	55.70	36.3	72.9	8.009
Covariates/Controls					
Social Support	18.429	19	5	25	5.503
Avoidance Coping	7.817	7.5	.00	23.42	4.950

Correlations

The first specific aim of this study was to **examine the association between caregiver burden, perceived discrimination, and psychological distress measures (depression and anxiety).** We hypothesized that *participants with higher levels of caregiver burden and perceived discrimination will have increased levels of psychological distress, including significantly higher levels of depression and/or anxiety*. In order to investigate this specific aim, a set of correlation procedures was conducted. The following table summarizes the initial results of the Spearman Rho's correlations conducted between the dependent and independent variables selected for this study. Several of the variables were slightly skewed, therefore nonparametric correlation procedures were deemed more appropriate for interpretation. CRP, in particular, was severely skewed; therefore natural log transformation was conducted to ensure accurate interpretation of relationships between selected variables.

As indicated in Table 4.3, a number of statistically significant positive as well as negative correlations were found in these analyses. First, Zarit total score was found to have a significant, positive, correlation with the Zarit personal strain and role strain subscales (not shown). The total Zarit Burden score was found to have a moderate, positive and significant correlation with everyday discrimination, and was found to have moderate, positive, and statistically significant correlations with depression and anxiety. Burden also had a positive and statistically significant relationship with the increased use of the avoidance coping style and negatively associated with social support and positive reappraisal. Lower levels of perceived social support and positive coping were associated with statistically significantly higher levels of perceived burden.

The total everyday discrimination score was found to have a positive, moderate, and statistically significant correlation with the discrimination vigilance subscale and moderate, and statistically significant correlations were found with depression and anxiety. A moderate, positive, significant correlation was found between the discrimination vigilance subscale and depression, while a strong, positive, and significant correlation was identified between depression and anxiety. This set of statistically significant correlations supported the hypothesis associated with our first specific research aim.

Depression and anxiety were additionally significantly correlated with selected covariates in this study. Both psychological distress measures were strongly and positively correlated with escape/avoidance coping styles. Increased use of this particular coping strategy was associated with statistically significant higher levels of depression and anxiety. Conversely, there was a statistically significant, negative relationship between depression, anxiety and positive reappraisal of stress.

Finally, CRP was found only to have a statistically significant and positive relationship with BMI. None of the other predictors or covariates was found to be significantly related to CRP. BMI, however, was also found to have a negative, statistically significant relationship with depression.

Table 4.3. Spearman's Rho Correlations between Predictors, Outcome Measures and Covariates

Measure	1	2	3	4	5	6	7	8	9
Depression[1]									
Anxiety[2]	.771**								
Social Support[3]	-.410**	-.375**							
Escape Avoidance[4]	.390**	.486**	-.233*						
Positive Reappraisal[5]	-.371**	-.321**	.085	-.370**					
Zarit[6]	.514**	.515**	-.388**	.380**	-.263*				
Discrimination[7]	.472**	.451**	.322**	.255*	-.230*	.498**			
Vigilance[8]	.374**	.229*	-.138	.179	-.147	.201	.474**		
BMI[9]	219*	.121	-.065	.099	-.164	-.020	.032	.021	
CRP[10]	-.017	.004	.131	.070	-.091	-.151	-.023	.053	.279**

Note. *p<.05, **p<.01.

Independent t-tests were conducted to determine if there were significant differences between various demographic variables. Specifically, age, gender, education and marital status were dichotomized to test for group differences in the sample. Caregivers were divided into younger (55 and below) and older caregivers (56 and above). Participants were also separated into those that had at least some college education and those that had none. Each of these groups was tested for differences in perceived burden, everyday discrimination, depression, and anxiety scores. The only significant difference in these set of analyses was that females had higher levels of anxiety than males (t=1.917, p=0.05).

In addition to testing group differences by age, gender, and educational level, we also tested for differences by marital status. Married caregivers had significantly lower burden scores than caregivers that were not married (t=2.112, p=0.037). Caregivers that were either single, divorced, separated, or widowed also perceived significantly lower levels of social support (t=2.628, p=0.010) and had higher levels of depression (t=2.339, p=0.028) and anxiety (t=2.337, p=0.021).

Linear Regression Analyses

Though we were able to support our first research aim with the correlation analyses conducted, we decided to also conduct a set of hierarchal regression models to determine the predictive value of both caregiver burden and everyday discrimination on depression and anxiety. A series of three hierarchical linear regression analyses were conducted on the outcomes of CRP, depression, and anxiety.

Due to extreme multi-collinearity, only the Zarit total score was included in these analyses. In total, predictors consisted of Zarit Burden score, everyday discrimination as well as vigilance, social support, avoidance coping, and BMI. In most cases, the addition of the covariates significantly improved model fit. Final models containing burden and discrimination measures are also reported. Additionally, further regression analyses were also conducted in order to determine whether any significant interactions were present between the independent variables. No significant interactions were found and therefore only main effects were included in these analyses.

Depression. Table 4.4 presented below summarizes the results of the regression analysis conducted on depression. In this analysis, statistical significance was indicated with respect to caregiver burden, social support and coping styles. The first model contained only caregiver burden and it shows that burden was a significant predictor of depression. In the second model, avoidance and social support were added to the model. A one-unit increase in the use of avoidant coping strategies was found to be associated with a .393 unit increase in depression. Additionally, these results indicated that a one-unit increase in the social support measure was also associated with .379 unit decrease in depression. Caregiver burden remained a significant predictor of depression scores, after controlling for covariates including both social support and avoidance coping. In this model, a one-unit increase in caregiver burden was associated with a .205 unit increase in depression (p<.001).

Table 4.4. Hierarchal Regression Model of Depression

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	39.339	2.243		17.538	.000		
	ZARIT Total	.305	.051	.538	6.028	**.000**	1.000	1.000
2	(Constant)	47.358	4.230		11.196	.000		
	ZARIT Total	.205	.055	.362	3.699	**.000**	.743	1.346
	Social Support	-.379	.150	-.232	-2.523	**.013**	.846	1.182
	Avoidance Coping	.393	.168	.216	2.345	**.021**	.839	1.192
3	(Constant)	43.817	4.413		9.928	.000		
	ZARIT Total	.153	.059	.270	2.604	**.011**	.631	1.586
	Social Support	-.341	.148	-.208	-2.307	**.023**	.835	1.197
	Avoidance Coping	.365	.164	.200	2.219	**.029**	.834	1.199
	Discrimination	.325	.142	.218	2.281	**.025**	.743	1.346

Note. 1. F(1, 90) = 36.341, p < .001; Adjusted R^2= .282; ΔR^2 =.290.
2. F(3, 90) = 17.749, p < .001; Adjusted R^2= .358; ΔR^2 =.090.
3. F(4, 90) = 15.255, p < .001; Adjusted R^2= .388; ΔR^2 =.035.

An additional regression model with the Zarit burden measure along with the discrimination measure was also conducted on depression scores. The third and final block, presented in the table above, shows the results from these analyses. Burden, coping, and social support were each independently predictive of depression in this model. The experiences of daily discrimination was a significant predictor of depression above and beyond caregiver burden, after taking social support and avoidance coping into account (β=.325, p=.025). For each one-unit increase of perceived discrimination predicted depression scores increased by 0.325 units. With respect to coping, a one-unit increase in the use of avoidant coping strategies was found to be associated with a 0.365 unit increase in depression.

These results indicated that a one-unit increase in the social support measure was also associated with 0.341 unit decrease in depression. The model was found to achieve statistical significance, while the adjusted *R*-squared indicated that approximately 39% of the variance in depression was explained on the basis of the predictors included in this final model. The R^2 change (.035) showed that perceived discrimination explained an additional 3.5% of the variance in depression.

Anxiety. The next set of hierarchal regression analyses conducted focused on the outcome of anxiety. The first table presented below in this section, Table 4.5, summarizes the results of the regression analysis conducted on anxiety with Zarit Burden total scores. In this analysis, statistical significance was indicated again with respect to caregiver burden and avoidance coping. In the first model, burden was entered by itself, showing a significant relationship with anxiety (β=0.260, p<0.001). Burden remained significant in the second model, after adding in demographic variables (β=0.174, p=0.001), as well as in the third model, controlling for both demographic variables and other covariates (β=0.132, p=0.017).

Table 4.5. Hierarchal Regression Model of Anxiety

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	44.961	2.045		21.990	.000		
	ZARIT Total	.260	.046	.513	5.637	**.000**	1.000	1.000
2	(Constant)	49.420	3.874		12.756	.000		
	ZARIT Total	.174	.051	.344	3.425	**.001**	.743	1.346
	Social Support	-.236	.138	-.161	-1.713	.090	.846	1.182
	Avoidance Coping	.437	.154	.269	2.846	**.006**	.839	1.192
3	(Constant)	46.555	4.069		11.441	.000		
	ZARIT Total	.132	.054	.260	2.432	**.017**	.631	1.586
	Social Support	-.205	.136	-.140	-1.503	.136	.835	1.197
	Avoidance Coping	.414	.152	.254	2.733	**.008**	.834	1.199
	Discrimination	.263	.131	.197	2.002	**.048**	.743	1.346

Note. 1. F(1, 90) = 36.341, p < .001; Adjusted R^2= .255; ΔR^2 =.263.
2. F(3, 90) = 15.616, p < .001; Adjusted R^2= .328; ΔR^2 =.087.
3. F(4, 90) = 13.118, p < .001; Adjusted R^2= .350; ΔR^2 =.029.

Similar to depression, a final model with both caregiver burden and perceived discrimination was conducted. In this regression model, when perceived discrimination was added to the model, burden did remain a significant predictor of anxiety. Discrimination was found to be an independent predictor of anxiety above and beyond the other predictors of anxiety in this sample of caregivers. For each one-unit increase in perceived discrimination, predicted anxiety scores increased by 0.263 units (p=0.048). Additionally, these results indicated that a one-unit increase in the use of avoidant coping was associated with a 0.414 unit increase in anxiety (p=0.008). Overall, the adjusted *R*-squared in the final model indicated that 35% of the variance in anxiety was explained on the basis of the predictors included in the final model. The R^2 change resulted in discrimination explaining close to an addition 3% of the variance in anxiety.

C-Reactive protein. The second research aim was **to assess the relationship between caregiver burden, discrimination, and CRP** and to determine the predictive value of both caregiver burden and discrimination. The hypothesis for this specific aim stated: *Participants with higher levels of caregiver burden and perceived discrimination will have significantly higher levels of C-reactive protein.* The following table summarizes the results of the regression analysis conducted focusing upon the outcome of the natural log transformed (LN) CRP. Caregiver burden was entered into the first model, followed by covariates in the second block. As indicated in Table 4.6, statistical significance was not found in caregiver burden in the model. In the third and final block, everyday discrimination and BMI were entered. BMI was the only variable found to have a significant relationship with CRP. In fact, in the second model, when BMI was added to the model, the change in R^2 showed an increase of 10%. In the final model, these results indicated that a one-unit increase in BMI was associated with a 0.059 unit increase in CRP.

Table 4.6. Hierarchal Regression Model of Natural Log (LN) Transformed CRP

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	1.136	.369		3.078	.003		
	ZARIT Total	-.009	.008	-.110	-1.036	.303	1.000	1.000
2	(Constant)	-1.612	1.021		-1.579	.118		
	ZARIT Total	-.009	.009	-.113	-.944	.348	.743	1.347
	Social Support	.037	.025	.163	1.460	.148	.845	1.184
	Avoidance Coping	.027	.028	.109	.965	.337	.828	1.208
	BMI	.060	.024	.259	2.495	**.015**	.977	1.023
3	(Constant)	-1.822	1.045		-1.744	.085		
	ZARIT Total	-.013	.010	-.160	-1.238	.219	.631	1.586
	Social Support	.040	.025	.175	1.556	.124	.834	1.198
	Avoidance Coping	.025	.028	.102	.896	.373	.824	1.214
	BMI	.059	.024	.253	2.429	**.017**	.973	1.028
	Discrimination	.023	.025	.114	.949	.345	.740	1.352

Note. 1. F (1, 88) = 1.074 p =.303; Adjusted R^2 = .001; ΔR^2=.012.

2. F (4, 88) = 2.658 p =.038; Adjusted R^2 = .070; ΔR^2=.100.
3. F (5, 88) = 2.304 p =.052; Adjusted R^2 = .069; ΔR^2 =.010

Logistic Regression Analysis

Additionally, a series of three logistic regression analyses were conducted in which all outcome variables were dichotomized. CRP was dichotomized into level greater than 3, but less than 10 and levels less than 3. Individuals with CRP levels greater than 10 were considered to have an acute inflammatory process and were treated as outliers (n=15). Both PROMIS measures were cut off at scores 50 or greater. It has been reported in the literature that scores greater than 50 indicate greater risk for poor mental health outcomes (NIH, 2013). The regression model conducted on CRP did not achieve statistical significance and no significant results were found.

The following table, Table 4.7, summarizes the results of the logistic regression conducted on depression. Statistical significance was indicated with respect to both burden as well as the vigilance subscale of discrimination. Specifically, we found that higher levels of burden were associated with a significantly higher likelihood of elevated risk for depression (β =0.084, p<.001). Likewise, a higher score on the vigilance subscale was also associated with a significantly increased likelihood of elevated risk for depression (β =0.178, p=.007). Interestingly, for every one-point increase in vigilance, the odds of elevated risk for depression were increased by approximately 20%. In this model, we discovered that vigilance had a stronger effect on depression than caregiver burden. This regression model was found to achieve statistical significance.

Table 4.7. Logistic Regression Analysis: Depression

Measure	B	S.E.	Wald	df	Sig.	Exp (B)
Burden	.084	.024	12.425	1	**.000**	1.087
Discrimination	.022	.059	.140	1	.708	1.022
Vigilance	.178	.066	7.265	1	**.007**	1.195
Constant	-4.808	1.145	17.639	1	.000	.008

Note. $\chi^2(3) = 39.609, p < .001$; *Nagelkerke* $R^2 = .481$.

The results associated with the final logistic regression analysis, focusing upon anxiety, are summarized in Table 4.8. Here, statistical significance was not found in any of the discrimination predictors in the model. Perceived caregiver burden, however, was a significant predictor (β=.089, p=.001), indicating that with a point increase of burden was associated with an increased likelihood of elevated risk for anxiety by slightly more than 9%.

Table 4.8. Logistic Regression Analysis: Anxiety

Measure	B	S.E.	Wald	df	Sig.	Exp(B)
Burden	.089	.026	11.275	1	**.001**	1.093
Discrimination	.047	.072	.433	1	.511	.954
Vigilance	.061	.070	.743	1	.389	1.063
Constant	-1.550	.934	2.754	1	.097	.212

Note. $\chi^2(3) = 18.778$, $p < .001$; Nagelkerke $R^2 = .302$.

Quantitative Results Summary

The results of the Spearman Rho’s correlations as well as the regression and logistical analyses indicated significant associations between the independent predictors and the outcome measures of interest. As hypothesized, perceived burden and everyday discrimination were significantly correlated with both depression and anxiety. The total Zarit score and everyday discrimination total were also found to have a significant correlation. Additionally, we found that caregiver burden and everyday discrimination predicted levels of both depression and anxiety. We were also able to establish that perceived discrimination was an independent predictor of depression and anxiety above and beyond caregiver burden. Covariates such as social support and avoidance coping were also significant predictors. Avoidance coping, in particular, had independent relationships with depression and anxiety and remained significant, regardless of other predictors we entered into the regression models.

There was not a significant relationship, however, between caregiver burden or everyday discrimination with CRP. In the set of hierarchal linear regression models, BMI was the only variable found to have a significant relationship with CRP. Specifically, we found those with higher BMIs had significantly higher predicted value of CRP. Overall, these results indicated that the hypothesis regarding the relationship between caregiver burden, discrimination and CRP was not supported. Logistic regression analysis results found that both caregiver burden and vigilance discrimination scores predicted elevated risk for depression, but not anxiety. Specifically, vigilance was found to have a more powerful effect on the increased risk of depression than either caregiver burden or everyday discrimination.

Qualitative Results

The purpose for adding a qualitative component to this project was to **explore the meaning of burden.** Specifically, we set out to compare the narratives told by the caregivers with survey data collected during the quantitative phase of this project. We also wanted to explore additional concepts of race and racism and how these meanings might shape and/or influence their roles as caregivers.

Sample Description

A sub sample of nine caregivers was selected for the qualitative component of this study. At the time of the interviews, all of the caregivers had successfully completed the randomized controlled trial that served as the parent study for this project. With the exception of one, all of the caregivers were still providing full time care for their loved ones. One of the participants experienced the loss of her husband approximately three weeks prior to her interview. The in-depth interviews were on average 45 minutes long and at times were up to an hour in length. The following table is a summary of characteristics of each of the respondents in the qualitative sub-sample.

Table 4.9. Qualitative Sample Characteristics

CG ID	Gender	Age	Marital Status	Education	Occupation	Relationship with CR	Age of CR	Length of Time as CG[1]
AD 10	F	56	Married	College	Retired	Mother	80	42
AD 13	F	43	Single	College	In Transition	Father	75	10
AD 39	F	70	Married	Post Grad	Retired	Husband	80	52
AD 43	F	67	Married	College	Retired	Mother	87	23
AD 54	F	60	Single	Technical	Unemployed	Aunt	73	38
AD 55	F	52	Married	HS Grad	Unemployed	Mother	75	77
AD 89	F	59	Married	College	RN[2]	Husband	65	60
AD 91	M	59	Married	Post Grad	Retired	Wife	57	36
AD 93	M	61	Married	HS Grad	Caregiver	Wife	63	36

Note: 1. Length of time in months 2. Registered Nurse

The mean age of the caregivers in the subsample was 59, while the recipients' age was an average of 73 year of age, both averages close to overall sample mean. The length of time the care recipients required care due to their dementing illness was close to 2 years with the range being as recent as one year and as long as 6 years. Overall, the caregivers reported moderate levels of caregiver burden with Zarit mean score of 34. In regards to risk of poor mental health outcomes, this group reported higher levels of anxiety with PROMIS scores of 54.

Table 4.10. Qualitative Sample Characteristics of Continuous Measures

Measure	Minimum	Maximum	Mean	Std. Deviation
Caregiver Age	43	70	58.56	7.92
Care Recipient's Age	57	87	72.78	9.50
Length of Time Needing Care	1	6	2.78	1.86
Zarit Burden Score	15	61	33.63	17.52
PROMIS Anxiety T-score	42	70	53.83	8.64
PROMIS Depression T-score	37	59	45.34	8.63
Everyday Discrimination	36	54	49.89	7.88
Discrimination - Vigilance	9	24	19.33	5.39

In order to address this specific aim, caregivers were asked general questions about their caregiving experience, then more specifically about burden. Racial differences between Black and White caregivers were also discussed. If caregivers felt racial differences existed, follow up questions were introduced to identify particular reasons. Finally, racism, discrimination, and other inequalities that might impact the role of caregivers were explored.

The ZBI was selected to operationalize burden in this study. The 22-item, 4-point Likert scale has a range from 0-88, with higher scores indicating greater levels of perceived burden. A total less than 21 would indicate low burden, whereas a total score above 40 is considered a high level of perceived burden. Scores within the range of 21-40 reflect moderate levels of burden. After examining how participants responded on the burden instrument in the quantitative phase of the study, caregivers were selectively interviewed for the qualitative component. Three caregivers were randomly selected to represent the low burden category, two caregivers for the moderate group and an additional four caregivers were chosen for the highly burdened group (see table 4.11 below).

Table 4.11. Perceived Burden of Sub-Sample Qualitative Group

Burden Group	**Participant ID**	**ZBI Score**
Low Burden *ZBI < 21*	AD 43	15.0
	AD 89	15.0
	AD 10	20.0
Moderate Burden *ZBI 21 - 40*	AD 55	25.0
	AD 91	38.0
High Burden ZBI > 40	AD 13	43.0
	AD 93	48.0*
	AD 54	52.0
	AD 39	61.0

**Missing one item – total including 21 items.*

Meaning of Burden

One of the research questions constructed for the qualitative portion of this study asked, "*What does caregiver burden mean in this sample of African American caregivers?"* Before comparing the similarities and differences in caregivers' experiences - by their level of perceived burden - it was important to determine how these caregivers defined the concept of burden as a group and what it meant to them. Some of the caregivers had difficulty defining caregiver burden but were able to talk about what was particularly “challenging” for them in their role as fulltime caregivers. Most caregivers perceived burden as a negative concept. After comparing all of the caregiver accounts, there were essentially two components that captured the essence of burden in this sample: having a *sense of obligation*, and experiencing *disruption* to their lives. Additional sub-themes were also discovered within the two components of burden. Obligation consisted of *“being there”* and *“being bound.”* The sub-theme of *“loss”* was an important aspect of the larger theme of disruption.

Obligation. When asked about the definition of burden, many were in agreement that caregiver burden comprised *“doing something you have to do but don’t want to do.”* This sense of obligation has roots in traditional values of collectivism and a commitment to family and caring for their family members. Statements like *“family got it” “family plays a big part”* and *“family is first”* support how caregivers understood the importance of family and the expectation that family members should care for each other. Caregivers acknowledged that they learned what is expected of them from what has been modeled by other family members. Several caregivers described how they had witnessed first-hand matriarchs in their families taking care of other relatives. Watching relatives care for family members influenced caregivers in their decisions in becoming a fulltime care provider. One caregiver talked about how she learned from one of her husband’s relatives:

> *I learned from my husband’s family. They had a niece and she donated her time to his mother, which was his grandmother. But, she was right there by her grandmother and her mother. She was right there for them when they passed... and her grandfather. Her father-in-law passed first and the same niece was right there by his bedside. So she really took care of both of her grandparents. I watched that and she was a young girl. I said okay… okay, if she can do it, I can do it. AD 10*

Many of these caregivers naturally assumed the role of the primary caregiver with very little hesitation. In general, caregivers accepted that *“this is what we do”* and that the expectations were for them to not let others do for their family members, if they could and were willing to do it. One of the male caregivers described how his mother cared for various members in her family:

> *I know that blacks have – taken care of their loved ones. I've seen it. My mom is one… my grandmother was sick. She would take care of her... My mom took care of her until she passed away. My momma would go up there every day. And then my dad had a stroke, too... My mom took care of him... So I see that and then I've seen it in other families, too. AD 91*

The expectation to care for family, however, appeared to create a great weight for many of these caregivers. Shaped by traditional and cultural family values, the caregivers' expected responsibilities also involved being available for their loved one at all times.

Being there. Caregivers frequently used the phrase *"being there"* as a way to show support to the care recipient. The sub-theme of being there was more than an emotional presence of support, but a responsibility to always be physically available. In fact, one caregiver discussed how this commitment is one of the distinct features differentiating black caregivers from White caregivers. Knowing that they were not abandoning their family members to deal with consequences of dementia alone appeared to be the primary motivation of caregivers' commitment to their loved ones. A caregiver described an incident where she had to put her mother in the hospital and what it felt like to be with her:

> *Like the night she was in the hospital, I spent the night there with her… she was never alone. So it was like we're there for her... Thank God had put me in a position where I can be here for her and I'm going to be there for her. AD 10*

Another caregiver caring for her father reported, *"… to know that he has someone that's there I think is rewarding enough because I can't fathom being alone having to deal with this and not having anybody around."*

Although some caregivers expressed gratitude and a sense of reward from being there for their family members, the expectation to physically be there for their loved one contributed to other caregivers' sense of obligation. Due to many of the caregivers' responsibilities involving assistance with basic daily living activities like bathing, dressing, and feeding, caregivers often spoke of not having the freedom and flexibility to just go when they wanted to. They often complained that when they needed to leave the house, they would have to either negotiate with the loved one about coming along or leave them alone. When the caregivers would leave their loved one at home, they would still worry while they were away. The caregivers' concern about the loved one's wellbeing and the need to ensure safety created feelings of being tied to the individual, so much so that they could not even be apart from their loved one. Tensions over staying with their loved ones and leaving them behind created feelings of stress, worry, and ultimately unhappiness.

> *What makes it hard for me is that when I have to go somewhere, I can't just up and go. I sometimes run across it when she don't want to go. She don't want me to put her clothes on or I'm tossed between to leave her by herself or take her with me. If I leave her here, then my brain is rattling because I'm so stressed out wondering has she fell. Has she bothered something? AD 54*
>
> *But in my mind, I was always worried, worried about is he all right, what is he doing? So but ultimately, it was a lot of anxiety while I was away from home. And so – and I would call trying to get him to answer the phone so I could talk to him and see if he was okay. It was hard in the beginning. It was really, really tough. AD 89*

Being Bound. In addition to caregivers feeling the need to physically be available to take care of their loved one's daily needs, they also felt a greater obligation to always remain the primary caregiver. Although the decision to become a caregiver was not forced upon the participants in this study, many felt they had no choice. The decision also appeared to be final - leaving the caregivers little option for anyone else to assume the caregiver role. Caregivers used the word *"commitment"* or *"promise"* as a way to describe their level of devotion to their loved one. This commitment, though, often created a sense of *being bound* to the family member, where the caregiver felt they had remain there for the care recipient. For some experiencing great difficulty managing their caregiving responsibilities, this layer of obligation represented another dimension of burden.

For spousal caregivers, this sense of being bound derived from a larger context of marital vows. They talked about being committed to one another for many decades and the importance of honoring their vows of matrimony. The expectation to continue to provide care for their spouse became a source of stress and strain for some of these spousal caregivers. A retired registered nurse described her husband as a good man who deserved the best because of his service to this country. Her husband was a Vietnam veteran who developed dementia because of his direct exposure to Agent Orange. Despite her feelings of wanting to give her husband the best care, she admitted that her obligation to care for him had become a *"cross to bear." "I feel like this is a burden that I'm bearing",* she stated through tears*, "I married this man, and it does say in sickness and in health, so I've got a commitment to him."*

Another lady had similar feelings of obligation to her husband. She had been caring for her husband for approximately 6 years and suffered verbal abuse from him throughout the entire time she had been his fulltime caregiver. Describing him as demanding and controlling, her commitment to care for her husband had become a significant source of stress. In this particular case, this caregiver felt stuck between her obligations to her husband and her own wellbeing. She described feelings of wanting to leave but being unable to do so because of her marital vows and her spiritual beliefs.

> *And I actually thought about leaving him, but here's where religion takes hold. How are you going to leave somebody when they're sick? That's not God's way because you did take wedding vows. You made a commitment to be with this person 'til death do you part. I hadn't thought about that until just now. I made a commitment until death do we part. That's the stressful part. AD 39*

"We take care of own." In addition to the personal responses of obligation, there was also a social expression of obligation. Caregivers felt more obligated to care for their loved ones because of their reluctance to place their family member in a long term care facility. In this study, caregivers repeatedly discussed their concerns about placing their loved ones in nursing homes and admitted to struggling with this decision. They are faced with the inevitable progressive decline of dementia, but hold on to cultural

values of *"taking care of our own"* and *"keeping them home as long as we can."* Despite levels of perceived burden, the majority of the caregivers wanted to care for loved ones *"as long as possible."* Caregivers acknowledged the fear of *"throwing away"* their love ones and leaving them alone – a fate that was simply unfathomable for these caregivers. Other caregivers endorsed beliefs that sending them to a nursing home could bring on premature death and ultimately lead to feelings of guilt knowing that they could be playing a role in the hastened death of their family member. They also discussed how making a decision like this would be frowned upon by others in their community. A caregiver caring for her elderly mother stated,

> *I also feel that as African Americans, we feel a certain guilt, which we should not, if we do put our parent away into situations like that. We feel like people will say oh, my God, did you know that (she) put her mother in a nursing home? Could you believe that? I think we take that kind of stuff to heart…AD 43*

Disruption The sense of *disruption* emerged as the second component of burden. Caregivers felt that having to provide continual care for their loved one created a sense of disorder in their lives in that they could not care for their loved one without its' compromising their own needs. Some of the participants described how declines in level of functioning caused a disruption to the ideas of what they thought they would be doing at this time in their lives. Caregivers discussed this disruption in their plans as one of the most disappointing aspects of the caregiving experience. Caregivers often had to sacrifice, make changes, and shift priorities; leaving them with feelings of frustration and discontent. When asked about burden, these two caregivers described the following examples:

> *… the plans I had in place have been disrupted because my vision was that when we retired, we would just kind of travel and go places and enjoy ourselves and do things. We're able to do it, but not on the same scale that I envisioned it, that we would just kind of take off and go and enjoy ourselves and just do things together more … AD 91*
>
> *… this is not what I wanted to be doing at this point in time. And we had other ideas about our life. And so I just – that's hard… I don't know… it's just not the place that I want to be in my life right now. I want to do so many other things, and it's like you have to put it on hold. It's a lot. AD 89*

Caregivers who struggled with this sense of disruption also appeared to have more challenges maintaining normal activities. For example, some of the caregivers identified traveling difficulties as a major source of stress, especially since traveling is a large part of the plans for many facing retirement. One caregiver talked about the difficulty she experienced when she traveled with her husband:

> *We were always talking about trying to do a lot of traveling and just kind of get away from home. And just do lots of things that we just never had a chance to do. I've tried to travel with him as it is now, and it's hard. I've kind of estimated we really cannot go over four hours somewhere, away from home, if we're traveling in the car because I can see him fatiguing. And then we have to consider, how are we going to manage the incontinence on the way? And we've had to strategically find the places, the rest stops with the family rooms, to be able to take him in there. And then he gets tired of sitting from long periods of time. So that part of traveling has been a challenge… And I am so worn out because I have to drive, take care of him, buy the food; it's not as easy as we think we can handle it. But that's hard. AD 89*

Loss of self. Because of the disruption caregiving created in the lives of these caregivers, many of them experienced a great number of losses, including losing the ability to care for themselves. They discussed how caregiving can be "an *interference"* to their existing lives and how they are no longer able to do things they enjoy because of their demanding responsibilities. Caregivers talked openly and frankly about feeling cheated. *"It's not fair"*, a couple of caregivers remarked. The following exert is an example how caregiving impinges on the average, routine aspects of the caregiver's life:

> *But most of the time I'm out, I'm still taking care of things that mostly concerns her, making sure she's okay. It's been over four years since I went and just sat down with some friends and just talked and just relaxed. AD 93*

They consistently made personal sacrifices for the wellbeing of their love one, but this occurred mostly at their own expense. They complain of not being able to care for their own needs and the consequences associated with these sacrifices. For example, many of these caregivers worked prior to becoming a fulltime caregiver. Some of them gave up jobs they loved or were not able to pursue opportunities they were interested in because of their commitment to their family. The sense of disruption created challenges in the caregivers' being able to care for themselves. The caregivers recognized a tension between choosing their needs and the need of the care recipient. Most of the caregivers consistently chose to meet their family member's needs over their own. Making these sacrifices, however, was not without consequence. Not only did caregivers wonder about their own dreams and wishes, but they also acknowledged the negative effects on their lives, including their own health.

Loss of family. The noted disruption in the caregivers' lives did not only affect them personally, but they also experienced the loss of family support. Not having sufficient support from family significantly increased stress for these caregivers and contributed to their feelings of burden. The majority of caregivers in this sample endorsed inadequate support from various family members at some level. The perceived lack of support was especially felt when family members did not assist with direct care responsibilities or when they stopped visiting the individual. Caregivers complained that family members *"don't step up", "don't show up", "don't have time"* and can not be relied upon. Interestingly, caregivers equated showing up and offering specific help with *"love."* When family members did not provide the support needed, their love was questioned. One caregiver caring for her aunt describes how the lack of support eventually leads to decreased expectations.

> *I have nobody to come here. I've got cousins that come here and they say they love her, this and that, but to say okay, I'm going to come and help you out, they say it, but they never show. So I don't look for it. AD 54*

Another caregiver experiencing conflict in his family expressed that his feelings of burden stemmed directly from lack of support from certain family members. Expectations of family members weigh differently than expected help from friends, church members, and formal help (i.e. nursing assistants). In this case, the caregiver frankly stated that he has some help from others; however, he is looking for particular help from his stepdaughters. Not getting expected support from certain family members was painful for these caregivers.

> *I don't have that family support that I need. I have other support, but I don't have – other support is good, but that family support, the one that you've been knowing for 20 and 30 years, that's the support that you look for. You look for somebody who knows you and should be able to understand you after all these years. But in some instances, you don't get it. And that's where the stress comes from because you try to figure out what are they thinking? Why are they not doing it? AD 93*

Family support emerged as a nuanced and complex continuum. On one end there were families with conflict and lack of cohesion, whereas on the opposite end there were families that work together as a team. Families that exhibited teamwork shared responsibilities and resources, greatly reducing their levels of stress and burden. Several families, however, fell in between these extremes. Some caregivers believed they have support from some family members, but perceived a lack of support from others – members whose presence and support that was deemed more valuable. There were also families where support was offered and available, but the caregiver felt ambivalent about asking family members for help, causing them to also perceive a lack of support. Several caregivers noted that although family members have offered to help, they have concerns because they have *"their own families."* For example, one caregiver expressed, *"I don't put any pressure on my kids, because they have their lives, they have their families to take care of."* Acknowledging the limitations of her family's ability to provide assistance, another caregiver stated, *"I have an amazing family. My children live here, and they're very cooperative. But they have lives, too."*

Burden: Does it all line up?

Four caregivers who scored low to moderate levels of burden reported they did not feel burdened by their role as a caregiver. When asked to describe the challenging parts of caregiving, two caregivers in this group stated caregiving was neither difficult nor challenging. In fact, one caregiver stated, *"it's a breeze."* Another caregiver noted, *"She's not hard to take care of."* The two caregivers who reported the lowest levels of burden, however, had narratives that would suggest that their experiences compared more with those experiencing higher levels of burden. Similar to the highly burdened group, these participants described caregiving as "*frustrating*", "*physically exhausting*", and that it "*interfered*" with their lives. In fact, when directly asked, one of the caregivers that scored the lowest of the ZBI admitted to feeling burdened by the role as a fulltime caregiver of her husband. The inconsistency between what is reported in the burden scale and what is actually experienced suggest other factors might influence one's perception of burden.

The original aim of the qualitative component of this project sought to explain the discrepancy between survey data and narrative reports from in-depth interviews. After exploring the meaning of the concept of burden, each of the caregivers' accounts was examined for similar themes and possible explanations. We discovered two particular reasons to explain why African Americans are reporting lower levels of burden, despite challenging and seemingly burdensome experiences. The first explanation for lower perception of burden in black caregivers is the notion of resilience. Secondly, due to cultural influences and the meaning of burden ascribed by black caregivers, it is hard for them to disclose negative feelings about caregiving.

"We've been through the hangar." One of the caregivers who fell into the lower burdened group reported, *"…we've been through the hangar…we endure more…we just deal with problems better (than Whites)."* This statement was made when asked about racial differences between African American and White caregivers. *"Through the hangar"* denotes the historical injustices, legalized mistreatment, and abuses suffered by African Americans in this country. Not denying that she has problems, this caregiver implied that because of the years of suffering African Americans have had to endure, a sense of resilience developed out of a need to simply *"survive."* Another caregiver talked about how African Americans have *"overcome monumental odds*". Most would not dispute that African Americans have disproportionately experienced immense levels of suffering. The experiences of overcoming these odds create the ability for African American caregivers to face difficulties in their roles as caregivers and not perceive them as significant challenges in their lives. When asked about the more difficult aspects of caregiving, one of the caregivers that denied feeling burdened reported, *"I'm just immune to it.*"

"We just keep going." Caregivers across the sample noted how they have handled the stressors associated with caregiving. The overall attitude was to *"just deal with the hand you've been dealt"*. Phrases *"just deal with it", "get over it*", and *"keep going"* were found in nearly every case. Notwithstanding the level of burden perceived, the caregivers overwhelmingly noted that acceptance and perseverance have been the primary ways they have coped with the difficulties of caregiving. In fact, when asked about this particular disposition, the caregivers noted that this approach was a cultural expectation. When probed about differences in culture, one caregiver recollected an incident that occurred many years ago that she thought would explain the differences.

> *Maybe because over the years, we've just been expecting this is what you do and you don't complain about it. You just do it. You just suck it up and do it. …we just do things. Years ago, I was a teacher in New Jersey. I shared a class, we taught basic skills and there were three of us in the classroom, and there was this White lady, a White man, and myself. And there was one day … I was moving desks and she told me leave that alone and let somebody else do it… we are so in tune to thinking, oh, I've got to move this and just do it. And she said oh, just leave that alone and let them do it. She didn't attempt to do it; she just sat there. And I noticed her from then on how I'd just work and work and work, and she was just taking life easy. AD 39*

The caregiver used this story to illustrate how as an African American she never thought to let others do for her what she felt she could do for herself. She acknowledged that it was a critical moment in that she realized her expectation was that life would be harder for her and that blacks did not have it as easy as White people. Expecting greater adversity and adjusting perspectives to accommodate these expectations provided these individuals tools to deal with caregiving situation differently and possibly protect them from feeling burdened.

"God worked it out." Spirituality and religious coping was also found to enhance this sense of resilience in these caregivers. Providing a foundation for optimism, meaning and purpose, faith in God

emerged as an essential part of their experience. Faith and spirituality was mentioned by all of the caregivers in our study. When asked how their faith helped them particularly in their roles as caregivers, they frequently noted how they found God to be source of strength *"God has given me the strength to do everything all that I'm doing."* They also described God as one who *"understands and knows all"* and provides for their basic needs. This trust and confidence in God was also evident in statements like *"God got me", "God worked it out", and "God turned it around"*. One caregiver stated *"If it wasn't for my faith in God at this point, I don't know where I'd be."*

In addition to discussing particular attributes of God, caregivers were also specific in their belief that they were "placed" in their role as a caregiver. Many of them endorsed that it was not by chance that they were in a position where they would be the primary caregiver. *"God set it up",* one caregiver stated. Another caregiver suggested, *"Sometimes things happen for a reason… maybe God put me here for that.*" Still another caregiver, who discovered her mother was taken by strangers to withdraw $3,000 from her bank account, found purpose in the incident and stated, *"So then again I look at it the Spirit moved to just to have her to move in with us."* This belief helped the caregivers frame the difficulties of caregiving with a perspective that what they are doing for their love one also serves a higher purpose. For these caregivers faith became a source of purpose and meaning – strengthening one's sense of commitment and obligation to care for their loved one. Because the application of faith in God is so deeply embedded in the African American community, one could see how difficult it would be to disentangle it from other spheres of the individual's life. One of the male caregivers caring for his wife reported,

> *…we realized that the marriage is not – it's a covenant relationship with God. We realized that. And if I'm not supporting her, I'm not supporting God. So I think we realized that, too. And so our faith keeps us going. AD 91*

Faith in God was acknowledged by all of the caregivers in this study whether they scored the lowest level of perceived burden or the highest score. All of the caregivers talked about believing in God, relying on faith and prayer, and attending church. Some of the caregivers who were taking care of individuals with greater functional impairment admitted to having to *"stop going to church"* or had "*difficulties going to church"* because of their caregiving responsibilities. These caregivers noted the importance of church attendance and desired to *"start going again."*

"We can't say we're stressed." The caregivers in this study believed that African American caregivers are having difficulty with their roles and responsibilities, but have trouble admitting they are burdened in an open and honest way. *"We want people to think they can endure anything",* stated one of the male caregivers, *"I can sit here and say that I'm not stressed and all the while I am."* He added that it's difficult to admit to the challenging aspects of caregiving because doing so would infer weakness.

Another caregiver, in the highly burdened group, added that even if caregivers did admit to the problems they would *"feel bad"* about saying it. She described a conversation with another African American caregiver and describing how she had to give her permission to say, *"it sucks."* She recalled how when she initially heard others talk about how African American caregivers admit they did not want to do it anymore, she would think that it was wrong for people to have those types of feelings. However, after becoming a caregiver, she realized that others' account of caregiving was a harsh reality and understood the importance of being honest about that experience.

It appears that African American caregivers are not only expected to care for their family members, but are not permitted to acknowledge the burden they experience attempting to fulfill this obligation. For example, one of the male caregivers caring for his wife was placed in the moderately burdened group (ZBI score of 38); when asked about burden, he stated he did not feel burdened by the responsibilities, but was noted to discuss feelings of stress, loss, concern and having to cope with stigma in the interview. The participant described how caregiving was challenging and even burdensome, but wanted to clarify that *"it's* *the disease"* and not his wife's *"fault."* It was obvious that he did not want to give the impression that his wife had become a burden. The African American caregivers, across the sample, accepted there is a reluctance to admit caregiving can become burdensome. One caregiver talked about her mother and how she cared for her (and her siblings), so she did not have the right to complain about caring for her mother, especially since the ones that have gone before them have had to endure so much:

> *How do we take all that stuff that came from 400 years ago (slavery) and now this is where we are? And what do I do with my mother? Do I complain about my back is breaking from giving her a bath? Do I complain that I have to cut up the food? Do I get frustrated because she can't remember what I said when I went out of the room and came back in? AD 43*

Difficulties expressing burden associated with caregiving may have roots in a larger social cultural setting, where African Americans consistently saw examples of their parents and other elders in their community representing strength and resilience, often denying being sick and hiding the fact their health was declining from even close family members. Caregivers talk about their loved ones with pride and esteem. This was particularly the case of participants caring for their parents. These mothers and fathers represented images of strength and independence. They spoke about the value of having this person in their lives, their families, and their communities. One caregiver caring for her father noted how her father was referred to as a *"strong bull."* She had this to say of her father:

> *… there weren't too many of us that had fathers in our house. But it was me and two other friends, we had fathers. Everybody else had just a mom and some folks didn't even know their father. But having a father that represented something. This is the guy that went out and he went to work and he brought the check home and he made sure we had this and … that, and having that little bragging rights, like my daddy takes care of that. AD 13*

Another caregiver talked about her mother and the symbol of strength she represented for the entire family.

> *… (she) was this amazing woman to me that was so strong and so in demand by the whole family … she was always available. She was a very active woman, very supportive woman of what you*

> *needed. She has friends that she adores and they adore her. She had a very active life in her church life… a very strong woman, a woman who lived by herself. So she's been – she's fiercely independent. I mean, she just does not accept that somebody else has to help. Now she does, she's like – I almost feel, and I hate to use the word broken, but I just hope her spirit isn't broken… AD 43*

Having parents as models, these caregivers witnessed up close examples of strength, perseverance, and resilience. These values transcended through generations and caregivers are now expected to model these same traits and behaviors for the next generation. Given this perspective, it is likely that caregivers feel the weight of perpetuating this image and are thereby unable to fully express how they are being affected by their caregiving responsibilities.

Physical Toll. Not being able to admit to the stressful nature of caregiving and feelings of frustration and disappointments could have a negative impact on the physical health of the caregiver. The caregivers who were more highly burdened were more likely to describe the physical toll caregiving has taken on them. Several of them complained of headaches, body aches, back pain, and exacerbations with chronic illnesses like elevated blood pressure, blood sugar levels and stroke symptoms. When asked about these symptoms, caregivers explained their belief is that the physical problems experienced were directly related to the stress of caregiving. The caregivers described themselves as being *"exhausted"* and *"worn out"* and not being able to go to the doctor and take care of their own medical needs. Below are examples of how caregivers would frequently mention somatic complaints and physical consequences as a direct result of the stress endured from caregiving:

> *Well, to that, I can tell that my body has sort of went down. I mean physically… I have more headaches, my body aches, my whole body aches sometimes. It's stressed, it's got to be, that's the only thing I can come up with because I don't do anything. AD 54*

> *I had excruciating back pain, I had a knee problem. The knee problem started before he got sick, but the back pain, I think that was directly related to the stress. And I have been told that I have … sciatic nerve in the back because it starts there and it runs down your legs. So I think it's stress related to his illness. AD 39*

The caregivers in this study described caregiving as both mentally and physically challenging. Some of the caregivers felt that "*mental piece of it"* was more difficult to cope with, whereas others thought the physical aspects and the *physical* consequences of caregiving were far more challenging. One caregiver attempted to make a distinction between how he felt he was being affected by "stress" of caregiving. He noted,

> *…it has been a real toll on me physically. Not mentally. Mentally I'm dealing with it, but physically I have been to the hospital twice for stress, a couple of months ago I went – two months ago I went to the hospital because I thought I was having a stroke. My face went numb and all that. I went to the hospital, it happened that evening, that day, but I had to make sure – I'm still – I know that I need to think about me a lot, but I'm still thinking about her. AD 93*

It is interesting that this particular caregiver believed that mentally he was dealing with the stress of caregiving and felt that it only affected him physically. Although he admitted to having stroke symptoms related to his stress, he did not attribute this outcome to mentally or psychologically being affected by the stress related to his caregiving role and responsibilities. This same caregiver also described moments of being so overwhelmed with sadness that he would have to pull over in his car to just sit and cry. This disconnect is another example how the African American caregivers were having difficulty accepting the emotional and physical consequences they have been suffering from being a fulltime caregiver.

Although caregivers were able to describe how disruption in their lives and difficulties they experienced garnering family support, to say they were burdened would be making a greater admission. The word "burden" has such a negative connotation in the African American community that deeply held cultural beliefs about family and caregiving hindered some caregivers from fully accepting they were feeling burdened. One caregiver made the distinction between Black and White caregivers. She stated, *"… Black caregivers do it (caregiving) for love. I think White caregivers do it because they feel they have to."* Given the cultural context coupled with how caregivers in this study defined burden (as something you have to do), the reluctance to accepting they are burdened by their responsibilities is understandable. For some of these caregivers, to admit that they are burdened potentially infers that they don't love their family member enough to care for them.

Differences in perception of burden

As noted, there were some discrepancies between quantitative and qualitative findings in this sub-sample of caregivers (e.g. caregivers with low ZBI score that admitted to feeling burdened and vice versa). There were distinctions, however, in caregivers that scored differently on the ZBI. In general, the caregivers in the moderately high to higher burden group more readily endorsed feelings of caregiving being "*hard", "stressful", and "frustrating."* In addition to perceiving more burden, the caregivers in this group also had greater difficulty caring for themselves and had less family support. On the other hand, those that scored lower appeared to be more resilient. They appraised caregiving as less stressful, maintained active lifestyles, found ways to care for themselves, and worked as a team with their family for support.

The caregivers who reported that they were having less difficulty with caregiving discussed keeping their loved one engaged in a lifestyle that would include activities such as church attendance and physical activity, social events and family gatherings. One caregiver described how she helps her mother stay active. This same caregiver talked fondly of how much fun she has with her mother and how people often confused them as sisters when they are out with one another.

> *… on Tuesday and Thursday, she has chair aerobics; I got her involved in chair aerobics….And then on Wednesday we go to Bible study, so we're always keeping her busy doing something. And then on Thursday night she goes to choir rehearsal with me. She's involved with the church… my theory is to keep her active. AD 10*

Another caregiver remarked how keeping his wife engaged in an active lifestyle helps him find strength to maintain his commitment to her. *"…it gives me the courage that what we're doing, being active, … trying to maintain the routine of what you've done before, as long as we're doing that, some semblance* *of that…. that's why I'm here, just us together and her quality of life, trying to maintain it. And that's what we do; we walk and go to the movies. We've gone on trips."*

The more resilient caregivers also found ways to continue to care for themselves. These acts of self-care included spending time with their friends, finding enjoyment in hobbies and social activities like dancing and going to the movies. In fact, some of the caregivers stated how they felt the need to ensure they took care of themselves so that they could remain healthy enough to continue in their caregiving role. They discussed exercise, eating well, and overall maintaining a healthy lifestyle.

Conversely, the caregivers in the moderately high to highly burdened group complained more of not being able to care for themselves or enjoy social activities. They discussed how most of their time was consumed with caring for their loved one and how they often were not able to make hospital appointments, take vacations, or spend time with their friends. One caregiver caring for her husband described how she met resistance from him when attempting to do something for herself, "*I'm going to join the senior citizens park so I can go be with other people so I can do line dancing twice a week for an hour. And this is for me, exercise for me to keep me healthy. And he would say things like oh, you're going to that class today, huh? Is that all you have to do? It would be something negative."*

The highly burdened group also had the greatest difficulty with dealing with the care recipient. The often had to manage aggressive and hostile family members who were described as *"mean"*, *"violent",* and *"nasty"* -- as opposed to the lower burdened group that described their loved ones as *"sweet"* and *"fun."* Surprisingly, this did not come across as the most challenging part of their experiences. The lack of adequate support from their family members, rather, emerged as particularly painful. The more burdened caregivers were more likely to describe family members as being unsupportive and unreliable.

In contrast to the challenges experienced by the highly burdened group, the caregivers who had lower levels of perceived burden were able to get family members to support them. Families coping relatively well worked together and shared responsibilities and resources. *"Everyone pulls together"*, said one caregiver. *"We all come together"*, said another. Married caregivers, caring for older parents with dementia, talked specifically how their spouses participated in caregiving duties. These responsibilities include watching the love one, helping with housework, assisting with basic activities of daily living. *"We take turns",* one caregiver remarked, *"He'll feed her, too… like sometimes if I go somewhere and stuff like that, he stays home."* This type of teamwork not only appeared to be important to relieve stress from the caregiver, but a husband's support was a mark of significance to the greater community. Another caregiver beamed with pride as she spoke of her husband's involvement and how others were able to recognize his support.

> *He helps out a great deal…The people at church say you have a good husband, or bless him for having your mother – to have him want your mother to move in because really it was his suggestion to have her come over here. AD 10*

At times, caregivers worked with siblings and other family members to coordinate care for their loved one. A primary caregiver of her father spoke of how she worked with her brother and sister to ensure her father's needs were met:

> *Everybody has something to offer. I would say this, even when me, my brother, and my sister sat down, my sister and I had the same thought process of my father on what needed to happen, then when my brother stepped in, he mentioned something and we were like we've got to give credit. We have to acknowledge that because from a male perspective he's speaking, and we realize we're dealing with a male, so it's good. AD 13*

Race and Disadvantage

To assess the role that race plays in influencing the African American caregiver's situation, all of the caregivers were asked about being a black caregiver and how their experiences differed from White caregivers. Though the participants differed on their experiences as a dementia caregiver, the discussion of race and racism brought out similar sentiments, despite their perception of caregiver burden. Most caregivers were quick to identify and articulate significant racial differences. The theme of *disadvantage* emerged from this particular discussion. Caregivers across the sample talked openly about how they believed they did not have same information and resources as Whites – resources that could make their lives as caregivers less difficult. They also shared how they often faced obstacles in acquiring community level support.

Examples of disadvantage included acknowledgment of both financial and service disparities between Black and White communities. In general, caregivers described how much "easier" and "nicer" life would be if African Americans had the money and resources like White caregivers. Several caregivers discussed how the lack of options (e.g. putting additions onto their home, bringing in 24-7 home health care) made it more difficult for them as caregivers, especially given the reluctance to place their family member in a long-term care facility. One caregiver described how she inquired about obtaining home health resources from another White caregiver. When she asked, *"how do you do (pay) for that"*, she stated the White caregiver explained that she was able to secure these services, *"out of her (mother) funds."* The caregiver used this example of how things were just different for them as Black caregivers. She stated, *"White people have more resources, they have more education about these kinds of things."* Others in this sample agreed.

The caregivers also talked specifically about the role of education. They agreed that African Americans, in particular, needed more knowledge about dementia, in order to understand the disease and reduce stigma in the Black community. *"Black people call it crazy",* one of the caregiver explained, "*They didn't understand it, and they didn't know and they didn't go see about it."* Another caregiver's statements about differences between Black and White families aligned with this sentiment. He highlighted the importance of African Americans being educated. This caregiver also made a connection between lack of knowledge and stigma.

> *…we just need to educate people. That's a little stigma to it, too, because I think probably stigma has probably been more in the black families. They kind of think it's a mental thing, they don't look at it as a disease like cancer or something. They think it's something like if you were on drugs and kind of gone crazy or something. AD 91*

Caregivers highlighted the nature of *pursuit* in order to get their needs met. These caregivers spoke of how they had to put forth extra effort to pursue knowledge regarding resources and opportunities. Several of them remarked, *"… you have to ask a lot of questions."* Some of them wondered if they would have been *"more persistent"* or *"pursue it more"* if they would have received more favorable outcomes. For instance, one caregiver talked about her attempts to get her husband in a nursing home. Asking about a specific facility, the caregiver was immediately told, *"There has only been two black people to get in there"* by a social worker. The caregiver reports that she had to end up with a different place that was *"not as nice."* She also expressed that perhaps if she would have put forth more effort, she might have been able to get him into that facility. The process of putting forth extra effort, or striving, added to the caregivers' sense of disadvantage and increased their strain and frustration.

Many of the caregivers did not overtly bring up the topic of racism during the interviews; however, the comments about race, difference, and disparity were mentioned with the understanding of the historical context of being black in America. In discussing access to quality healthcare, one caregiver asked, *"Why can't they have that in our neighborhood",* suggesting unfairness in availability of resources for her family. Another caregiver spoke explicitly about negative stereotypes African Americans have to endure in this country and how that affected the black community:

> *So when … you've grown up always being put down, … it's like people look at you, they pull their bags away. You're always going to get caught for shoplifting because when you walk in a store, I think that's part of their training, make sure that you watch out for this, this and this. And we don't take these lessons. We don't respect elders. I don't know how we got so far from that. We don't*

> *take care of our own. I grew up in a multicultural community and Jewish people, they say never again, and they mean it. Their community is so tight; there is nothing they don't do for each other. We have been so taught to divide and conquer. Your skin is lighter, my skin is darker, your hair is straighter, that's crap. We buy into that. AD 43*

This caregiver described the relationship between negative stereotypes placed on blacks in this county and the deterioration of the Black community. She explained how because African Americas have bought into the beliefs about them, the overall community has been fractured and the people have moved away from the values that have held them together for so long.

It is important to note, however, two caregivers felt that Black and caregivers were possibly more alike than different. One brought up examples of various accounts when white caregivers having similar values and experiences as African American caregivers. Another participant commented, *"be it Black or White",* she believed that all caregivers were facing similar circumstances, but perhaps disease progression and coping strategies were different.

Overall, caregivers felt that white caregivers had advantages over Blacks in terms of having adequate knowledge and resources to take care of their loved ones with dementia. The resources that caregivers sought after had to deal primarily with ascertaining available community support, managing insurance options, and long-term care decisions. The lack of knowledge regarding disease symptoms, availability of resources, and stigma were directly related to race and culture. In general these caregivers noted that Blacks did not have the same opportunities as White caregiver and that may suffer more because of these differences.

Qualitative Results Summary

The caregivers who reported lower levels of burden were more likely to describe the coping mechanisms of African American caregivers as having to *"survive" and "handle problems better."* They mentioned how they *"can't complain"* about their current situation. The value of family, love and commitment were held values in both low and high burden groups. Caregivers spoke of the importance of sticking by their love one, taking care of them, and not abandoning them in their time of need. The essence of reciprocity was highlighted across both groups. The caregivers talked about how the need to give back was important to them. Caregivers in this study defined burden as an obligation to care for a family member. They also believed lack of family support and having life disrupted contributed to feelings of being burdened. Given the deeply rooted cultural values of taking care of family, honoring elders, and showing love by being available coupled with strong convictions of faith and spirituality that caregivers derive meaning and a sense of purpose, it is quite understandable as to why African Americans might respond differently to researchers in regards to feelings of burden.

CHAPTER 5

DISCUSSION

The purpose of this cross-sectional, mixed methods study was to examine the psychological and biological effects of chronic psychosocial stress, specifically caregiver burden and perceived discrimination, on the health of African American caregivers of patients diagnosed with dementing illnesses. The data came from a program project grant that includes a study of African American caregivers of dementia patients. This chapter presents a summary of findings in the context of related literature on caregiver burden, discrimination, and health. We also examine the strengths and limitations of the study as well as provide a summary of research, practice, and policy implications.

Since the role of perceived discrimination on caregiver burden and health has been largely unexplored in African American caregivers of adults with chronic illnesses, the aims of this project were to not only examine the effects of caregiver burden but also to elucidate the role of perceived racial discrimination as an added burden on African American caregivers. The first two aims addressed psychological (depression/anxiety) and biological (C-Reactive Protein, CRP) consequences of stress. The qualitative component of the project was framed by a phenomenological approach. Designed to meet the third specific aim, this portion of the study explored the essence of burden in this sample. The qualitative approach added richness by obtaining more details from the individual caregiver’s life experiences.

Using a sequential mixed methods design, the study of 100 African American informal family caregivers was conducted in two phases. The first phase used a cross-sectional survey design to collect quantitative data from baseline measures through the parent study. The quantitative analysis examined the relationship between caregiver burden and racial discrimination with both psychological and physiological measures for caregiver health. The qualitative phase followed the quantitative analyses. The goal of the qualitative component of this project was to gain insight into individual experiences as well as shared experiences of a group of caregivers. Caregivers were categorized based on how they responded to the Zarit Burden Interview (ZBI). A selective sampling strategy was used to collect data from a smaller subsample of caregivers with diverse perceptions of burden. A total of nine caregivers (including those with low, moderate, and high levels of burden) were interviewed.

The overall sample of African American caregivers was highly educated with 75% of the respondents having some college-level education and 28% having some graduate-level of education. Fifty percent of the sample were still working, and 32% reported that they were retired. The majority of the caregivers (70%) were providing care for an elderly parent, and an additional 17% were caring for their spouses. This sample was also considered highly burdened with a ZBI score close to 42.

Caregiver Burden and Health

C-Reactive Protein

The link between caregiver burden and health has been consistently documented in the social gerontology literature. One of our specific aims was to examine the relationship between caregiver burden, perceived discrimination, and CRP. In addition to a set of multiple linear regression models, a series of logistic regression analyses were also conducted in which CRP was dichotomized into levels greater than 3 but less than 10, and levels less than 3. Individuals with CRP levels greater than 10 were considered to have an acute inflammatory process and were treated as outliers (n=15). Our regression model did not achieve statistical significance, and we were unable to find evidence to support this aim.

The relationship between CRP and caregiver burden has been established in the literature (Clark et al., 2013; Gouin et al., 2008; Von Känel et al., 2012). Results from studies examining the association between CRP and discrimination, however, have been mixed. Lewis and colleagues (2010) found significant relationships between racial/ethnic discrimination and elevated CRP levels. In their study of older

African Americans, researchers found a positive, linear relationship in which individuals with higher levels of perceived discrimination also had corresponding higher levels of CRP (Lewis et al., 2010).

Other researchers, however, have not been able to find significant findings. Using data from the Dallas-Heart study, Albert and colleagues (2008) were not able to establish an association in stratified analyses of middle-aged Blacks, Whites, and Hispanics (Albert et al., 2008). Likewise, Cunningham and colleagues (2012) were not able to establish a positive, linear association between experiences of racial/ethnic discrimination and CRP among Black women and men. In fact, researchers observed a negative, linear association among Black men and a curvilinear association between discrimination and CRP among Black women (Cunningham, et al., 2012). The relationships found between discrimination and CRP were also determined to not be independent of additional risk factors, including smoking and obesity.

Similar to these recent studies, we were also unable to establish a positive, linear relationship between discrimination with CRP in this sample. The relationship between chronic stressors, such as discrimination, and inflammatory cytokines is complex. Researchers have speculated that heterogeneity in samples (i.e., differences in gender and coping responses) and diverse psychometric instruments could explain the mixed results in the literature (Cunningham et al., 2012). Our study had a relatively small sample size and was possibly underpowered to detect small effect sizes. Though neither burden nor discrimination significantly predicted C-reactive protein, CRP did have a significant correlation with BMI. BMI was significantly associated with depression, and depression with caregiver burden. Therefore, these sets of relationships suggest that burden could have an indirect association with CRP through depression and BMI.

Depression and Anxiety

Although being unable to support our hypothesis that caregiver burden and perceived discrimination would significantly explain variances in CRP levels in this group of African American caregivers, we found a positive, significant relationship between caregiver burden and both measures of psychological distress. We were able to establish that burden had a statistically significant association with depression and anxiety. Additionally, through a set of hierarchal multivariate analyses, we were also able to demonstrate the predictive value of burden in levels of depression and anxiety. The findings from our study support previous work examining mental health outcomes in caregivers (AA, 2012; Pinquart & Sorensen, 2005; Vedhara, Shanks, Anderson, & Lightman, 2000). Though African American caregivers have been historically described as having less depression and anxiety, compared to their White counterparts, we found that these caregivers were on averaged burdened and distressed by their caregiving responsibilities. We also discovered that caregivers who were more burdened also suffered higher levels of depression and anxiety.

Race, Discrimination, and Health

It is important to note that in addition to the negative impact burden has on health outcomes for caregivers, national data have shown that African Americans report similar levels of stress as their White counterparts (NAC & AARP, 2009). Dilworth-Anderson et al. (2002) suggest that despite being depicted as less strained and depressed, African Americans could be potentially suffering from depression and other mental health disorders in silence. Due to differences in methodological approaches and emotional expressions, however, the psychological consequences of African American caregivers are arguably being underestimated (Dilworth-Anderson et al., 2002). Researchers closely examining racial differences have supported this concern (Chadiha & Fisher, 2002; Cloutterbuck & Mahoney, 2003; Hargrave, 2006; Kingsberry et al., 2010).

The first specific aim of this study was to examine the relationship between caregiver burden, discrimination, and psychological health outcomes. We hypothesized that not only would caregiver burden and discrimination independently predict depression and anxiety, but we also posited that perceived discrimination would be able to predict levels of both psychological outcome measures above and beyond caregiver burden. In a series of hierarchal multivariate regression models, we were able to find evidence for this hypothesis. Discrimination was found to remain a significant predictor of both depression and anxiety, after controlling for caregiver burden, social support, and avoidance coping.

Other studies examining the linkage between discrimination and mental health outcomes have consistently found that higher levels of discrimination correlate with poorer mental health statuses (Ahmed, Mohammed, & Williams, 2007). Perceptions of discrimination have been associated with depression, anxiety, and post-traumatic stress disorder (Banks et al., 2006; Lincoln et al., 2007; Pole et al., 2005; Veling et al., 2007). Recent systematic reviews and meta-analyses have found that discrimination not only increases the risk of psychological consequences but physiological problems, as well (Paradies, 2006; Pascoe & Richman, 2009; Williams & Mohammed, 2009).

We found discrimination and caregiver burden to have a strong, positive, and statistically significant correlation. Caregivers who were experiencing higher levels of discrimination were also experiencing higher levels of caregiver burden. It is unclear precisely how these two distinct stressors are related to one another. The correlation between burden and discrimination raises questions over African Americans' vulnerability to numerous stressors. Are African American caregivers who perceive more discrimination less able to cope with their caregiving responsibilities, causing them to perceive higher levels of burden? Researchers examining the distribution of stress across racial groups have found African Americans to have higher prevalence in cumulative exposure to various types of stressors (Sternthal et al., 2011).

It is also likely that there are other common characteristics of the caregivers that would incline them to perceive or be more sensitive to aspects of caregiver burden or discrimination that we have not accounted for in this current study. For example, the personality trait neuroticism has emerged in the public health literature as a relevant characteristic to consider when studying stress concepts (Lahey, 2009).

Neuroticism has been defined as a tendency to respond negatively to perceived threat, frustration, or loss (Costa & McCrae, 1992). Measures that operationalize neuroticism include items such as: irritability, anger, vulnerability, worry, and hostility (Lahey, 2009). Individuals endorsing more of this particular personality trait are also more likely to suffer negative life events (Suls & Martin, 2005), have poorer social support, (Kendler, Gardner, & Prescott, 2006), and less likely to cope effectively (Watson & Hubbard, 1996).

To our knowledge, this study is the first to consider race-related stressors in addition to traditional caregiving variables like caregiver burden. Although the specific relationship between these two variables was not evident in this study, these findings have particular relevance when considering how multiple stressors in caregivers' lives can potentially relate to the caregiving experience.

Racial Differences

As noted in the review of literature, there are differences in the African American caregiving experience, compared to White caregivers. African Americans have been noted to be younger, caring for their parents, and co-residing with their loved ones. These caregivers also keep their family members home longer and perceive their role and responsibilities as less burdensome. Understanding the reasons for these differences, particularly in the context of caregiver burden, was one of the intentions of this project. Exploring racial differences and caregiver burden through qualitative methods, we found that our sample reflected similar results to other caregiver studies including African Americans. For example, nursing home placement was a prominent topic of discussion.

It is well documented in the social gerontology literature that African American caregivers avoid long-term institutionalization. Multiple studies have shown that African American caregivers delay nursing home placement significantly longer than their White counterparts (Cagney & Agree, 1999; Gaugler, Leach, Clay & Newcomer, 2004). Possible reasons for this difference have ranged from limited financial resources to cultural traditions and family values. The caregivers in our study also voiced reluctance to place their loved ones in nursing homes and long-term care facilities. We discovered, however, that caregivers considered highly burdened (by burden scores) were more open to the notion of nursing home placement. A study looking at predictors of nursing home placement found that there was a strong empirical link with caregiver burden and institutionalization (Gaugler et al., 2004). In their three-year study period, Gaugler and colleagues found that caregivers who experienced the highest level of burden were much more likely to expedite nursing home placement for the care recipient.

In addition to discovering similar results as previous researchers, we also found that caregivers revealed dimensions of their experiences not fully captured in other studies. For instance, anticipating discrimination was a unique feature of the caregiving experience for the caregivers in the current study. Many of the caregivers in this study discussed the importance of ensuring that their loved ones were provided the best care, and some felt they were not *"comfortable"* with their family members around *"strangers." "I love her enough not to see her go stumbling around strangers,"* one caregiver described. It was apparent that the caregivers in the current study were concern that their loved ones would not be adequately cared for in a nursing home. *"I would have to be involved every day like when she was in the hospital, go every day, show my face – that I'm looking out for this lady and I want to make sure everything is going right for her,"* she went on to explain. While some considered the temperament of the family member, fearing that they could potentially be abused if they started exhibiting difficult behavior, others felt that race was an issue and were concerned about the *"number of blacks working [at the facility]."* Caregivers felt that if there were too few Black staff members that their loved ones might be more vulnerable to mistreatment.

Vigilance

Anticipating discrimination is a component of anticipatory stress and has started to gain more attention in the discrimination literature at large. Vigilance—a concept used to describe the thoughts and behaviors involved with anticipating unfair treatment—has been suggested as being as predictive of negative mental and physical health outcomes as actual discriminatory events (Williams & Mohammed, 2009). Examples of vigilance and anticipatory stress include caregivers wondering about the number of Black employees in long-term care facilities and delaying placement in nursing homes out of fear of race-based mistreatment. Carter (2007) referred to this experience as "cultural paranoia."

Previous studies have reported that African Americans' reluctance to place family members in nursing homes revolves mostly around discussions of cultural expectations. The dynamic of racism and its influence on decision making in regard to institutionalization has not been explored. Receiving even less attention are the negative emotional and potentially physical outcomes as a result of this type of anticipatory stress. In the quantitative analysis, we included a measure for vigilance and found that this specific type of stress has a moderate, statistically significant association with both depression and anxiety. Through logistic regression analysis, we also found evidence that vigilance was predictive of an elevated risk for depression in this sample of caregivers. In a model with both caregiver burden and everyday discrimination, vigilance had a more powerful effect on the increased risk for depression than the other two predictors in the model. For every one-point increase in vigilance, the odds of an elevated risk for depression were increased by approximately 20%.

Although understudied, researchers examining both psychological and physical consequences of vigilance for racial/ethnic discrimination have found similar results (Clark, Benkert, & Flack, 2006; Lindstrom, 2008). In a very recent study, researchers investigated the role of vigilance in explaining racial/ethnic disparities in hypertension (Hicken, Lee, Morenoff, House, & Williams, 2014). They found in their sample of over 3,000 adults that vigilance was not only reported more in African Americans but that it was also positively associated with hypertension prevalence in African Americans, but not Whites: as vigilance increased, the disparity between African Americans and White hypertension prevalence rates also increased (Hicken et al., 2014).

Disadvantage

The theme of *disadvantage* emerged in our study as a significant part of the caregiving experience but has not been studied extensively in this population. A few of the qualitative studies that have examined African American dementia caregivers have mentioned racism and how it has affected their situation as caregivers. For example, Lampley-Dallas and colleagues (2001) found that African American caregivers in their study were frustrated with health care providers and the availability of local support groups. The scarcity of support and resources was seen primarily as a service disparity and was attributed to race. Likewise, Loukissa and colleagues (1999) discovered in their study with African American dementia caregivers that feelings of frustration about dealing with the heath care system was also a relevant theme. The researchers found that caregivers often felt they were not provided adequate information about the illness, nor did they have needed resources and support. Likewise, Levy and colleagues (2000) found that African American caregivers discussed lack of support four times more than other caregivers. Healthcare providers added to caregivers' sense of frustration; this was often because providers were perceived as culturally insensitive to the needs of caregivers (Kelley, 1994; Lampley-Dallas et al., 2001).

In addition to service disparities and frustrations with the formal health care system, caregivers in the current study also believed that African Americans were not part of as closely knit a community as they were traditionally understood to be. Accepting negative stereotypes and not honoring historical legacies were given as potential reasons that black communities were not as unified and able to care for elders as they once were generations ago. These unique concerns and aspects of disadvantage, in terms of social support and caregiver burden, have not been specifically addressed or examined empirically in this population.

Results from our study also point to the seminal work of James and colleagues (1983) that developed *John Henryism*. This high-effort coping with inadequate resources can produce a vulnerability to stress in the face of persistent and systematic discrimination and oppression suffered by African Americans. Our findings revealed that the caregivers felt they had to put forth additional efforts to pursue resources and necessary information to care for loved ones. *"I've also found … you have to ask a lot of questions because people are not readily giving up the information about different things,"* one caregiver remarked. The caregivers verbalized frustration with the lack of resources and admitted to feelings of being disadvantaged. They frequently commented on having to ask more questions and work harder to adjust to their caregiving situation. Multiple caregivers mentioned how they believed African Americans lacked the knowledge that they needed as a fulltime caregiver; placing them at a further disadvantage compared to their White counterparts. Although John Henryism was not measured directly, the caregivers in this study acknowledged the need to exhibit strength and determination. Our findings add how socio-historical and cultural influences contribute to the phenomenon of caregiver burden.

Meaning of Burden

In our attempt to discover the meaning of burden, it became apparent that familial values and cultural expectations help create the structure of this phenomenon within these caregivers' lives. The term burden was seen, overall, as a negative concept. Burden was commonly described as something a family member *had* to do, not because she or he *wanted* to do it. Whether the caregivers admitted to feeling burdened or not, there was a sense that burden was seen mostly as a responsibility or an *obligation* and not necessarily a consequence of their responsibilities. The sub-themes of "*being bound" and "being there"* emerged as important aspects of obligation that contributed to the meaning of burden. Additionally, the *sense of disruption* to the caregivers' lives and future hopes was another significant component of burden. These caregivers struggled with honoring their traditional family values while managing the disruption caregiving had created in their lives.

Obligation

Our finding that obligation and disruption are meaningful components of burden in the African American experience extends the results of earlier qualitative studies examining African American caregivers. Previous qualitative reports have portrayed obligation primarily as a positive aspect of caregiving. For example, Kelley (1994) found that African American caregivers expressed a sense of duty to care for their loved ones at home and that this value subsequently led to delays in institutionalization. Likewise, Nkongho and Archbold (1995) also found that a sense of duty or obligation was a significant component of the African American caregiving experience and explained why African Americans cared for their elders at home. Similarly, Sterritt and Pokorny (1998) also identified the theme of caregiving as a traditional family value and discussed obligation as a personal responsibility that caregivers willingly accepted. In these studies researchers focused on how the African American caregivers reported positive rewards from their caregiving experiences.

Although obligation was explored as a possible dimension of caregiver burden within the African American population in the previously discussed studies, other researchers have implied that the sense of duty possibly increases stress and burden for caregivers. For example, Calderon and Tennstedt (1998) examined ethnic differences in the expression of caregiver burden. In their study, they found that minority caregivers (Puerto Rican and African American) were more likely to verbalize familial obligation. Caregivers in their study reported strong cultural values that pertained to expected roles and responsibilities. The researchers noted how caregivers accepted their responsibilities, despite the difficulties they faced in their roles as caregivers. Calderon and Tennstedt also revealed that minority caregivers expressed burdensome experiences differently than White caregivers, including feelings of anger and frustration. Although many of the caregivers in these types of studies are female, the sense of obligation has also emerged as a theme for men as well. Neufield and Harrison (1998) discovered, in their study of male caregivers, that men who felt obliged to care for family members were also more angry, frustrated, burdened, and alone.

More recently, researchers who have empirically examined obligation have found that deeply held values of familism contribute to one feeling obligated to care for the individual with dementia. Familism can be defined as strong identification and solidarity with family members as well as strong normative feelings of dedication, reciprocity, and attachment to both nuclear and extended family members (Sabogal, Marin, Otero-Sabogal, Marin, & Perez-Stable, 1987). The cultural value of familism has been studied in a variety of ethnically and culturally diverse groups of caregivers. Using path analysis, Sayegh and Knight (2010) found in their study of 95 African American and 65 White dementia caregivers that feelings of obligation had an indirect effect on poor mental and physical health by way of avoidance coping styles.

The conclusion that obligation is a component of the burden experience for African American caregivers is supported by earlier qualitative studies with African American participants and more recent empirical studies examining familism. Researchers originally theorized familism as a protective factor against caregiver burden (Kim et al., 2007). These assumptions were based largely on earlier works with African American caregivers. For example, Lawton et al. (1992) found that African Americans were more likely to embrace traditional caregiving ideology than Whites. Likewise, Dilworth-Anderson, Williams, & Williams (2004) found that African Americans scored higher on the Cultural Justification for Caregiving scale, a measure reflecting reciprocity and sense of duty. It appears, however, that strongly held family values and traditions create expectations that caregivers feel obliged to uphold, despite challenges and stressful experiences. The nuance of this cultural value is revealed in the narrative reports of the caregivers in this current study. Caregivers acknowledged similar feelings of familism and expressed that a sense of obligation to care for family members is a significant aspect of caregiver burden.

Disruption

Like the theme of obligation, some researchers have not explored the notion of disruption in depth in previous studies with African American caregivers, while others have noted that it is a significant component of burden. Although briefly mentioned in studies with African American caregivers (Kuhlman et al., 1991; Lampley-Dallas et al., 2001), it appears that these researchers may have overlooked the theme of disruption as an aspect of the burden experience. Kuhlman and colleagues (1991) suggested that, while caregivers experienced disruption to their lives, over time these experiences might be perceived as less stressful due to lowered expectations in the caregiving process. In their study with minority caregivers, Calderon and Tennstedt (1998) noted that African American caregivers were more likely to mention caregiving as demanding and requiring a lot of their time. Caregivers also remarked about the sacrifices they had to make, including giving up employment opportunities. Although the word disruption was not used in the study, the discussion of these caregivers' experiences highlighted a similar sense of disruption we found in this current study.

The sense of disruption has been conceptualized as a component of burden by other researchers. The concept of burden has been divided into "subjective burden" and "objective burden" (Platt, 1985; Montgomery et al., 1985). The distinction between subjective and objective burden is not consistently used in the literature (Chou, 2000). Some instruments measure only one aspect, while others measure both. Unlike one-dimensional burden measures (i.e., ZBI) that only measure subjective burden (a caregiver's emotional response to the caregiving situation), Montgomery and colleagues (1985) created a two-dimensional instrument (subjective and objective burden). Objective burden on this instrument has been defined as the extent of disruption that caregiving has caused the caregiver's family and household.

Differences in Burden Perception

In quantitative reports, when African American dementia caregivers are compared to their White counterparts, African Americans are consistently portrayed as less burdened, as less depressed, and as perceiving more rewards in their caregiving role. Qualitative studies, however, have found that African Americans describe burdensome experiences that are not fully captured on current burden instruments. In the current study, nine caregivers were selected for further investigation, based on how they responded on the ZBI. This subsample of caregivers ranged from scoring low on the ZBI to being categorized as highly burdened. As in previous studies, we also found discrepancies between caregivers' responses on the burden instrument and their narrative accounts. Disconnects between what is reported in survey data and what is richly described in the caregivers' accounts highlight the original question: *why are there differences?* More recently, researchers have argued that burden is experienced differently in racial/ethnic minority groups compared to White caregivers (Hargrave, 2006; Kingsberry et al., 2010; Dilworth-Anderson et al., 2002).

Our qualitative findings suggest two explanations why African American caregivers have traditionally scored lower than White caregivers on burden instruments—despite having seemingly burdensome experiences. The first explanation is that because of the hardships African Americans have historically experienced as a people, the daily hassles associated with caregiving are not perceived as challenging. Having to endure chronic levels of stress over time reduced sensitivity, causing some caregivers to become more resilient. The second reason caregivers are not reporting regarding the difficulties of caregiving is that there is a reluctance to admit the negative aspects of providing fulltime care for family members. Because of strongly held beliefs, values, and expectations about caring for family members, caregivers often experience difficulty admitting feelings of resentment, dissatisfaction, disappointment and burden.

The discrepancies of perceived burden found in this current study mirror findings from similarly designed studies including African American dementia caregivers. Lampley-Dallas and colleagues (2001) found in their mixed methods study of 13 African Americans that caregivers accepted their role, but some denied feelings of burden, despite having moderately severe levels of burden on the ZBI. Reasons for these differences, however, were not explicitly explored. Jones-Cannon and Davis (2005) also found discrepancies in their study with African American daughters caring for dementia and stroke patients. Also using a mixed methods design, they found that intense and burdensome experiences described by the focus group participants were in stark contrast to quantitative findings that showed that the caregivers were "overwhelmed" but not necessarily "burdened" (Jones-Cannon & Davis, 2005). Again, the researchers in this study did not fully explore these differences in findings but explained that African American caregivers appeared to be coping more effectively due to their dependence on faith in God and spiritual practices. Researchers have found African Americans to exhibit positive affect in situations of chronic stress and that the resilience could be a result of the caregivers' ability to find meaning through positive reappraisals, spiritual beliefs, social support, or other adaptive strategies to manage stress (Folkman & Moskowitz, 2000).

Resilience

Psychological distress in the form of depression and anxiety are potential adverse effects of chronic stress. African Americans who find meaning in their difficult situations can emerge from adversity with greater levels of resilience. Resilience in African-American dementia caregivers may be attributed to numerous influences—cultural and otherwise. Garmezy, Masten, and Tellegen (1984) developed a protective model of resilience and posited multiple factors buffering individuals from the influences of various risks, thereby reducing the chances of being negatively affected and preserving their level of resilience. These moderating or protective traits subsequently served as a type of immunity against future exposure to stress (Garmezy et al., 1984). When asked about how coping with the challenges of caregiving, one of the caregivers in our current study responded, *"I'm just immune to it."*

Our findings showed that caregivers who appeared more resilient found meaning in their situation, had great support from family members and other caregivers, and maintained a healthy and active lifestyle. These results support earlier research that has suggested that strong collectivist values and spiritual coping mechanisms significantly contribute and maintain this sense of resilience in African Americans in the face of adversity (Bowen-Reid & Harrell, 2002; Daly, Jennings, Beckett, & Leashore, 1995).

***Faith in God**.* Religious and spiritual coping has long been understood as playing a fundamental role in the African American experience, and particularly in the African American caregiver experience. Many researchers examining the relationship between stress and health have acknowledged this specific coping mechanism for African Americans in the caregiver literature (Kosberg et al., 2007; Spurlock, 2005). Researchers have also found that religious and/or spiritual coping can enhance resilience by providing a foundation for optimism and a cognitive framework for understanding stressful situations (Barbarin, 1993). Dilworth-Anderson, Boswell, and Cohen (2007) found in their study of African American caregivers that spirituality was a source of strength to conduct daily activities; it gave caregivers a reason to honor elders as well as a sense of reciprocity in their ability to give back to their loved ones.

Sorensen and Pinquart (2005) found that higher levels of religious coping were related to lower levels of depression. Likewise, Lee, Czaja, and Schultz (2010) found in their recent analyses of the REACH participants that African American caregivers reported higher levels of religious coping than White caregivers. They also found that black caregivers with lower religious coping appeared to be more in need of alternative resources at baseline and therefore benefited more from the intervention of this study (Lee et al., 2010). The researchers argued that their findings supported the idea that caregivers with less religious coping were more vulnerable and less resilient than other Black caregivers in their study who engaged in higher levels of religious coping.

Our findings add to what is currently understood about religious coping and spirituality being a source of support and meaning for African American caregivers. Additionally, our results highlight that the relationship between religious engagement, spiritual meaning, and social support is diverse. Although the caregivers in our study were active and noted great reliance on their faith in God, some discussed having difficulty going to church, at times not receiving expected support from church, and experiencing disappointment and dissatisfaction with church leaders. Previous qualitative studies exploring faith in Black dementia caregivers have picked up on some of these nuances. For example, Fox and colleagues (1999) discovered in their study that some African American caregivers noted that they did not describe themselves as spiritual. Our finding that at times caregivers felt they were not able to get particular needs met from church members support earlier findings in similar studies with African American dementia caregivers. Dilworth-Anderson and colleagues found that, when caregivers did reach out to church members for assistance, they often received spiritual but not tangible support (2007).

Other researchers have come to the conclusion that reliance on faith and dependence on religious and spiritual practices could possibly explain why African Americans are perceiving lower levels of stress than White caregivers and scoring lower on burden instruments (Spurlock, 2005; Kosberg et al., 2007). God as a source of strength has been repeatedly found in many of the caregiver studies examining African Americans. These conclusions, however, appeared to be made without exploring whether African Americans are being burdened by their role and whether, due to cultural factors and expectations, they feel prohibited to express their more negative feelings about caregiving.

Social Support. Social support is another critical variable to consider when examining burden, specifically among African American caregivers. This familiar concept that is often included in caregiving studies can be categorized as either formal support (assistance/affiliation from social or health agencies) or informal support (assistance from family members or friends). African Americans have consistently been depicted as having extensive informal support. However, researchers are now hypothesizing that differences in levels of social support in African American and White caregivers could be related to socio-demographic factors (e.g., income, education) and possible methodological artifacts rather than cultural or ethnic differences. In their recent study of rural-dwelling African American and White dementia caregivers, Kaufman and colleagues did not find a significant difference in social support scores between African American and White participants (Kaufman, Kosberg, Leeper, & Tang, 2010).

The findings in the literature are mixed in terms of how minority caregivers' use and benefit from social support. Researchers originally posited that minority caregivers used formal services less than their White counterparts due to having more diverse informal social support systems such as support from the church (Dilworth-Anderson et al., 2002). There is speculation, however, that this broad, expansive network of support could be overestimated and potentially dwindling (Hargrave, 2006; Kingsberry et al., 2010). This is a relevant concern backed by the strong and consistent scientific evidence on the health benefits of having supportive relationships (Berkman & Glass, 2000). It has been suggested that lower levels of social support can contribute to greater levels of caregiver burden (Shurgot & Knight, 2005).

Our current study found that social support played a pertinent role in the caregiving experience. Higher levels of perceived social support, as measured by the EnrichD Social Support Instrument (ESSI), was found to have a statistically significant association with lower levels of burden, depression, and anxiety. Additionally, results from the hierarchal regression models found that social support had a significant and independent relationship with depression. Caregivers who perceived higher levels of social support had lower levels of depression and anxiety. Likewise, in the qualitative component of the current study, we found that caregivers who had greater social support from family and other caregivers also appeared to be less depressed and anxious and overall more resilient, despite the challenges they faced as fulltime dementia caregivers.

Clay and colleagues (2008) found in a five-year longitudinal study of African American and White caregivers that African American caregivers were more resilient than White caregivers, largely because they were more satisfied with their social support networks. The African American caregivers also reported higher levels of life satisfaction and fewer depressive symptoms when compared to their White counterparts (Clay, Roth, Wadley, & Haley, 2008). Shurgot and Knight (2005) also found in their study of African American and White dementia caregivers that the African Americans caregivers were more likely to report higher perceived social support (which was associated with lower levels of burden). Earlier studies, however, have found dissimilar results among the relationship between social support and burden. For example, Allen-Kelsey (1998) found that in a sample of both White and African American caregivers, the effects of social support on burden were not significant.

The findings of this current study support more recent suggestions that the dynamics of social support are changing in the African American community. Findings from both the quantitative and qualitative component of this project suggest that caregivers do not perceive high levels of support from their family or church members. The average ESSI score was 18.4 in this sample of caregivers, indicating moderately low levels of perceived social support. Although the quantitative results reveal that social support had a significant, negative relationship with burden, depression, and anxiety, overall the average caregiver did not perceive high levels of social support. Similarly, the more highly burdened caregivers who were interviewed corroborated the quantitative findings by reporting inadequate support, specifically from family members.

Our findings that African American caregivers were dissatisfied with family support confirm findings from other qualitative studies with this population. For instance, Loukissa and colleagues (2005) conducted a qualitative study with 34 caregivers, the majority being African American, and found that caregivers expressed feelings of sadness and frustration about not having adequate support from other family members. They also complained of not feeling supported when facing difficulty in their role of caregiving and felt that family ignored or denied the presence and/or severity of the situation (Loukissa et al., 2005). Other researchers have found that African American caregivers repeatedly reported that they often felt frustrated over not receiving sufficient support from other family members, particularly from siblings (Jones-Cannon & Davis, 2005; Sterritt & Pokorny, 1998).

Suppression of Negative Emotions

In addition to finding caregivers in our study to be resilient and appraising their caregiving situation as less burdensome than other caregivers, we also discovered caregivers who had difficulty managing their situation and were reluctant in expressing their negative emotions with others. With the commitment to their caregiving role fortified by cultural values and expectations, caregivers in this current study often felt unable to express dissatisfaction with their experiences. They found themselves stuck between wanting to care for their loved one and being unable to even take care of their own basic needs. Some caregivers felt they had to maintain images of strength and resilience—traits that had been modeled by parents and grandparents in their families.

This finding aligns with qualitative studies examining the meaning of the “superwoman schema” in African American women (Woods-Giscombé, 2010). Woods-Giscombé discovered that participants reported benefits and liabilities of maintaining an image of strength and resilience. In this study of 48 African American women, eight focus group discussions were conducted to elicit themes of strength and to discover how socio-historical contextual factors influence health behaviors. The researchers found that the African American women in this study felt an obligation to manifest strength and to suppress emotions. There was a resistance to being vulnerable to or dependent on others. Although the women perceive benefits of survival and community, they also acknowledged strain in relationships and lack of self-care as a result of maintaining an image of strength (Wood-Giscombé, 2010). These findings support our argument that perpetuating an image of strength, one that has been modeled by foremothers and fathers, hinders caregivers from fully expressing their emotions, particularly if their feelings regarding caregiving are perceived as negative.

Similarly, Beauboeuf-Lafontant (2007) investigated the relationship between strength and depression in African American women and found comparable results. In a qualitative study of in-depth interviews with 44 black women, researchers identified several themes including a cultural mandate of strength, self-silencing, excessive attunement to the needs of others, and denial of one's own needs. They also found that the expectation to be strong contributed to selflessness that ultimately led to increased psychological distress and risk for depression (Beauboefu-Lafontant, 2007).

More recently, Black and Woods-Giscombé (2012) used qualitative methods to examine how African American women cope with stress and how this, in turn, affects health-seeking behaviors. The researchers found that Black women verbalized a need to project an image of strength and invulnerability that often created excessive caregiving of others and delay in self-care. Women reportedly expressed coping mechanisms consistent with the "strive to survive" phenomenon that might best describe the reactions used by Black women to socio-historical and cultural stress (Black & Woods-Giscombé, 2012). The works of Black and Woods-Giscombé (2012), Woods-Giscombé (2010), and Beauboeuf-LaFontant (2007) were done exclusively with women. Findings from our study extend these previous examinations in that we found that African American men also feel obligated to care for their loved ones, a need to exemplify strength, postpone self-care, and suppress emotions—all leading to a more burdensome caregiving experience.

Restricting or suppressing emotions has been found to have negative health outcomes. One study of African American women found that participants who were inhibited emotionally suffered higher nocturnal blood pressure readings and smaller drops in diastolic blood pressure from day to night (Steffen, McNeilly, Anderson, & Sherwood, 2003). The suppression of emotions has also been framed as cognitive or emotional regulation coping. This particular style of coping has been defined as an adaptive strategy that evolved out of hundreds of years of oppression in which African Americans faced harsh penalties for the open expression of emotion (Utsey, Ponterotto, Reynolds & Cancelli, 2000). Although these studies primarily examined suppression of angry emotions related to unfair treatment, it is possible that suppression of emotions that are appraised as socially less desirable could potentially have similar negative effects on the health of African Americans and could explain the somatic complaints that often arise.

Somatic complaints were a common form of the expression of burden in this sample. We found that interviewed caregivers who scored higher on the ZBI were more likely to describe how caregiving has affected their physical health. Particularly interesting, some caregivers felt that they were coping effectively with their caregiving responsibilities yet discussed how stress caused excruciating pain, stroke-like symptoms, and exacerbation of other chronic illnesses, like hypertension. Other researchers have noted that African American caregivers are more likely to report their burden as physical complaints (Dilworth-Anderson et al., 2007; Dilworth-Anderson et al., 2002). Calderon and Tennestedt (1998) made similar suggestions in their research with minority caregivers. In their study of 18 caregivers, they found that minority caregivers were more likely to express burden indirectly through frustration, anger, isolation, and somatic complaints.

Avoidance Coping. The restriction of emotions and not discussing how one is being affected by prolonged exposure to high levels of stress are examples of avoidant/escape coping styles. We found significant correlations between avoidant coping styles and depression, anxiety, and burden. Additionally, when entered in the multiple regression models, avoidant/escape coping strategies had an independent, predictive relationship with depression and anxiety. Our findings are consistent with a number of other studies in the literature with regard to mental health outcomes. Theories surrounding avoidance coping and risk of adverse mental health outcomes have developed out of the larger stress and coping literature (Carver & Connor-Smith, 2010; Del-Pino, Fras-Osuna, Palomnio, & Pancorbo-Hidalgo, 2011).

Avoidance coping has been studied in a variety of populations and diversity of health outcomes including depression, anxiety, chronic pain, and PTSD (Grant et al., 2013). Blalock and Joiner (2000) found that the use of avoidance coping strategies was predictive of depression levels in undergraduate students. In addition to depression outcomes, a recent meta-analysis found that the relationship between avoidance coping and anxiety was also significant. Effect sizes were determined to be in the medium to large range (Aldao, Nolen-Hoeksema, & Schweizer, 2010).

The harmful effects of avoidance coping on physical health measures in African Americans have also been studied. Singleton, Robertson, Robinson, Austin, and Edochie (2008) recently found in their study examining the impact of coping responses to perceived racism on blood pressure levels that avoidance coping predicted higher blood pressure levels. On the other hand, the researchers also found that active coping predicted lower blood pressure levels. The health benefits of active coping have also been substantiated in the literature (Clark et al., 1999). Similarly, in addition to the positive association we discovered between avoidance coping and depression and anxiety in this current study, we also found that the use of positive reappraisal, a form of active coping, was significantly associated with lower levels of depression and anxiety.

Previous caregiver studies specifically discovered that the value of *familism* increased utilization of avoidant coping styles, which consequently led to worse outcomes for both physical and mental health in dementia caregivers (Kim et al., 2007; Sayegh & Knight, 2010). Kim and colleagues (2007) argue that the correlation between familism and avoidant coping styles supports the view that familism may represent *obligation* more than positive feelings about providing support for the family member. This is particularly interesting given that obligation emerged as a significant component of caregiver burden in the qualitative sample of this current study. In another study of dementia caregivers, researchers found significant relationships among behavioral problems, burden, avoidant coping, and emotional distress in African American caregivers (Knight et al., 2000).

Additionally, it appears that race and gender could potentially influence this particular coping response. Researchers have found that African Americans are more likely to use avoidance coping than their White counterparts (Dilworth–Anderson et al., 2002). In addition to African Americans, studies have found that women are also more likely to select this particular coping strategy when dealing with stress. In a study that examined the coping strategies used by African Americans in the management of stress associated with racism, researchers found in their sample of 213 participants that women preferred using this particular coping style when dealing with racism (Utsey et al., 2000). These findings have increased relevance for African American female caregivers, making them more vulnerable to the negative health outcomes associated with this specific coping style.

Strengths and Limitations

There are several strengths of this study including consideration of additional psychosocial stressors, such as discrimination, and exploring concepts such as burden both quantitatively and qualitatively. There are a number of limitations, however, that are important to note. First, this was a cross-sectional research study; therefore, we could not make inferences regarding causality or examine relationships over time. Another limitation was the use of a non-random, convenience sampling method. Additionally, this was a relatively homogenous sample of well-educated African American caregivers recruited primarily from the southeastern region of the United States; therefore, the conclusions drawn from this study are not representative of other populations.

Additional limitations include the potential for subjectivity bias due to the use of self-reported data and the lack of other control variables. Other factors such as neuroticism can influence the relationship between caregiver burden, discrimination, and health. Social desirability can also determine how participants respond to questionnaires and have been included and accounted for in similar studies exploring discrimination. Since these data were obtained from a larger parent study with a significant numbers of existing instruments, there was a concern for respondent burden, and additional scales were not included for this current study.

Despite these limitations, this study makes several contributions to the existing caregiving and stress literature. There have been numerous studies investigating the negative emotional and physical health effects of caregiver burden. To our knowledge, this current study is the first to comprehensively examine both discrimination and burden. We were able to establish that both discrimination and caregiver burden have independent relationships to health outcomes in this population. Although this sample did not have high levels of perceived discrimination, we discovered that discrimination was a significant predictor of both depression and anxiety, above and beyond caregiver burden. Additionally, we explored the concept of burden further in a subsample of nine caregivers and were able to not only provide support to previous studies that have found discrepancies in burden perceptions by methodology, but because of the phenomenological approach of the qualitative component, we were also able to establish a meaning of burden for these caregivers and possible explanations for the incongruities.

Conclusion

One of the primary aims of this mixed methods study sought to examine the relationship between caregiver burden and discrimination with psychological distress outcomes, including both depression and anxiety. Quantitative analyses revealed a number of significant correlations to these variables of interest. Overall, we found evidence to support the negative effects of both burden and discrimination on the health of African American caregivers. Importantly, we discovered that discrimination predicted depression and anxiety above and beyond caregiver burden. Findings regarding the impact of caregiver burden and discrimination on psychological distress measures, including depression and anxiety, are consistent with prior research that demonstrates that exposure to chronic stress can significantly impact the mental health of African Americans (Williams & Mohammed, 2009).

The caregivers in this study were on average highly burdened and talked openly about their caregiving experiences during the in-depth interviews conducted in the qualitative phase. We concluded that the meaning of burden for the African American in this sample consisted of feelings of obligation and disruption. Overall, the concept of burden had a negative connotation and was not easily accepted by the participants as a common experience for caregivers. Some caregivers had difficulty identifying as burdened, despite describing rather burdensome experiences. They discussed concerns of not being able to care for their own needs and the consequences associated with personal sacrifices. This experience, coupled with additional losses of not having ample knowledge, support, and resources, made it increasingly difficult to maintain their responsibilities without having feelings of worry, frustration, and sadness about their situation. Other caregivers appeared to be more resilient, enjoyed the caregiving experience, had adequate support from family and friends, and found ways to care for themselves.

Consistent with other mixed methods studies with African American caregivers, perceptions of burden collected on the ZBI did not consistently align with narrative accounts provided in the qualitative interviews. Discrepancies were specifically explored with caregivers. After analyzing quantitative and qualitative data, we discovered that caregivers were either more resilient and perceived less burden or they felt restricted in expressing negative feelings regarding the care of their loved one. The present study also underscores the significance of caregivers having access to adequate resources, enhanced family support, and opportunities to express feelings of dissatisfaction in the process of caregiving. Findings on resilience, restriction of emotional responses, and nuance of family support also support prior research focused on the availability of coping resources and social support networks.

Implications for Research

The findings from this project highlight various research opportunities. It is critical for researchers to continue to explore how multiple stressors can have a cumulative effect on minority caregivers. Researchers conducting caregiver studies involving African Americans should consider how these cultural- and societal-level determinants influence the caregiving experience.

Resilience can develop as a result of exposure to stress; however, researchers have discovered that this psychological benefit might be limited to particular amounts of distress. African Americans experiencing higher levels of stress, numerous stressors, or more severe stress over time can become less resilient. For example, a study of African American survivors of the Hurricane Katrina disaster found that higher levels of psychological distress mediated resilient outcomes, and those who showed more psychological distress showed less psychological resiliency (Lee, Shen, & Tran, 2009). Because of their social position, African Americans are particularly at risk for disproportionate levels of stress. This increased risk of exposure coupled with cultural values that encourage detachment and avoidance could lead to poorer health outcomes, further marginalizing African Americans in this country. The current study, along with others, points to the need for additional exploration of the relationships between burden, cultural values, coping styles, and resilience.

We argue that resilience could be one of the reasons that African Americans perceive lower levels of burden, compared to their White counterparts. Resilience in African Americans, though, remains poorly understood and understudied relative to Whites (Utsey et al., 2000). More research is needed to develop a more complete understanding of how African Americans are affected by chronic stress and the development of resilience in this population. This is particularly relevant given our results that demonstrate that discrimination can be an added psychosocial risk factor for African Americans already experiencing high levels of existing stressors.

The accumulation of psychosocial stressors connected with socioeconomic disadvantage, discrimination, and other chronic stressors, such as caregiving, can affect one’s ability to cope effectively. The daily experiences of African Americans need to be placed within the context of the legacy of slavery, legalized segregation, and ongoing daily discrimination. Other researchers have concurred and added that the importance of developing the understanding of stress exposure and resilience should also take into consideration the structural and pervasive nature of African Americans’ stressors and protective factors specific to the African American culture (Teri et al., 2012). Although these experiences are not always appraised as stressful, the literature is consistent in the negative effects of caregiver burden and discrimination on the health of African Americans. There are opportunities for caregiver researchers to also empirically examine these interactive and recursive relationships with African American dementia caregivers.

Our findings also suggest that researchers re-examine the concept of “burden” and whether existing instruments capture the unique features of the African American experience, including a sense of obligation, particularly incorporating the need to always be available, a sense of disruption, and somatic complaints. Although the ZBI has been “validated” in studies with African American caregivers, the findings from this study raise questions regarding the instrument’s ability to reflect the complex dynamics of the African American culture that influences how burden is perceived and reported. The present language of the ZBI, including the word burden itself, may not resonate with African Americans. In order to not violate traditionally and culturally held values, African Americans might minimize their true feelings regarding their felt strain and burden they experience as caregivers. Including measures of social desirability could possibly reduce this form of bias. However, controlling for social desirability may not fully resolve these challenges, if the scale items do not capture distinct aspects of the meaning of burden in African Americans.

Instruments such as the Montgomery Burden Scale (Montgomery et al., 1985), which adds the objective burden dimension and takes into consideration the social context of caregiving, could also be considered when exploring burden in African Americans. Caregivers admitted to not always being able to verbalize negative feelings regarding their role as caregivers. Future research is also needed is examining the relationships between caregiver burden and emotional inhibition along with other physiological measures of stress (e.g., blood pressure).

The phenomenon of racial and ethnic health disparities is complex. Incorporating concepts such as discrimination and biological variables only begins to explain how social factors can predict health. As in previous studies, we were unable to establish a relationship between discrimination and CRP. Exploring the relationship between discrimination and physiological biomarkers of stress could also be conducted using more innovative approaches, such as the inclusion of implicit measures of discrimination (Krieger, Carney, Lancaster, Waterman, Kosheleva & Banaji, 2010). Furthermore, findings from these types of studies can be used to create specific policies and clinical practice guidelines to promote wellbeing in the caregiver population.

Implications for Clinical Practice

In addition to researcher opportunities, our study also provides clinicians and other health care providers suggestions to improve care for this population. Practitioners should consider strategies to promote resiliency, strength, and determination for members of the African American community who are potentially suffering from chronic stress. The average caregiver in this sample perceived moderately low levels of social support. We also discovered in our follow-up interviews that caregivers were disappointed by expected support from family members. Providers are cautioned not to overestimate resiliency and social support and to look for opportunities to also encourage vulnerability and openness to disclose feelings about the stressful nature of caregiving. Given that social support plays a significant role in the relationship between chronic stressors and mental health outcomes, it is critical that practitioners also look for ways to integrate individual clinical approaches with community empowerment models. By leveraging public and private resources, selected community-based interventions (i.e., support groups) can be implemented rather inexpensively. Health care professionals could also facilitate partnerships between public and private entities and ongoing efforts in churches and other community-based groups.

Implications for Policy

Understanding the relationship between caregiver burden and health in African Americans is critical in creating interventions targeted at reducing burden for this population. Estimates of the cost-effectiveness and health-promoting benefits of these interventions can be used to justify expanding particular services such as respite care and adult day care to predominantly African American communities. Having support groups in predominantly Black communities, community education (e.g., information in libraries and businesses in African American communities), public service announcements on minority radio stations, and ads in newspapers with a large Black readership have also been suggested in the literature (Lampley-Dallas et al., 2001). The responsibilities for providing adequate resources for African American caregiver cut across various social systems along spheres of the individual, family, private agencies, and governments.

Despite growing acknowledgment of caregiving as a salient policy concern, services in the United States continue to be greatly variable. Although there are federal laws to specifically address the needs of caregivers, there is a continued need for additional resources and support for the multiple needs of caregivers (FCA, 2007). While the rapid aging of the US population and the growing strength of advocacy groups such as AARP are addressing the needs of the elderly population, if these efforts do not include the diverse needs of African American family caregivers, one of our most important resources may very well be drained. In order to move the research and policy agenda forward for family caregiving, key stakeholders including researchers, national aging network representatives, and congressional policymakers have noted a continued need for understanding the role race and racial diversity plays in family caregiving, especially over the life course (NAC, 2006).

There are growing opportunities for nurse scientists to partner with sociologists, psychologists, and public health researchers to examine the complex ways inequalities in society shape differences in health outcomes in minority populations through interdisciplinary research. Involvement in health policy is an extension of our roles at patient advocates. Although nursing is a practice discipline, as nurse scientists we have the responsibility of translating our research into policy and ultimately into social change. Translation begins by incorporating more upstream social determinant variables strategically into our research. In addition to “downstream” interventions such as psycho-educational workshops and skills training seminars that largely focus on individual behavior, we need more socially relevant interventions to address racial inequities in health. Research that reflects the relationship between social determinants and health will be critical in the development of social policies that are needed to ultimately bring an end to disparities in health.

Appendix A. Qualitative Interview Guide

Thank you so much for agreeing to meet with me today and to discuss your personal caregiving situation. As you know, I am a PhD student from the nursing program at Emory University and currently a research assistant on the Emory School of Nursing caregiver project looking at caregiver stress and health. I am currently in the dissertation phase of the program and have started conducting interviews with selected individuals that have participated in the caregiver project. The purpose of these interviews is to help me gain more insight into the experiences of African American caregivers caring for older adults with chronic illnesses. Each interview will be approximately 45-60 minutes. I will ask you a series of questions. There are no right and wrong answers. I am hoping to learn more about your individual experience. Participation in these interviews is completely voluntary and if at any time you would like to withdraw or do not want to participate further you can do so without any negative consequences. I will be recording the interview. You may be asked to review the transcript and preliminary interpretations for accuracy. Copies of the transcripts can also be made available upon request. Although you have previously consented for us to contact you after your initial participation, I have an additional consent specifically for this interview (see attached). Please read the consent in its entirety before signing it. Thank you for taking the time to meet with me. I sincerely appreciate the opportunity to hear your story. Again, this interview will be used for research purposes, any identifying information will be held in strict confidence.

Open-ended, exploratory questions with probes:

1. Some caregivers describe caregiving as hard. What aspects of caregiving are particularly challenging or difficult for you?
2. Tell me more about other family members and friends and how they assist you in your role as a caregiver.
3. In what ways have race or racism affected your roles as a caregiver?
4. Caregiver burden is a concept that has been studied widely within caregivers. How would you define burden?
5. Would you describe yourself as being burdened? Why or why not?

Appendix B. Emory University School of School of Nursing Services Consent to Participate in Research

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Title: Promoting Health and Wellbeing in African American Dementia Family Caregivers

Substudy: Caregiver Burden in African Americans: A mixed methods study of chronic stress

Principal Investigator: Debbie Stevens, Nell Hodgson Woodruff School of Nursing

Funding Source: National Institute of Nursing Research, John A. Hartford Foundation, Hartford Centers of Geriatric Nursing Excellence

Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.**

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

Study Overview

You are being asked to volunteer for this study because you have agreed to be re-contacted after participating in the larger parent caregiver study. The purpose of this study is to examine the psychological and biological effects of chronic stress in adult African American caregivers of patients diagnosed with chronic illnesses. The rationale for the proposed work is that it will provide an enhanced understanding of how perceived racial discrimination can be an added stressor for African American caregivers that are already experiencing increased levels of stress and burden.

Procedures

You will be asked a series of questions regarding your caregiving experiences. The interview will be approximately 45 to 60 minutes. This discussion will be audio taped to help us to accurately capture your insights in your own words. A transcriptionist and Debbie Stevens, MSN, RN PMHCNS BC will be the only ones to hear the tapes. The transcription is for the purpose of comparing your story to other caregivers' accounts. About 2-4 weeks after the first interview, the investigator will ask to schedule a second interview to review your responses to the first interview and ask follow up questions.

Risks and Discomforts

The risks to you for being in this study are few. Talking about personal experiences may bring up feelings of sadness and anxiety. If at anytime during our time together you feel like the discussion is too distressful, you have the right to stop the interview.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about how African American caregivers are uniquely affected by their caregiving responsibilities. The study results may be used to help others in the future.

Compensation and Costs

Upon completion of this interview, you will be given a $25 gift card for participating in this study. There is no extra cost to you for participating in this study.

Confidentiality

Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Office for Human Research Protections, the National Institute for Nursing Research, the Emory Institutional Review Board, the Emory Office of Research Compliance and the Office for Clinical Research. Study funders may also look at your study records. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results. Study records can be opened by court order. They may also be produced in response to a subpoena or a request for production of documents.

The results will be presented in a dissertation by Debbie Stevens, RN PMHCNS-BC . They will be seen by an advisor and other committee members. The dissertation may be read by future students. The study may be published in a research journal. We will ensure that no clues to your identity appear in either presentations or publications. Any extracts from what you say that are quoted in the dissertation will be entirely anonymous.

Voluntary Participation and Withdrawal from the Study

You have the right to leave a study at any time without penalty. This study will involve a face-to-face interview. You will be asked questions regarding your caregiving experience. You may refuse to answer any questions that you do not wish to answer.

Contact Information

Contact Debbie Stevens at 404-825-8992 or Kenneth Hepburn at 404-712-9286.

- If you have any questions about this study or your part in it, or
- If you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

- If you have questions about your rights as a research participant.
- If you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Consent

Please, print your name and sign below if you agree to be in this study. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the signed consent, to keep.

____
Name of Subject

____ ________________
Signature of Subject Date Time

____ ________________
Signature of Person Conducting Informed Consent Discussion Date Time

Appendix C. Emory University School of Nursing Research Subject HIPAA Authorization to Use or Disclose Health Information that Identifies You for a Research Study

Title: Promoting Health and Wellbeing in African American Dementia Family Caregivers

Substudy: Caregiver Burden in African Americans: A mixed methods study of chronic stress

Principal Investigator: Debbie Stevens, Nell Hodgson Woodruff School of Nursing

Funding Source: National Institute of Nursing Research, John A. Hartford Foundation, Hartford Centers of Geriatric Nursing Excellence

Introduction

The privacy of your health information is important to us. We call your health information that identifies you, your "protected health information" or "PHI." To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act (HIPAA). We refer to all of these laws in this form as the Privacy Rules. This form explains how we will use your PHI for this study.

Please read this form carefully and if you agree with it, sign it at the end.

Description of Research Study

The purpose of this sub-study is to examine the effects of chronic stress, specifically caregiver burden and racial discrimination, on the health of African American caregivers of patients diagnosed with chronic illnesses. We will also explore caregiver burden through in-depth interviews.

PHI That Will Be Used/Disclosed

The PHI that we may use or disclose (share) for this research study includes: medical history, information collected on the questionnaires, lab test results, and interview transcripts.

Purposes for Which Your PHI Will Be Used

If you sign this form, you give us your permission to use your PHI for the conduct and oversight of this research study.

People That Will Use or Disclose Your PHI and Purpose of Use/Disclosure

Different people and groups will use and disclose your PHI. They will do this only in connection with the research study. The following persons or groups may use and/or disclose your PHI:

- The Principal Investigator and the research staff.
- The Principal Investigator may use other people and groups to help conduct the study. These people and groups will use your PHI to do this work.
- The National Institute of Nursing Research is the Sponsor of this Research. The Sponsor may use and disclose your PHI to make sure the research is done correctly. They may also use your PHI to collect and analyze the results of the research. The Sponsor may have other people and groups help conduct, oversee, and analyze the study. These people or groups will use your PHI.
- The following groups may also use and disclose your PHI. They will do this to make sure the research is done correctly and safely. The groups are:
    - the Emory University Institutional Review Board
    - [any other Institutional Review Boards that will also review the study]
    - the Emory University Office of Research Compliance
    - research monitors and reviewers
    - data and safety monitoring boards
    - any government agencies who regulate the research including the Office for Human Research Protections
    - public health agencies

We will use or disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or elder abuse. We also will comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

Expiration of Your Authorization

As this is a research study, your authorization will not expire. You may, however, revoke your authorization later.

Revoking Your Authorization

You do not have to sign this form. Even if you do, at any time later on you may revoke (take back) your permission. If you want to do this, you must write to: Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu

After that point, the researchers would not collect any more of your PHI. But they may use or pass along the information you already gave them so they can follow the law, protect your safety, or make sure the research was done properly. If you have any questions about this, please ask.

Other Items You Should Know

If we disclose information to people who do not have to follow the Privacy Rules, your information will no longer be protected by the Privacy Rules. People who do not have to follow the Privacy Rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them. Let us know if you have questions about this.

You do not have to sign this form. If you do not sign, you may not participate in the research study.

We will put a copy of your signed informed consent form for the research study and your signed HIPAA Authorization form into any medical record that you may have with Emory Healthcare facilities.

During the study you will generally not have access to records related to the research study. This is to preserve the integrity of the research. You may have access to these records when the study is complete.

If identifiers are removed from your PHI, then the remaining information will not be subject to the Privacy Rules. It may be used or disclosed with other people or organizations, and/or for other purposes.

Contacts

If you have any questions regarding the study, you may call Dr. Kenneth Hepburn at 404-712-9286. If you have any questions about the study, or your rights as a study subject, you may contact the Emory University Institutional Review Board at 404-712-0720 or 1-877-503-9797.

Authorization

A copy of this form will be given to you.

Signature of Study Subject Date Time

Printed Name of Study Subject

Signature of Person Obtaining Authorization Date Time

Printed Name of Person Obtaining Authorization

Appendix D. Zarit Burden Interview (22-item summary measure, range: 0-4, α =.092)

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

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

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

4. Do you feel embarrassed over your relatives behavior?

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

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

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

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

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

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

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

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

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

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

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

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

17. Do you feel you have lost control of your life since your relatives illness?

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

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

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

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

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

(0=Never, 1=Rarely, 2=Sometimes, 3=Quite Frequently, 4=Nearly Always)

Appendix E. EnrichD Social Support Instrument (7-item summary measure, range: 1-5, α =.089)

1. Is there someone to whom you can count on to listen to you when you need to talk?

2. Is there someone available to you to give you good advice about a problem?

3. Is there someone available to you who shows you love and affection?

4. Is there someone available to help with daily chores?

5. Can you count on anyone to provide you with emotional support?

6. Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide in?

7. Are you currently married or living with a partner?

(1=None of the time, 2=A little of the time, 3=Some of the time, 4=Most of the time, 5=Nearly Always; 7. Yes/No)

Appendix F. Ways of Coping - Avoidance/Escape Subscale Items (8-item, range: 0-3, α =.068)

58. Wished that the situation would go away or somehow be over with.
11. Hoped a miracle would happen.
59. Had fantasies or wishes about how things might turn out.
33. Tried to make myself feel better by eating.
40. Avoided being with people in general.
50. Refused to believe that it had happened.
47. Took it out on other people.
16. Slept

(0=Does not apply/Not used, 1=Used somewhat, 2=Used quite a bit, 3=Used a great deal)

Appendix G. Everyday Discrimination Scale with Vigilance Subscale (9-item summary subscale, range: 1-6, α =.088)

DAILY DISCRIMINATION	**IF YES, PLEASE ANSWER THE FOLLOWING QUESTIONS:**					
How often on a day-to-day basis do you experience each of the following types of discrimination?	**Almost Everyday**	**At least once a week**	**A few times a month**	**A few times a year**	**Less than once a year**	**Never**
1. You are treated with less courtesy than other people.	1	2	3	4	5	6
2. You are treated with less respect than other people.	1	2	3	4	5	6
3. You receive poorer service than other people at restaurants or stores.	1	2	3	4	5	6
4. People act as if they think you are not smart.	1	2	3	4	5	6
5. People act as if they are afraid of you.	1	2	3	4	5	6
6. People act as if they think you are dishonest.	1	2	3	4	5	6
7. People act as if they think you are not as good as they are.	1	2	3	4	5	6
8. You are called names or insulted.	1	2	3	4	5	6
9. You are threatened or harassed.	1	2	3	4	5	6

FOLLOW-UP QUESTION AT END OF SCALE:

What do you think was the main reason why these experiences happened to you? ***(You may check more than one reason)***

❒ 1. Your ancestry or national origin
❒ 2. Your gender
❒ 3. Your race
❒ 4. Your age
❒ 5. Your weight
❒ 6. Your accent
❒ 7. Some other aspect of your physical appearance
❒ 8. Your sexual orientation
❒ 9. You don't know
❒ 10. Other (Please Specify): ____

Vigilance (4-item, range: 1-6, α =.078)

VIGILANCE	**IF YES, PLEASE ANSWER THE FOLLOWING QUESTIONS:**					
In your day-to-day life, how often do you do the following things:	**Almost Everyday**	**At least once a week**	**A few times a month**	**A few times a year**	**Less than once a year**	**Never**
1. You try to prepare for possible insults from other people before leaving home.	1	2	3	4	5	6
2. Feel that you always have to be very careful about your appearance (to get good service or avoid being harassed).	1	2	3	4	5	6
3. Carefully watch what you say and how you say it.	1	2	3	4	5	6
4. Try to avoid certain social situations and places.	1	2	3	4	5	6

Appendix H: PROMIS Psychological Distress Measures (8-item summary Depression subscale, range: 1-5, α =.093)

Depression Measure

1. I felt worthless
2. I felt I had nothing to look forward to
3. I felt helpless
4. I felt sad
5. I felt like a failure
6. I felt depressed
7. I felt unhappy
8. I felt hopeless

(7-item summary Anxiety subscale, range: 1-5, α =.091)

Anxiety Measure

1. I felt fearful
2. I felt anxious
3. I felt worried
4. I found it hard to focus
5. I felt nervous
6. I felt uneasy
7. I felt tense

(1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always)

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