

Washington University in St. Louis
Washington University Open Scholarship

All Theses and Dissertations (ETDs)

January 2010

African American Caregiver Resiliency: Resources,
Vulnerabilities, Coping, And Well-Being Among
Caregivers Of Persons With Chronic Illness

Kimberly Carter

Washington University in St. Louis

Follow this and additional works at: <https://openscholarship.wustl.edu/etd>

Recommended Citation

Carter, Kimberly, "African American Caregiver Resiliency: Resources, Vulnerabilities, Coping, And Well-Being Among Caregivers Of Persons With Chronic Illness" (2010). *All Theses and Dissertations (ETDs)*. 56.
<https://openscholarship.wustl.edu/etd/56>

This Dissertation is brought to you for free and open access by Washington University Open Scholarship. It has been accepted for inclusion in All Theses and Dissertations (ETDs) by an authorized administrator of Washington University Open Scholarship. For more information, please contact digital@wumail.wustl.edu.

WASHINGTON UNIVERSITY

George Warren Brown School of Social Work

Dissertation Examination Committee:

Enola K. Proctor, Chair

Wendy Auslander

Nancy Morrow-Howell

Vetta Sanders Thompson

Ed Spitznagel

Renee M. Cunningham-Williams

AFRICAN AMERICAN CAREGIVER RESILIENCY: RESOURCES, VULNERABILITIES, COPING,
AND WELL-BEING AMONG CAREGIVERS OF PERSONS WITH CHRONIC ILLNESS

by

Kimberly A. E. Carter

A dissertation presented to the
Graduate School of Arts and Sciences
Of Washington University in
Partial fulfillment of the
Requirements for the degree
Of Doctor of Philosophy

December 2010

Saint Louis, Missouri

Copyright by
Kimberly Anissa Elizabeth Carter
2010

ABSTRACT

Using a sample of African American family members from the National Survey of Families and Households (NSFH), this study explored the experience of caring for a family member with chronic illness. Guided by the Model of Family Stress, Adaptation, and Resiliency the study looked at the role that family stress and coping factors (specifically, resources, vulnerabilities, and coping behaviors) have on caregiver well-being. T-tests and chi-square analyses of the entire sample, both the caregivers and non-caregivers (N = 2390) revealed no significant differences, other than gender, between caregivers and non-caregivers across demographic, stressor, and coping factors. Caregivers were more likely to be female. Moreover, though a correlation did exist between caregiving and depression (using the CES-D depression scale), regression analyses revealed that this relationship was not significant when other independent family stressors, namely divorce and unemployment, are controlled for. Thus, caregiving as an independent family member stressor was not related to depression or other well-being indicators. Finally, an investigation of a subset of caregivers (N = 369) in the sample was conducted, via path analyses, to look at the relationship between model factors and caregiver well-being. Results revealed that caregiver vulnerabilities, particularly employment and caring for more than one ill member, were significantly related to health reports. Coping behaviors did not mediate these relationships. The results of this study suggest that the context of the caregiver's family life is directly related to their well-being, perhaps more so than coping behaviors. This has implications for future development of family-based support interventions.

Acknowledgements

If this working on this dissertation has taught me anything it is truly that “God” is in control of IT ALL!! ..and that which seems impossible IS POSSIBLE when we believe in our abilities, have patience with the process, and glide on the wings of the angels that are around us.

I started this journey in an attempt to just get my Masters degree and 10 years later here I am having not only accomplished that goal, but also having finished my Doctorate. My accomplishments as great as they are, are indeed a profound reflection of the Love and Support that others have so generously given me all my life. It was that affection that encouraged me to ‘go back to school’ and start this journey, gave me reasons to continue when the road got tough, always reminded me of why I was traveling this road, believed in me despite my misgivings, and cheered me on to the very end.

So THANK YOU!!!

Enola, my dissertation chair, for tolerating and making me dig deep. You never let me disappear and in your supportive and firm way you kept me accountable and made sure I got to the end of the road. You will never know how special you are to me.

My dissertation committee, for their tireless efforts to help me improve my work. Dr. Spitznagel for his statistical help and introduction to MPlus; Dr. Morrow-Howell for caring for me beyond the dissertation; Dr. Cunningham-Williams for encouraging excellence; Dr. Auslander for bending over backwards to always provide last minute help; Dr. Thompson-Sanders for being my professional mentor and recognizing my worth for the past fifteen years and Lucinda for being my PhD “Mom” ☺

My professional mentors Richard S., Marge P., Dr. David P. and Dr. Danny W., Dr. Don E.B. (and my NAMI friends) for pushing me beyond mediocrity.

My 'True Girlfriends' & Sisters – Erica, Janel, Latizia, Chrissie, Lakisha, Jessica, August, Hawaii, Roeshelle. I met you all at different phases of the journey, but no matter when I met you, you guys were all there through thick and thin, kept me grounded, kept me laughing despite it all, and never let me forget my other life.

My Family, more than anyone you guys know the sacrifices I've made to complete this degree. Despite the countless days on the pc, unanswered phone calls, and 'zoned out' times where I just needed to focus you were always there rooting me on and being a source of unconditional love. Little did you know that it was thoughts of you and OUR life on the other side that got me through each day. I owe this achievement to ALL OF YOU! I could not have done this without you.

Special thanks to Regina, Toni, Wendy, Audrey, Donny, Darlene and the rest of the Elstons, your quiet support was much appreciated. Aunt Boeey, your visit showed me how to survive. My surrogate Mom, Merite, you taught me how to 'put on my black dress' and get through 😊. I love you for that. Garron, this degree is for us big brother – our journey together taught us how to be headstrong and never give up. Mom, there are not enough words. You never let me give up and reminded me that I had it in me to do this. Thanks for the long nights of gossip, I needed the break and for all you've done for us while I've been on this journey. I love you dearly.

My 'John' and My 'Deija' – the loves of my life! You sacrificed so much for me to do this. John, thanks for carrying our little family and trusting in my journey. You are an awesome man. Deija, 'my little bird' thanks for your late night support, ever-flowing love and being my best friend. Kisses to you and Princess.

I also want to thank the Unbelievers or those we refer to as "The Haters" you know who you are – for not believing that I could. You just convinced me that I can!!

Dedication

This dissertation is especially dedicated to Arthur Carter Jr. (Dad). Thanks for spiritually supporting me along the way. I know you were always there.

...and my Grandparents, Mom Delores, Aunts Olivia (Lee) and Mable, and Uncle Ceasar. I carry our legacy with pride. Thanks for all you've instilled me.

Table of Contents

ACKNOWLEDGEMENTS	II
DEDICATION	VI
CHAPTER ONE: THE RESEARCH PROBLEM.....	XI
STUDY RATIONALE	1
STATEMENT OF PROBLEM	3
SIGNIFICANCE TO SOCIAL WORK	5
<i>Public Health Significance</i>	5
<i>Significance of Focusing on African American Caregivers</i>	9
STATEMENT OF PURPOSE ~ RESEARCH QUESTIONS	12
PART I – CHRONIC ILLNESS & CHRONIC ILLNESS CARE	16
<i>General Overview</i>	16
<i>African American Prevalence</i>	17
<i>African American Chronic Illness Care</i>	27
PART 2 - CAREGIVING AND CHRONIC ILLNESS	28
<i>General Overview</i>	28
<i>Caregiving & Other Family Life Stressors</i>	29
<i>Divorce</i>	31
<i>Unemployment</i>	33
<i>African American Caregivers</i>	34
<i>Resources</i>	38
<i>Vulnerabilities</i>	43
<i>Coping</i>	46
<i>Well-Being – Global happiness, Depression, & Health</i>	50
SUMMARY	55
CHAPTER THREE: THEORETICAL FRAMEWORK	57
OVERVIEW - MODEL OF FAMILY STRESS, ADAPTATION, AND RESILIENCY	57
<i>Relevance to African American Caregiving & Chronic Illness</i>	59
SPECIFICATIONS OF THE MODEL	61
MODEL CONCEPTS & THEIR RELATIONSHIPS	61
<i>Limitations of the Model</i>	65
<i>Applications of Model to Proposed Study</i>	68
<i>Model Constructs Tested in Study</i>	70
<i>Specifying the Model to African American Caregivers</i>	73
CHAPTER FOUR: RESEARCH METHODOLOGY.....	76
METHODS.....	76
<i>Data Source</i>	76
<i>Rationale for Choosing the NSFH</i>	76
<i>Comparison to Other Chronic Illness & Caregiving Surveys</i>	76
<i>Comparison to African American Family Life Surveys</i>	78
<i>Rationale for Choosing Wave 1 of NSFH</i>	79
<i>Description of Sample</i>	80
<i>Data Collection</i>	84
<i>Study Measures</i>	84
<i>Demographic Variables</i>	84

<i>Family Stressors</i>	86
<i>Family Resource Variables</i>	88
<i>Family Coping Variables</i>	92
DATA MANAGEMENT	98
<i>Analysis Software</i>	98
<i>Weighting</i>	101
<i>Data Preparation</i>	101
<i>Assessing Variable Distributions</i>	101
<i>Testing Bivariate Correlations</i>	103
<i>Analytic Approach by Research Question</i>	105
CHAPTER FIVE: STUDY RESULTS	112
SAMPLE DESCRIPTION & DEMOGRAPHIC PROFILE	112
ANALYSES RESULTS, BY RESEARCH QUESTION	115
<i>Research Question 1: Caregiver & Non Caregiver Differences</i>	115
<i>Table 16: Caregiver & Non-Caregiver Group Differences, Significance Testing</i>	117
<i>Research Question 2: The Role of Caregiving, Divorce, Receipt of Care for Pre-existing Chronic Condition, & Unemployment</i>	118
<i>Research Question 3: Caregiving as a Family Stressor</i>	120
<i>Research Question 4: The Role of Coping Mediators in Predicting Caregiver Well-Being</i>	125
CHAPTER SIX: DISCUSSION	134
OVERVIEW	134
<i>Limitations</i>	143
<i>Strengths</i>	146
CONCLUSIONS	148
<i>Future Research</i>	148
<i>Implications for Practice & Policy</i>	153
<i>Summary</i>	155
APPENDIX 1: 12-ITEM CES-D MEASURE OF DEPRESSED MOOD	158
APPENDIX 2: INTERCORRELATION OF STUDY VARIABLES	159
REFERENCES	161

List of Tables

TABLE 1: DEMOGRAPHIC CHARACTERISTICS OF ILLNESS PREVALENCE RATES BY RACE/ETHNICITY AND GENDER: 1992 HEALTH AND RETIREMENT STUDY	20
TABLE 2: AGE ADJUSTED PERCENTAGES OF SELECTED DISEASES AND CONDITIONS AMONG PERSONS 18 YEARS OF AGE AND OVER, BY SELECTED CHARACTERISTICS: UNITED STATES, 2005	22
TABLE 3: CROSS-RACIAL COMPARISON OF THE RATES OF SEVERE MENTAL ILLNESS FOR AFRICAN AMERICANS AND WHITES, BY STUDY AND DISORDER TYPE	25
TABLE 4: MODEL ABBREVIATIONS & TERMS	65
TABLE 5: CHARACTERISTICS OF NSFH AND OTHER FAMILY LIFE, CAREGIVING, AND AFRICAN AMERICAN SPECIFIC SURVEYS.....	77
TABLE 6: AFRICAN AMERICAN CAREGIVER SAMPLES ACROSS NSFH WAVES 1-3.....	80
TABLE 7: DESCRIPTION OF FAMILY MEMBER CAREGIVER DEMOGRAPHIC VARIABLES.....	85
TABLE 8: DESCRIPTION OF FAMILY MEMBER STRESSOR VARIABLES.....	87
TABLE 9: DESCRIPTION OF FAMILY MEMBER RESOURCES.....	89
TABLE 10: DESCRIPTION OF FAMILY MEMBER VULNERABILITIES	91
TABLE 11: DESCRIPTION OF FAMILY MEMBER COPING VARIABLES	93
TABLE 12: DESCRIPTION OF FAMILY MEMBER HEALTH & LIFE SATISFACTION VARIABLES	96
TABLE 13: FREQUENCY DISTRIBUTION OF STUDY VARIABLES	100
TABLE 14: TESTS FOR NORMALITY OF OUTCOME VARIABLES	103
TABLE 15: LIST OF CARE RECIPIENT ILLNESSES	113
TABLE 16: CAREGIVER & NON-CAREGIVER GROUP DIFFERENCES, SIGNIFICANCE TESTING	117
TABLE 17: EXAMINING THE RELATIVE INFLUENCE OF FAMILY STRESSORS (CAREGIVING, DIVORCE, AND UNEMPLOYMENT) ON WELL-BEING (N =2390).....	120
TABLE 18: OLS REGRESSION OF DEPRESSION ON RESOURCES, VULNERABILITIES, & DEMOGRAPHICS.....	122
TABLE 19: OLS REGRESSION ON SELF-REPORT HEALTH ON RESOURCES, VULNERABILITIES, & DEMOGRAPHICS.....	125
TABLE 20: PATH ANALYSIS OF FAMILY MEMBER RESOURCES, FAMILY MEMBER VULNERABILITIES AND COPING MEASURES ON CAREGIVER DEPRESSION.....	128

List of Figures

FIGURE 1: CHRONIC ILLNESS AMONG ADULTS AGE 50 AND OLDER, BY RACE/ETHNICITY	18
FIGURE 2: DEMOGRAPHIC CHARACTERISTICS OF ILLNESS PREVALENCE RATES BY RACE/ETHNICITY AND GENDER: 1992 HEALTH AND RETIREMENT STUDY	20
FIGURE 3: RESILIENCY MODEL OF FAMILY STRESS, ADAPTATION, & RESILIENCY	64
FIGURE 4: THE ABRIDGED VERSION OF THE MODEL SPECIFIC TO PROPOSED STUDY.....	70
FIGURE 5: STUDY SAMPLING FLOWCHART	83
FIGURE 6: RESEARCH QUESTION #4- PATH ANALYSIS DIAGRAM	110
FIGURE 7: SIGNIFICANT DIRECT AND INDIRECT PATHWAYS OF FAMILY MEMBER RESOURCES, FAMILY MEMBER VULNERABILITIES, COPING MEASURES, AND DEPRESSION.	129
FIGURE 8: SIGNIFICANT DIRECT AND INDIRECT PATHWAYS OF FAMILY MEMBER RESOURCES, FAMILY MEMBER VULNERABILITIES, COPING MEASURES, AND SELF-REPORT HEALTH. ...	132

List of Equations

EQUATION 1: RESEARCH QUESTION #2 ANALYTIC EQUATION.....	106
EQUATION 2: RESEARCH QUESTION #3 ANALYTIC EQUATION.....	107

Chapter One: THE RESEARCH PROBLEM

Study Rationale

As a social institution and system of care, family caregivers play a crucial role in their ill-member's health care and service utilization. A vital institution in American society, they are often the first and frequently the last source of support for individuals suffering from chronic health conditions. The act of 'caregiving' has been described as a stressful role that leads to poor life and health outcomes for involved family members (Beach, Schulz, Yee, & Jackson, 2000; Huang, 2004; Navaie-Waliser et al, 2002). The literature suggests that for African American caregivers, culturally-justified ideologies about roles, responsibilities, and coping shape the caregiving process (Dilworth-Anderson et al, 2005). Moreover, due to the historically disadvantaged social history of this ethnic group, a number of unique stressors, resources, and vulnerabilities have emerged which could inform caregiving experiences, caregiver well-being, and ultimately family adaptation. This study will attempt to elucidate how these variables interrelate. First, it will explore the extent to which the stress of caregiving impacts well-being, in light of other possible independent family stressors that an individual might be facing. The, it will further extend prior research by investigating how specific variables that have a history of being identified as conventions in the African American family affect adaptation to caregiving in terms of well-being. Specifically, it will identify and test the relationships between demographic family caregiver characteristics, available resources, conflicting vulnerabilities, indigenous coping patterns, and well-being factors. Through this analysis, this study will uncover some of the heterogeneity

that exists within the wider group of African American caregivers as a whole. It will challenge social scientists to consider with caution oversimplified assumptions about possible similarities among the larger group of African American caregivers and increase their understanding of how contextual factors inform the caregiving experience. Thus it will afford the opportunity to explore whether the effects of caregiving are general across all African American caregivers or dependent on the specific context of the caregiving experience. This knowledge has implications for advancing practitioner knowledge and interventions aimed at helping these families.

The specific focus on African American families addresses a gap in the knowledge base. Though research in the area of chronic illness caregiving has increased exponentially in the past few years, limited attention has been paid to understanding the unique experience of African American caregivers. Existing comparative work suggests that the experience of African American caregivers often varies from other ethnic groups, particularly their White counterparts (Dilworth-Anderson et al, 2005; Dilworth-Anderson, Goodwin, & Williams, 2004; Haley et al, 2004; Magana, 2004; Shurgot & Knight, 2005). Variations exist in the appraisals of the situation, sense of familial obligation, methods of help-seeking and coping, and well-being outcomes. One key criticism of this comparative work is that it does not consider the environmental and ecological circumstances that influence caregiving (Magana, 2004). These cross-cultural comparisons are incapable of addressing the shared social phenomena and key aspects (e.g. racial disparities, socioeconomic disadvantage, discrimination, and cultural value systems) of African American life that shape African American family functioning. This

study is important because it will consider the social context and experience (e.g. resources, vulnerabilities, and coping) of African American caregivers and non-caregivers and uncover the heterogeneity that exists within the group using a within-group analytic approach. This approach will help identify the multitude of possible variables that inform caregiver functioning and unravel the unique differences that exist among this seemingly similar ethnic minority group. Thus it has the ability to identify subgroups of African American caregivers so that health and family support programs can be designed to aptly address the variety of concerns that plague these caregivers.

Statement of Problem

Advancements in medicine , demographic changes in the client-base of the existing healthcare system coupled with increased healthcare costs have brought about an increased need for family members to become actively involved in the health care of their ill loved ones (Wilkinson & Lynn, 2005). This is particularly true in the case of chronic illness. Chronic illnesses such as heart disease, mental illnesses, cognitive aging disorders, cancer, and diabetes are among the leading causes of disability and death in the U.S. These illnesses cause a major limitation in daily living for more than 1 of every 10 Americans (Centers for Disease Control and Prevention, 2000) and result in long-term disability requiring extensive medical treatment, therapeutic supports, and long-term care. These limiting conditions affect a person's ability to care for themselves, attend to daily living routines, and function independently in life. Though chronic illnesses directly impact the ill member, they have an exponential impact on the family unit (Biegel, Sales,

& Schulz, 1991; Shaw & Halliday, 1992; Newby, 1996). Though all family members are impacted, the family caregiver is encumbered the most. As the individual who provides the most care for the ill member the family caregiver assumes great responsibility for their loved one's illness, general healthcare, and lifestyle management (Biegel, Sales, & Schulz, 1991; Marks & Lambert, 1997; Wilkinson & Lynn, 2005). As a result, caregivers experience the illness in very profound ways, which has implications for their health and well-being.

Exploring the multiple dimensions of caregiving presents a number of inherent challenges, but the concept of culture can confound these issues. While there is no question that the general presence of chronic illnesses is not contingent upon culture, there exist differences in health risk factors across ethnic and culturally diverse groups which inform rate variations in the incidence of specific chronic disorders (Liao, Tucker, & Giles 2004). Cultural beliefs and values shape individual response to illness, functional status, health care decisions, and treatment preferences. For caregivers, there is the added dimension of 'cultural justification' – this is the process by which caregivers call upon cultural mores, styles of communication, and indigenous support systems to justify their role and responsibility as primary care providers for their chronically ill loved ones (Dilworth-Anderson, Goodwin, Williams, 2004). Thus, context, including cultural context, informs how the caregiver perceives the situation, the scope of available resources, the extent of competing demands, coping strategies, and available social supports. This is true for African American caregivers. The family's background (e.g. cultural, social, and demographic) informs not only the capacity of the caregivers, but

also their response and ability to adapt (Dilworth-Anderson, Williams, Gibson, 2002). Consequently, any attempt to examine caregiving without considering socio-cultural factors and context limits social scientists and family practitioners' abilities to fully appreciate the complexities of the caregiving experience. Thorough examination of these factors will help illuminate specific family schemas, attributes, and practices that shape caregiver functioning in the face of family crises, such as chronic illness.

Another problem that this study will attempt to confront is the divergent research findings regarding African American caregiver well-being outcomes. Mainly based on comparative studies, these findings do not show consistent well-being outcomes for these caregivers, particularly on well-being indicators such as quality of life, depression, perceptions of health, and global happiness (Pinquart & Sorensen, 2005). Pinquart & Sorensen (2005) suggest that this may be due to issues in methods, particularly sampling (e.g. the use of convenience sampling) and measurement. Accordingly, there is the need for additional research in this area using large national probability samples, theory driven hypotheses, and more widely accepted, reliable, and valid constructs of well-being. Findings from such studies will better clarify the extent to which African American caregivers experience positive or negative outcomes and shed light on how contextual and demographic factors influence this relationship.

Significance to Social Work

Public Health Significance

As social constructs independent of each other, 'chronic illness' and 'family caregiving' are both burgeoning areas of interest in public health. It is estimated that nearly 1 in 2 Americans (133 million persons) has a chronic condition or illness and within the next 10 years at least 157 million Americans will be afflicted (Anderson & Horvath, 2004; Rundall, Shortell, Wang et al., 2002). Of those afflicted, sixty percent are between the ages of 18 and 64 (Anderson, 2002; Anderson & Horvath, 2004) and within the senior population the numbers are higher, with nearly 90% of seniors having at least one chronic health condition and 77% having two or more (Anderson, 2002; Anderson & Horvath, 2004). Compounding the issue is the fact that chronic illnesses, such as cancer, diabetes, heart disease, and depression, are the leading cause of death and disability in the United States (Centers for Disease Control and Prevention, 2006). They have negative consequences on life quality and health outcomes, resulting in seven out of every ten deaths in the U.S. The cost of care and treatment is estimated to over \$350 billion dollars, which accounts for over seventy five percent of all health care spending (Anderson, 2002; Anderson & Knickman, 2001; Hoffman, Rice & Sung, 1996). Thus, chronic illnesses place an enormous economic and service burden on the health care industry.

The World Health Organization characterizes the family as "the primary social agent in the promotion of health and well-being" (World Health Organization, 1976). Families, particularly family caregivers, are highly involved in health care decision-making, support, and provision with the caregiver being the most involved. With over 25 million caregivers providing personal assistance to adult (aged 18 and over) family

members with a chronic condition or disability (Arno, Levine, & Memmott, 1999; National Alliance for Caregiving & AARP, 2004; National Family Caregivers Association & Family Caregiver Alliance, 2006) it stands to reason that attention must be paid to this population. Consequently, the act of caregiving in conjunction with the related caregiver health and quality of life issues has also emerged as an important public health issue (DeFries et al, 2009; National Alliance for Caregiving & AARP, 2004; Talley & Crews, 2007). Objective 6-13 of Healthy People 2010 specifically appeals for national attention and public health surveillance and promotion for persons with disabilities and their caregivers (UDHHS, 2000). Caregivers are an asset to the health care industry and provide a significant amount of care for their loved ones. They have a vital social and economic role in healthcare (Arno, Levine, & Memmott, 1999). According to the Department of Health and Human Services (2003) they are the largest and fastest growing long term care service sector in the health care industry today. The economic value of the services, which they provide for 'free' for their loved ones, is estimated at \$306 billion a year, a dollar amount that is twice as much as is spent on other auxiliary health care services, such as homecare and nursing homes (National Family Caregivers Association & Family Caregiver Alliance, 2006; National Alliance for Caregiving & AARP, 2004). Moreover, the role of caregiver is often rife with stress situations and potentially contributes to psychiatric and physical morbidity for the caregivers. The combination of perceived loss, prolonged distress, and the physical demands of caregiving may compromise physiological functioning and increase caregivers risk for physical health problems, leading to increased mortality (Schulz & Beach, 1999; Ekwall, Sivberg, &

Hallberg, 2007; Vitaliano, Zhang, & Scanlan, 2003). In essence, these family members become the “hidden patient” and consequently their health becomes vulnerable as a result of attending to their chronically ill loved ones (Hill, 2003; Navaie-Waliser et al, 2002). As a result, the overall health care costs of chronic illness are exponentially increased. Thus, directing practice, research, and policy attention to caregiving in chronic illness exposes opportunities for cost-saving service improvements for the health care industry.

A unique approach put forth by this study is to examine the differential impact of caregiving alongside other well-documented family member life stressors. Though it is commonly accepted that caregiving is a stressful role for many family members and there is evidence supporting this supposition, there limited studies available that look at how the act of caregiving is disentangled from other competing stressful life events that the individual might be enduring. It is possible that the true effect of caregiving is masked. To uncover the true impact of caregiving on family members, researchers must consider and control the contributing effects of other contending stressors. Only then is its possible to examine whether caregiving is truly related to negative life outcomes or whether it compounds the stress brought on by other life hardships. This study addresses this issue and fills a necessary gap in the literature. Specifically, it will consider, not only the relationship between caregiving and well-being outcomes, but particularly it will look at how caregiving stacks up against other identified life stressors, (e.g. unemployment, divorce, and receipt of care for a pre-existing disability or chronic condition).

Significance of Focusing on African American Caregivers

Although there is a growing interest in the caregiving experience and family coping dynamics of families affected by chronic illnesses, limited attention has been paid to the unique experience of African-American families. The third largest racial-ethnic group in the United States comprising 12.9% of the United States population, African Americans tend to bear a significantly higher burden of death, disease, and disability compared to the larger sub-populations of White and Hispanic/Latino Americans (Braithwaite & Taylor, 2001; LaVeist, 2005). Epidemiological studies exploring ethnic variations in illness incidence have consistently shown significantly unequal rates of chronic health conditions among African Americans compared to White, Latino, and Asian Pacific Islanders (Braithwaite & Taylor, 2001; LaVeist, 2005; Liao, Tucker, & Giles, 2004; James et al, 2007). Specifically, they have significantly higher rates of diabetes, cancer, cardiovascular disease, asthma, obesity, and hypertension (National Center for Health Statistics, 2000, 2005; LaVeist, 2005; James et al, 2007; Liao, Tucker, & Giles, 2004; Bowen & Gonzalez, 2008) and experience chronic health conditions for longer periods of time. Compounding this issue, is the fact that African Americans report poorer health status, more psychological distress, and lower levels of life satisfaction on most subjective indicators of life quality and health status, which cannot be explained by socioeconomic variance (Braithwaite & Taylor, 2001; LaVeist, 2005; Mayberry, Mili, & Ofili, 2000; James et al, 2007; Hayward, Miles, Cummins, & Yang, 2000). Conversely, they have lower rates of psychiatric disorders

(LaVeist, 2005). The costs of these disparities to the health care industry are staggering. In his study investigating the financial costs of racial and ethnic healthcare disparities, Waidmann (1999) suggests that disparities in care and treatment among African American and Hispanic persons will cost the health care system \$23.9 billion, with \$5.1 billion being incurred by private insurers as a result of higher rates of chronic illness among these racial subgroups. For caregivers in particular, these disparities result in a cumulative disadvantage that increases burden (Crewe, 2005).

African Americans are subject to a number of unique health related vulnerabilities and social experiences that demand the attention of social scientists - particularly, ethnic-specific risk factors that compromise their physical and mental health, such as a history of oppression, discrimination, racism, and diminished social status (Mayberry, Mili, & Ofili, 2000; Williams & Collins, 2001). These risk factors are not only related to illness incidence, but also to help-seeking and service utilization (Satcher, 2000; Smedley, Stith, & Nelson, 2002). There is overwhelming evidence that African American caregivers and their ill loved ones experience disparities in care, lower rates of formal service use, and under-treatment (Smedley, Stith & Nelson, 2002). The presence of these disparities heightens the significance of studying this population, as it has direct implications for morbidity and mortality. One of America's most significant public health dilemmas is the persistence of health disparities in health care experienced by members of racial ethnic groups, such as African Americans (AHRQ, 2003; Satcher, 2000; Smedley, Stith, & Nelson, 2002). Developing knowledge in this

area can inform culturally relevant quality care for members of this ethnic group and inform the transformation of the current system of health care.

In the attempt to understand and eliminate existing health care disparities as it relates to African Americans, special attention must be paid to the rich tradition of resiliency, sense of familial obligation, and culturally-informed coping, that exist within this ethnic population. With respect to resilience, evidence suggest that despite being engaged in similar caregiving activities as their non-African American counterparts, African American caregivers report greater caregiving meaning, less distress, less negative health outcomes, greater affection, and positive interactions (Dilworth-Anderson, Williams, Gibson, 2002; Wilcox, Bopp, Wilson, Fulk, & Hand, 2005). For African Americans, the individual is an extension of the larger family unit and his or her behaviors are both informed by and shape the social structure of the family (Caldwell-Colbert, Daniel, and Dudley-Grant, 2003). Moreover throughout their social history unique coping mechanisms have evolved which promote family health and vitality among African Americans (McAdoo, 1998). Self-care, collective reasoning, family reliance, and spirituality have emerged as safe, reliable, and non-discriminating outlets that aid in life crises management, even in family caregiving. These factors play a critical role in health care promotion and wellness among African Americans.

Besides addressing the public health concerns raised by health care disparities as they exist among African Americans, this study extends the social science research and knowledge base as it specifically applies to African American caregivers. Given that a majority of the existing knowledge base on African American caregiving and chronic

illness is based on comparative data contrasting African Americans to other racial - ethnic groups, there is a need for an analysis exploring within group variations and unique contextual attributes that exists within African American caregivers as a distinct group (Dilworth-Anderson et al, 2005; McAdoo & Younge, 2009; Neville, Tynes, & Utsey, 2009). Such a within-group focus using a large national probability sample may shed light on the heterogeneity that exists among members of this racial-ethnic group. In particular it will allow for an in-depth analysis of contextual factors, such as social life experiences, limited resource distribution, and competing life stressors that uniquely plague African American caregivers. This has obvious implications for public health.

Statement of Purpose ~ Research Questions

Using a national probability sample of African American caregivers, this dissertation investigates the demographic difference between caregivers and non-caregivers to assess whether or not variations exist in the two subgroups. Particularly it will explore whether or not the caregivers are different from non-caregivers in their demographic characteristics, presence of family resources, presence of vulnerabilities, and coping patterns. Secondly, the study will look at the role that other family life stressors have on the relationship between caregiving and well-being. Finally, it will examine the relationship between demographic family characteristics, family stressors, family resources, vulnerabilities (e.g. competing demands), and coping on the well-being (e.g. health and global happiness) of African American caregivers of adults with chronic illness.

The specific study research questions are as follows:

- (1) *Do African American caregivers and non-caregivers differ on*
 - a. *Individual demographic & social characteristics,*
 - b. *Illness and non-illness related stressors,*
 - c. *Illness and non-illness related resources,*
 - d. *Vulnerabilities, in the form of competing roles and pile-up demands,*
 - e. *Illness and non-illness related family coping patterns*
 - f. *Well-being, in the form of depression, subjective health, and subjective happiness*
- (2) *Controlling for other objective stressors (e.g. divorce, unemployment, and receipt of care for pre-existing chronic condition or disability), is caregiving associated with depression, health and global happiness?*
- (3) *Among African American caregivers, are family member resources and vulnerabilities related to depression, health and global happiness?*
- (4) *Among African-American caregivers, do two forms of coping – help-seeking and church participation – mediate the associations of family member resources vulnerabilities on depression, health and global happiness?*

Examination of these issues provide a framework for understanding and appreciating caregiving as it exists within African American families coping with chronic illnesses. There is overwhelming evidence that suggests that resource availability, competing life demands, and informal coping mechanisms are important factors that

inform adaptation and well-being among all caregivers. Yet, understanding how this plays out among African American family members faced with caring for a loved one with chronic illness is important. Though a communal sense of identity may exist among African American families, the role strain, if any, brought on by caregiving may be informed by a number of social and demographic variables which would result in variations in how caregiving is experienced among members of this ethnic group. This study is an exploratory inquiry that will take initial steps in revealing how chronic illness is experienced by the African American family caregiver. It will explore the extent to which the act of caregiving is perceived as a stressful role, by examining how the outcomes of caregiving compare against other supplementary life stressors. In addition, it will dissect the contextual variables that inform caregiving while examining pathways by which African American caregivers respond and adapt to their caregiving role, with emphasis being paid to vulnerabilities, resources, and coping- that are linked to their well-being (e.g. depression levels, perceived health, and global happiness). Ultimately, the study will expose some of the family factors, caregiver attributes, and coping processes that are associated with well-being and contribute to adaptation and resilience. There currently are no published studies that take an in-depth look at the unique profile and coping processes of African American caregivers of adult family members, aged 18 and over, with chronic illness using a national probability sample. Existing studies are limited in that most focus on a specifically defined group of caregivers (e.g. women, caregivers of older adults, parent caregivers, etc.), they focus on caregivers of specific disorders, used cross-ethnic comparative analysis, or they use

convenience sampling and/or include a limited number of African Americans in the sample pool. This study will address these limitations and answer the call for a study that addresses African American caregiving, using a large nationally representative sample of diverse African American caregivers (Dilworth Anderson et al, 2005; Rozario & DeRienzi, 2008; Wilcox et al, 2005). Moreover, it will address the identified need put forth by other researchers (Grogger & Mayberry, 2001; Dilworth-Anderson, Williams, Gibson, 2002), for a study that looks at intragroup variations in caregiving experiences among African Americans. Thus, this study will produce valuable knowledge and contribute to the dearth of literature on chronic illness caregiving and African American family life.

Chapter Two: REVIEW OF THE LITERATURE

The goal of this chapter is to discuss chronic illness as it applies to African American caregivers. The first half of the chapter will review chronic illnesses and chronic illness care and their distinctiveness among African Americans, with special attention being paid to stressors that confront members of this ethnic group. The second half of the chapter will more intently discuss the experience of African American caregivers when confronted with chronic illness care. It will present the evidence on how these caregivers respond to their role, employ resources, and manage competing demands (e.g. vulnerabilities). This half of the chapter will also review coping and problem solving mechanisms that African Americans commonly use to help them manage their caregiving roles.

Part I – Chronic Illness & Chronic Illness Care

General Overview

Chronic illness is a term used to refer to wide array of medical conditions that have significant long-term health effects on an afflicted individual. Though they are not as life threatening as other serious medical conditions, such as infectious diseases, their affects are devastating, permanently disabling, and have resounding impact on the life of the afflicted. Unlike acute illnesses which are shorter in duration, chronic illnesses last at least a year or more, are not easily treated or cured, require ongoing medical care, and limit activities of daily living (Hoffman, Rice & Sung, 1996; Anderson, 2004). Moreover, because they compromise the capacity of the afflicted individual to care for

themselves the mere presence of these illnesses necessitate the involvement of ongoing medical care and support services.

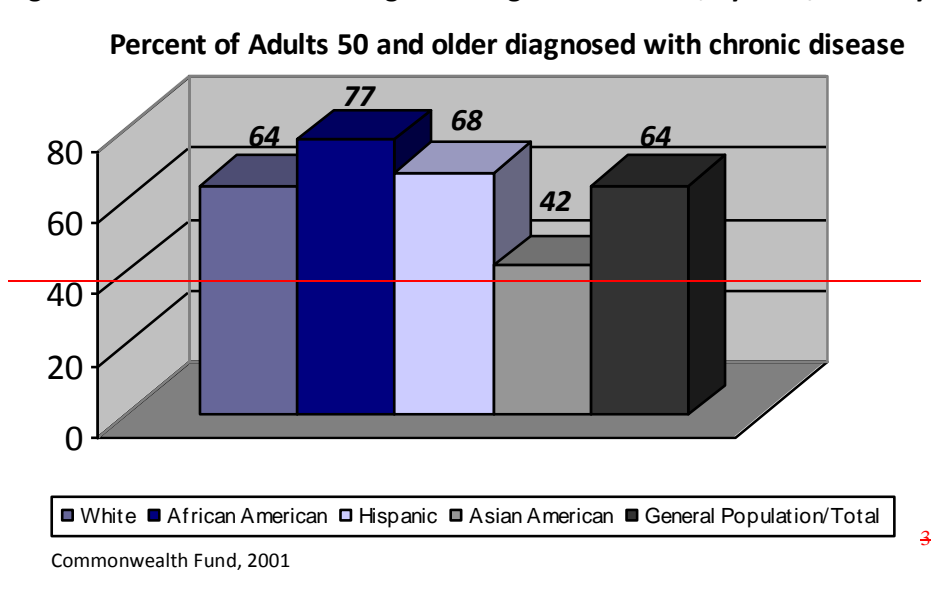
Research suggests that half of all Americans suffer from some form of chronic illness (Anderson 2002; Anderson & Horvath, 2004; Rundall et al., 2002). Though these illnesses are not bounded by age limitations, the prevalence of chronic illness does increase with age (Anderson 2002, Anderson & Horvath, 2004; 2002; Paez, Zhao, & Hwang, 2009). Medical advances have prolonged the life of those afflicted, thus increasingly larger numbers of individuals are living with these conditions. It is estimated that approximately two-thirds of those afflicted are adults between the ages of 18 and 64 (Anderson et al, 2002) and approximately three-fourths (74%) of those are over the age of 65 (Center for Medicare Advocacy, 2002). A major cause of death and disability, chronic illnesses account for 70% of all deaths in the United States (Centers for Disease Control and Prevention, 2002). These rates are even higher among minorities and disadvantaged populations, as a disproportionate amount of premature deaths within these subset populations are due to chronic conditions (Centers for Disease Control and Prevention, 2000).

African American Prevalence

With respect to African Americans, a number of disparaging differences exist. Comprising approximately 12.9 % of the U.S. population, African Americans have higher rates of chronic health conditions compared to other ethnic minority groups (Collins, Tenney, & Hughes, 2002; Becker, Beyene, Newsom, & Rodgers, 1998). Specifically

across adult populations they are more likely to report the presence of a chronic condition, more likely to report having more than one condition, and have incidence rates of chronic illness that are at or above national averages (Collins, Hall, & Neuhas, 1999; Collins, Tenney, & Hughes, 2002; Becker, Beyene, Newsom, & Rodgers, 1998; Liao et al, 2004). Results from the Commonwealth Fund 2001 Health Care Quality Survey¹ detail these results (Figure 1).

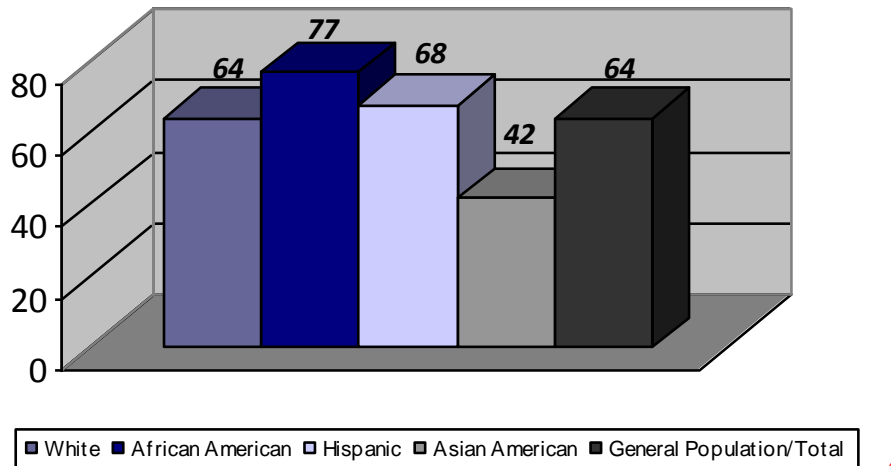
Figure 1: Chronic Illness² Among Adults Age 50 and Older, by Race/Ethnicity



¹ Collins, K. S, Hughes, D.L., Doty, M.M., Ives, B.L., Edwards, J.N. & Tenney, K. (2002). Diverse Communities, Common Concerns: Assessing health care quality for minority Americans. Finding from the Commonwealth Fund 2001 Health Care Quality Survey. *The Commonwealth Fund*, New York, Publication #523

² Includes one of the following conditions: High Blood Pressure, Heart Disease, Cancer, Diabetes, Anxiety/Depression, Obesity, or Asthma

Percent of Adults 50 and older diagnosed with chronic disease



Studies using both large representative and small convenience samples report similar findings (Kingston & Smith, 1997; Bowen & Gonzalez, 2008), particularly for more common chronic physical conditions such as hypertension and cardiovascular illnesses (Davis, Liu, & Gibbons, 2003; Kingston & Smith, 1997; Bowen & Gonzalez, 2002; National Center for Health Statistics, 2005), pulmonary illnesses (Bach, 1999), cancer (Bach, 1999; Bowen & Gonzalez, 2002; National Center for Health Statistics, 2005), diabetes (Davis, Liu, & Gibbons, 2003; Kingston & Smith, 1997; Bowen & Gonzalez, 2008; National Center for Health Statistics, 2005), asthma (Lester et al., 2001; Rose, Mannino, & Leaderer, 2006; National Center for Health Statistics, 2005), kidney and renal illnesses (Young & Gaston, 2000; National Center for Health Statistics, 2005) and obesity (Ogden et al, 2006; James et al 2007).

In their study examining socioeconomic status and racial ethnic differences in chronic health conditions, Kingston & Smith (1997) found significantly higher rates of chronic illness among African American community dwelling adults, compared to their

White and Hispanic counterparts. According to their study African Americans have higher prevalence of hypertension, diabetes, heart conditions, and arthritis, compared to their White and Hispanic counterparts even when socioeconomic status is considered (Table 1; Figure 2).

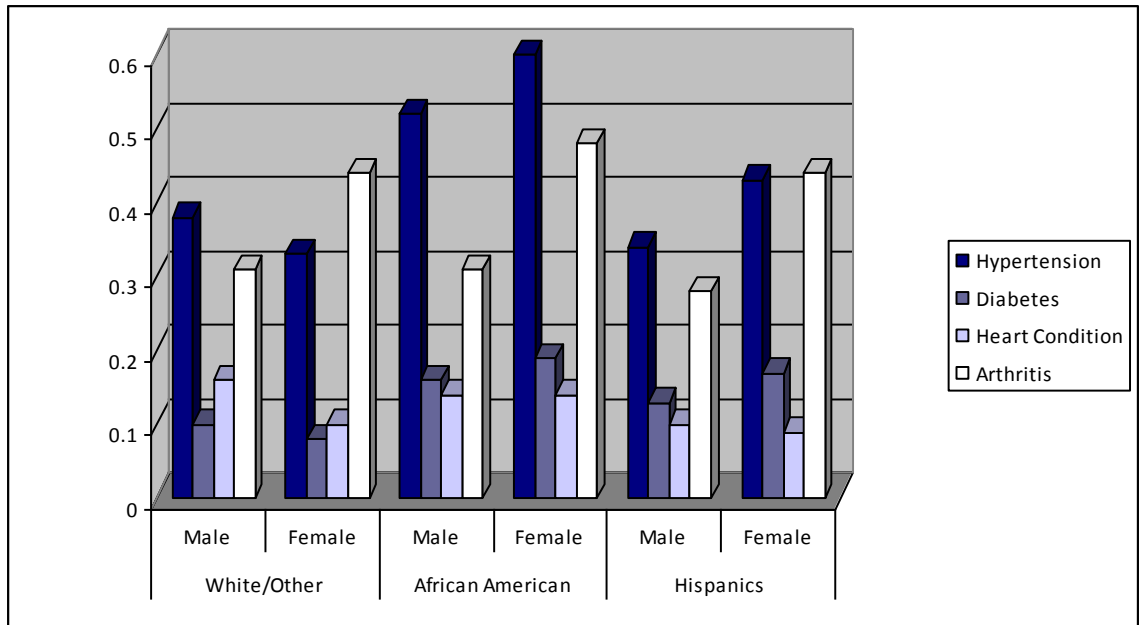
Table 1: Demographic Characteristics of Illness Prevalence Rates by Race/Ethnicity and Gender: 1992 Health and Retirement Study

	White/Other (N = 7185)	African American (N = 1659)	Hispanics (898)
Hypertension	.38 Male; .33 Female	.52 *Male; .60* Female	.34 Male; .43* Female
Diabetes	.10 Male, .08 Female	.16* Male; .19* Female	.13 Male; .17* Female
Heart Condition	.16 Male, .10 Female	.14 Male; .14* Female	.10 *Male; .09 Female
Arthritis	.31 Male, .44 Female	.31 Male; .48* Female	.28 Male; .44 Female

*P .05 for difference in prevalence compared with White/other of same gender

Kingston & Smith (1997)

Figure 2: Demographic Characteristics of Illness Prevalence Rates by Race/Ethnicity and Gender: 1992 Health and Retirement Study



More recent findings are equivocal (Bowen & Gonzalez, 2008; National Center for Health Statistics, 2005; Hayward et al, 2000). For example, Bowen & Gonzalez (2008) report similar findings identifying rate differences. Like Kingston & Smith (1997) they used data from the Health and Retirement Study (1992-2004) and confirmed the presence of higher rates of disability and chronic disease among minority respondents over the age of 50. Though their study showed similar rates of illness prevalence between African Americans and Latinos, significant differences did exist between African Americans and Whites, particularly in respect to diabetes, cancer, and strokes. These findings are reaffirmed by the 2005 National Health Interview Survey, using a different and much broader national dataset. Based on a national probability sample of non-institutionalized adults over the age of 18, this survey conducted by the Centers for Disease Control and Prevention provides one of the most thorough sources of information on health statistics. Hence findings are not limited to older adult

populations. Analyses of their data reveal that compared to other ethnic groups African Americans have the 3rd highest rate of liver disease and arthritis compared to Whites, Latinos, Asian Americans and Native Americans. African Americans have the 2nd highest rate of diabetes and kidney disease compared to these same ethnic groups, with Native Americans showing higher rates, and African Americans have the highest rate of hypertension. In fact, compared to Caucasians alone, African Americans show higher rates of hypertension, asthma, diabetes, and kidney disease. (Table 2).

Table 2: Age adjusted percentages of selected diseases and conditions among persons 18 years of age and over, by selected characteristics: United States, 2005⁵

% (standard error)	White (N = 180,477)	African American (N = 24,817)	Hispanic/Latino (N = 27,770)	Asian (N = 8,155)	American Indian (N = 1,469)
Hypertension	21.0 (0.26)	31.2 (0.79)	20.3 (0.72)	19.4 (1.28)	25.5 (3.54)
Asthma	10.7 (0.24)	11.7 (0.58)	7.8 (0.46)	7.8 (1.09)	9.1 (2.61)
Diabetes	7.0 (0.17)	11.3 (0.54)	9.8 (0.54)	6.5 (0.97)	13.6 (2.78)
Kidney Disease	1.6 (0.09)	2.6 (0.30)	2.4 (0.32)	1.5 (0.55)*	2.8 (1.30)*
Liver Disease	1.3 (0.08)	1.3 (0.21)	1.5 (0.20)	1.0 (0.35)*	1.9 (0.95)*
Arthritis	21.6 (0.28)	21.2 (0.69)	16.9 (0.63)	12.6 (1.17)	26.8 (3.64)

⁵ Pleis, J.R., & Lethbridge-Ceiku M. (2006). *Summary health statistics for U.S. adults: National Health Interview Survey, 2005*. National Center for Health Statistics. Vital Health Stat 10(232).

* Estimates with an asterisk have a relative standard error greater than 30% and less than or equal to 50% and should be accepted with caution as they do not meet the standard reliability of precision (Pleis & Lethbridge-Ceiku, 2006).

Studies sufficiently demonstrate variations in chronic conditions across racial/ethnic groups. In reference to African Americans, studies show unequal and often higher prevalence rates in many chronic conditions. Though they contribute substantially to the knowledge they only focus on physical chronic health conditions and do not consider psychiatric morbidity or cognitive impairments, both of which are considered long-term chronic health conditions. Impaired functioning in psychiatric and cognitive ability is equally disabling and deserves attention in the study of chronic illness. Illnesses such as clinical depression, schizophrenia, bipolar disorder, and anxiety disorders are just as debilitating as chronic physical conditions, such as cardiovascular illness, pulmonary illness, and cancer. Equally, cognitive conditions, such as Alzheimer's and dementia also have long-term devastating health impact. But unlike the trend observed in chronic physical disorders, African American rates of cognitive impairment and psychiatric illness show more variation and are not always higher.

In respect to chronic cognitive impairments that plague older adults, there is evidence of differential prevalence rates of dementia across ethnic groups. In their study of the prevalence of cognitive impairment in a multi-ethnic community, Demirovic et al. (2003), found significantly higher rates of dementia among African American men compared to Whites and Hispanics. In fact, the prevalence rates were more than double among African American men (14.4% versus 5.4%). Similar findings are reported in other studies (Heyman et al., 1991; Husaini et al, 2003; Gurland et al., 1995, 1997). In regards to Alzheimer's, one of the most common forms of dementia, African Americans show higher risk and incidence (Tang et al, 2001). Though these results overwhelmingly

show that older African Americans are more cognitively incapacitated, these findings must be approached with caution. Most studies are based on small institutionalized non-representative sampling frames. Such sampling frames limit the generalizability of study findings. As suggested by Husaini et al (2003) these samples, many of whom are recruited from nursing homes, are not necessarily representative of the broader group of African Americans with cognitive disabilities that exist within the larger U.S. population.

The prevalence of serious mental health disorders must also be considered. In general researchers suggest that the prevalence rate of chronic psychiatric disorders among African Americans is lower and in some instances at least comparable to that of Whites (Chernoff, 2002; UDHHS, 2001; Snowden, 2001; Sue & Chu, 2003; Jackson et al, 2004). In fact, SAHMHSA (2002) estimates that the prevalence rate of serious mental health disorders among African Americans is 7.5%, a rate comparable to Whites. The Epidemiological Catchment Area Study (ECA) (Robins & Regier, 1991) and the National Comorbidity Study (NCS) (Kessler et al., 1994) provide estimates of the prevalence and incidence of specific psychiatric disorders (both current and lifetime) in representative samples of African Americans (and other populations) within institutionalized and non-institutionalized populations. Similarly, the National Institute on Alcohol Abuse and Alcoholism's (NIAAA) National Epidemiological Survey on Alcohol and Related Conditions (NESARC) provides solely (current) 12 month, as opposed to both current and lifetime, estimates of major mood and anxiety disorders (Grant, Moore, Shepard, & Kaplan, 2003). Results of these studies are depicted in Table 3.

Table 3: Cross-Racial Comparison of the Rates of Severe Mental Illness for African Americans and Whites, by study and disorder type

		ECA		NCS		NESARC	
Diagnostic Instrument		DIS		DSM-IV, WHO-CIDI		NIAA AUDADIS-IV/ (DSM-IV)	
		African American	Whites	African American	Whites	African American	Whites
<i>Mood/Affective Disorders</i>							
Rates	Current	3.5	3.7	0.8	1.0	8.8	9.4
	Lifetime	6.3 ^b	8.0	0.6 ^b	1.0	-	-
<i>Psychotic Disorders (e.g. Schizophrenia)</i>							
Rates	Current	1.5	0.9	-	-	-	-
	Lifetime	2.1 ^b	1.4	0.9	1.0	-	-
<i>Anxiety Disorder (e.g. Panic)</i>							
Rates	Current	1.0	0.9	0.9	1.0	10.43 ^b	11.68
	Lifetime	1.3 ^b	1.6	0.8 ^b	1.0	-	-
<i>Phobic Disorders</i>							
Rates	Current	16.2 ^b	9.1	-	-	2.0 ^{a b}	3.0 ^a
	Lifetime	23.4 ^b	9.7	0.8 ^b	1.0		
<i>Somatization Disorder</i>							
Rates	Current	0.4 ^b	0.1	-	-	-	-
	Lifetime	0.5 ^b	0.1	-	-	-	-

Source: Epidemiological Catchment Area Study; National Comorbidity Study; National Epidemiology Survey on Alcohol & Related Conditions

^a Only includes social phobias; ^b Results significantly different from Whites

Though the diagnostic instruments for each of these studies varied similar results were found. In general, African American showed lower rates of affective, anxiety and phobic disorders compared to White reference groups. Using the Diagnostic Interview Schedule (DIS), Robins & Regier (1991) found significantly lower rates of affective/mood,

anxiety, phobic, and somatization disorders among African Americans, compared to Whites. Though it was not a national survey, its results were confirmed by the NCS (Kessler et al, 1994) and NESARC (Smith et al, 2006), both national surveys exploring mental illness prevalence. Using different versions of the DSM-IV, Kessler et al (1994) & Smith and colleagues (2006) found similar results. Both found lower rates of affective/mood, anxiety, and social disorders among African Americans. Though the NESARC did not measure the prevalence rates of psychotic disorders (e.g. schizophrenia), the ECA and NCS did and initial findings were mixed. The ECA found higher rates of psychotic disorders among African Americans and the NCS found lower rates. Yet when socioeconomic factors were controlled for these differences disappeared and rates of psychotic disorders among African Americans were lower in the ECA (Robins & Regier, 1991) and the NCS (Kessler et al, 1996).

No matter the type of chronic illness –physical, cognitive, or psychiatric- all chronic illnesses have the potential to be related to higher mortality rates. A number of studies report higher chronic illness related death rates among African Americans. Presumably related to disparities in formal health care service use, African Americans have increased mortality rates in respect to asthma, cancer, diabetes, renal disease, cardiac disease, stroke, and obesity, compared to their White counterparts (Smedley, Stith & Nelson, 1997; Bach, 1999; Grant, Lyttle, & Weiss, 2000; National Center for Health Statistics, 2000; Braithwaite & Taylor, 2001; LaVeist, 2005; James et al, 2007). Thus as a population, African Americans have relatively poor health and short life

expectancy as a result of chronic health conditions (Centers for Disease Control and Prevention, 2000; Braithwaite & Taylor, 2001; LaVeist, 2005).

African American Chronic Illness Care

Besides differences exhibited in illness incidence, there exist disparities in chronic illness care. African American chronically ill persons have more economic barriers to healthcare and use fewer formal services (Kingston & Smith, 1997; Mayberry, Mili, & Ofili, 2000; Braithwaite & Taylor, 2001; Collins, Tenney & Hughes, 2002; SteelFisher, 2004; Wang et al, 2005a). According to Corbie-Smith et al (1999) and LaVeist, Nickerson, & Bowie (2000) this may be due to their stated distrust in medical research and clinical care. Studies indicate that African Americans are more likely to use emergency rooms and community health clinics and are less likely to have a regular source of health care such as a primary medical doctor (Collins, Tenney, & Hughes, 2002; Smedley, Stith & Nelson, 2002; Snowden & Pingitore, 2002; James et al, 2007). In fact compared to other ethnic groups, African Americans diagnosed with chronic disorders are more likely to turn to family or friends for support and informal care services (Belgrave et al, 2004; Lum, 2005; Reinhart & Horowitz, 1995). Moreover investigators have found notable differences in healthcare treatment and quality among African American chronically ill individuals (Collins, Hall, and Neuhaus, 1999; Wang, Berglund, & Kessler, 2001; Braithwaite & Taylor, 2001; Smedley, Stith, & Nelson, 2002, LaVeist, 2002; James et al 2007; Wang et al, 2005b). Compared to other ethnic chronically ill individuals, African Americans are offered different types and different

levels of care services. Such differences may be related to a number of cultural and social factors such as education, economics, discrimination, help-seeking patterns, health beliefs, health practices, and family history (Fiscella, K et al, 2000; Williams & Collins, 2001). These contextual factors also inform the caregivers' experience – their characteristics, resources, vulnerabilities, and coping ability. Accordingly, the cultural and social factors that bring about disparities in chronic illness affect not only the ill-member's health care decision, but have direct implications for caregiving, specifically the ill-member's choice to utilize informal services, the family's decision to participate in informal caregiving, the extent of informal care provided, and caregivers access to supportive resources.

Part 2 - Caregiving and Chronic Illness

General Overview

As prolonged conditions, which do not resolve spontaneously, are not easily treated, and are rarely completely cured, chronic illnesses have a devastating impact on the ill-member's life. Moreover, they can be disruptive and financially draining for the ill members and their families - plummeting them into unexpected distress and strain. In the absence of chronic illness families already attend to a myriad of roles and responsibilities that contribute to individual and collective functioning. In the advent of a chronic illness these families experience new responsibilities and life-style interference that inevitably increases their role strain and stress (Wilkinson & Lynn, 2005). Chronic illness in adulthood is particularly disruptive. Ultimately, these adults must reorganize

their family, social, and professional lives around the demands of the illness. This is especially true for 'The Caregiver' – the person who assumes the most responsibility for the ill-member and provides the most unpaid informal care (McDaniel & Campbell, 1998). Caregivers experience depression, anger, guilt, disappointment, helplessness, & resentment. The stress of caregiving has been shown to be associated with a number of factors, such as caregiving demands, ill-member impairment, illness symptomology and behavior manifestations, illness duration, the intensity of care, the level of daily dependency of the ill member, caregiver competing demands, financial hardships, pre-existing conflictual familial relations, and the presence and utilization of caregiver supports (Wilkinson & Lynn, 2005). According to Beach, Schulz, Yee, and Jackson (2000) caregiver stress is further compounded by pre-existing stressors or stressful life events, such as being a victim of crime, death, job loss, or relationship troubles. For the caregiver the impact of the illness is physical, psychological, emotional, and social (Schulz & Sherwood, 2008; Veldhara, Shanks, Anderson, & Lightman, 2000) and their ability to cope informs their health and well-being.

Caregiving & Other Family Life Stressors

In the study of family stress theory, the family is viewed as an entity that exists and changes in response to normative and non-normative family transitions and hardships (e.g. stressors) (McCubbin & McCubbin, 1991). The ability of the family and its members to adapt to these changes and hardships is best understood by looking at the family's available resources, the family's competing demands, and the family's

coping processes, but the degree to which adaptation is possible is very much a function of the number and type of family stressors the family is faced with. Moreover understanding the impact of any one stressor can best be accomplished by disaggregating them one from another. Chronic illness caregiving is one of many possible stressors that can impact a family and its members. As previously mentioned, there are a number of events in the course of family life that are considered stressful including relationship disruptions, such as divorce, job loss, and compromised health of head of household members. Each of these secondary stressors has the capacity to influence family member roles, family member responsibilities, and produce lifestyle interferences. Moreover there is evidence, as noted below, that they also contribute to the family member's burdens and well-being. This is particularly the case in the study of family caregiving where divorce, unemployment and caregiver illness have been found to have an impact on caregiver's emotional health and well being, as is further discussed below. Thus for families in general and family caregivers specifically, the stress process can be multifaceted. The well-being of a caregiver is then a function of their response to both the primary stress of caregiving and other secondary normative family stressors. Given this, it becomes even more complex to understand the extent to which caregiving as an independent stressor, in the absence of other secondary family stressors, may compromise a family member's well-being. This is important because it sheds light on the extent to which the overload of caregiving, alone, is related to a family member's well-being. It perhaps could be the case that the stress of caregiving and other family stressors act conjointly on influencing family member well-being. Thus, the study

addresses whether or not caregiver well-being is only compromised with the additive function of other normative family stressors, such as divorce, unemployment, and receipt of care for a pre-existing chronic condition or disability.

Divorce

A well-researched family life transition stressor, divorce is recognized as a cause of negative well-being in family members. The act of divorce or marital separation signifies changes in parenting roles, family social roles, family economic base, resource allocations, individual self image, and family and individual family member routines (Amato, 2000; Sprecher et al, 2006). Family members who endure divorce often experience role overload and an increase in daily responsibilities. Their social networks are reshaped and in many cases this translates into reduced emotional support, increased family tension, and smaller or damaged social networks (Sprecher et al, 2006). Moreover divorce often translates into decreased personal income, which has direct implications for head of household members and caregivers, who are consequently left with less family resources from which to provide family care. This fractured state leads to emotional distress and compromised well-being.

Though it is evident that divorce has an immediate impact on the divorced individual, a number of researchers suggest that the overall negative impact on well-being is long-term because the person still has reduced resources, social networks, and increased role strain. Over the course of time, as the individual deals with the relationship loss they are apt to experience depression, reduced happiness, and poor

health outcomes. Johnson & Wu (2002) investigated the effects of divorce over a 12-year period to determine the immediate and long-term impact of divorce on psychiatric distress. Findings from their study revealed lower levels of happiness and increased psychiatric distress as long as 12 years post-divorce. Given these findings they argue that divorce is a chronic family stressor that has long-term negative effects which can only be ameliorated upon remarriage, repartnership, or new relationship formation (Johnson & Wu, 2002). Similar findings were reported by Waite, Luo, & Lewin (2009) who also found decreased psychological well-being among divorced individuals over a 5 year time span using longitudinal data from a national probability sample (e.g. The National Survey of Families and Household (NSFH)). Other studies using NSFH data replicated these findings and report not only an inverse relationship between marital status and depression, but also increase symptomology during the duration of the divorce (Kim & McHenry, 2002; Marks & Lambert, 1998; Simon, 2002). In fact, there is overwhelming evidence in the literature that divorced individuals are at higher risk for poor mental health outcomes, such as depression and anxiety (Cano & O-Leary, 2000; Christian-Herman, O-Leary, & Avery-Leaf, 2001; Kessler et al, 2008; Maciejewski, Prigerson, Mazure, 2001). In respect to health in general, trends are similar. Divorce and the transition out of marriage has been shown to be related to a wide array of health outcomes, such as health behaviors, perceived health, wellness, and health service use (Amato, 2000; Schoenborn, 2004; Waite, Luo, & Lewin, 2009; Wood, Goesling, & Avellar, 2007).

Unemployment

Unemployment is an external stressor that arises as a result of problems within the family member's social environment, namely his or her work environment. The loss of a job can have devastating effects on an individual and his or her family functioning. In families job loss obviously means reduced acquisition of additional financial and material resources within family which translates into less available resources for the family during the unemployment term. The reduction of resources is but one of many deleterious effects of job loss on the individual and the family. Unemployment compromises social identity, social contacts, and social status. Moreover, it has grave implications for individual psychological well-being, health and wellness (McKee-Ryan, Song, Wanberg, & Kinicki, 2005; Wanberg, Kammerer-Mueller, & Shi, 2001; Paul & Moser, 2009).

An abundance of studies report a relationship between employment and well-being. A meta-analysis exploring advances in research on the health and well-being of the unemployed, conducted by McKee-Ryan and colleagues (2005), present overwhelming evidence that unemployed persons have poorer well-being than employed persons. According to the results of their review, previous studies identified a number of factors, such as duration of employment, coping resources, social networks, cognitive appraisal, individual demographics, which are critical in shaping well-being outcomes. Similar results documenting negative mental health outcomes were found by Paul & Moser, 2009. Examining over three hundred studies on the relationship between unemployment and mental health outcomes, they found evidence that

unemployment is associated with psychiatric distress, psychiatric morbidity, self-esteem, subjective well-being, anxiety, and depression. In a number of studies outcomes appeared to be worse for men (Paul & Moser, 2009; Artazcoz, Benach, Burrell, & Cortes, 2004; Mossakowski, 2009) and for individuals who had lower socioeconomic status, previous financial difficulties prior to divorce, or blue-collar jobs (Paul & Moser, 2009; Thomas, Benzeval, & Stansfeld, 2007). The effect of unemployment on mental health is continuous and long-lasting, with symptoms of psychiatric distress and depression manifesting both at the point of transition into unemployment and throughout the duration of the job loss state (Thomas, Benzeval, & Stansfeld, 2007; Mossakowski, 2009).

The health effects of unemployment are multi-dimensional and not just limited to mental health. Physical health and chronic illness also show a causal relationship to employment. Employment is related to health care access, affordability, and mortality. Numerous studies report higher risk for chronic disease such as hypertension, heart disease, smoking, and alcohol use among unemployed persons (Bartley, 1994; Gallo, Bradley, Seigel, Kasl, 2000; Gallo et al., 2006; Mossakowski, 2008). Though it is not clear whether or not poorer health may result in increased likelihood to become unemployed or if the loss of a job might have an adverse effect on an individual's health, the evidence overwhelmingly suggests that unemployment is a family member stressor that has implications for individual and family well-being.

African American Caregivers

Though chronic illnesses affect all caregivers, there are variations in response based on socio-cultural and contextual factors (Knight et al., 2000, Navaie-Waliser et al, 2002; Crewe, 2005; Roth et al, 2008). Culture informs the caregiving experience. As best expressed by Dilworth-Anderson et al (2005) in their study examining the cultural justifications for caregiving, culture is a social resource for understanding caregiving. Though individual variations may exist among members of a racial-ethnic group, there exists general trends in family behavior that are influenced by culturally informed beliefs, shared social history, values, traditions, and norms. On the whole this is true for African Americans. Perhaps as a result of a history of limited resources, inability and/or difficulties in accessing formal services, and a mutual aid system that permeates the culture, the act of caregiving is a deep-seated part of the African American tradition. African Americans express stronger cultural reasons for providing care and these cultural justifications they attribute to caregiving are related to their well-being (Dilworth-Anderson et al 2005).

Existing evidence provides a profile of the typical African American caregiver. Even though this profile is limited in that it is primarily based on investigations of African American caregivers of older adults with chronic conditions, on comparative analyses comparing African American caregivers to other ethnic caregiver groups, and on convenience samples, it offers a basic demographic description of the typical African American caregiver. When the ill-member is an older adult, African American caregivers tend to be adult children, extended relatives, or close family friends (Hargrave, 2006; Scharlach, 2001; Williams, 2005), and less likely to be spouses (Janevic & Connell, 2001;

Williams, 2005). In comparison to White caregivers, in general they are more likely to be younger, unmarried, have less formal education, and fewer financial resources (Nkongho & Archbold, 1995; Knight et al., 2000; Hargrave, 2006; Janevic & Connell, 2001; Williams, 2005).

Though there is evidence that the responsibilities of caregiving do not vary by caregiver race or ethnicity (Rittman et al, 2006), there are racial and ethnic variations in the degree of care provided. In the Fredman, Daly, and Lazur (1995) study comparatively investigating burden in African American and White Caregivers, African Americans were found to provide a greater amount of informal care than their white counterparts. In a more extensive study looking at caregiving across multiple ethnic groups other than just White and African American caregivers' similar results were found. Other than Asian Americans, African Americans provided the highest level of caregiving (National Association for Caregiving, AARP, 1997). When care is provided, it is as likely provided to 'extended family members', who are often unrelated relatives (NAAS, 2000; Burton et al., 1995; Scharlach, 2001). Perhaps as a function of their cultural values about familial responsibility and family care as well as lack of ability to secure supportive services for their ill loved ones, care provided by African American caregivers tends to be very extensive. Comparative studies of ethnic caregivers reveal that even when controlling for the ill-member's disability, African American caregivers are more likely to provide high intensity care (Navaie-Waliser et al, 2002), provide help with instrumental activities of daily living (IADLs), such as shopping, household tasks, and meal preparation (Alliance for Caregiving & AARP, 2005), provide of care for longer

periods of time for more disabling conditions (Dilworth-Anderson, Williams, Gibson, 2002; Hargrave, 2006; McCann et al., 2000; Pinguart & Sorensen, 2005; Tennstedt & Chang, 1998; Fredman, Daly, & Lazur, 1995; Kosberg et al., 2007) and report more unmet needs in terms of support and services (Hargrave, 2006; McCann et al., 2000; Navaie-Waliser et al, 2002; Fredman, Daly & Lazur, 1995). Compared to Caucasians, they provide more direct care in the form of assistance with personal care activities and illness management. (Scharlach, 2001) and are less likely to seek the assistance of formal care services, like treatment homes and nursing facilities, to aid them in caring for their ill loved ones (Dilworth-Anderson, Williams, Gibson, 2002; Hargrave, 2006; McCann et al., 2000). Compounding their role is the fact that these caregivers are also usually actively caring for other people in the household, such as minor children and frail elderly (Hargrave, 2006; McCann et al., 2000). Despite this grim profile, African American caregivers demonstrate unique resiliency, coping, and acceptance with their caregiving role and are less likely to report difficulties in providing care (Navaie-Waliser et al, 2002). In fact, when compared to Caucasians, African American caregivers demonstrate lower levels of caregiving-related stress and burden (Connell & Gibson, 1997; White, Townsend, & Stephens, 2000). According to White & Gonzales (2000) this difference may be related to caregiving resources and social supports such as levels of religiosity, values, role expectations, and coping mechanisms.

Though this information is valuable in informing our understanding of who the African American caregiver is, it is important to keep in mind that it is limited in its scope. As previously mentioned, much of what is known is based on previous studies of

caregiving among older adult populations. Limited attention has been paid to the experience of African Americans who provide care to other adult chronically ill populations. Available knowledge that does exist on adult chronic illness caregiving among African Americans suggest that these caregivers tend to provide more instrumental care (Guarnaccia & Parra, 1996; Guarnaccia, 1998) report less financial obligation (Johnson, 2000), and have high rates of co-residence (Guarnaccia & Parra, 1996; Guarnaccia, 1998). An additional limitation of the available knowledge is that much of it is based on small convenience samples (Dilworth-Anderson, Williams, & Cooper, 1999; Navaie-Waliser et al, 2002) and thus is not generalizable to larger populations of African American caregivers. Limitations withstanding, it is important to note that even though there is evidence which suggests unique ethnic -specific characteristics of these caregivers, researchers suggest that within group variations may still exist (Dilworth-Anderson et al, 2005; McAdoo & Younge, 2009; Neville, Tynes, & Utsey, 2009).

Resources

Families rely on a number of resources to help them adapt to stressful life events. This is no different in the face of chronic illness caregiving. The stress brought on by the responsibilities of providing care for a loved one can be overwhelming. Inevitably caregivers must call upon, both material and social, resources to help adapt. The strain associated with caregiving has the capacity to shape the quantity, type, and utilization of adaptation resources. Conversely, resource quality and quantity informs the caregiving experience (Morano, 2003; Goode, Haley, Roth, & Ford, 1998). In

situations where the chronic condition is such that caregivers require additional formal supportive services for themselves or the ill member, material resources are likely to become more necessary. Equally, when material resources are available it allows caregivers to access needed formal services for themselves and their loved ones. Whilst trying to adapt to the ever-changing and sometimes stressful role demands of being a caregiver, individuals are apt to call upon psychological and social resources, such as extended networks and spirituality. The absence of said resources – material, social, psychological- can have harmful effects for the caregiver, such as reduced life satisfaction, increased burden, and increased psychological distress (Borg & Hallberg, 2006; Rozaria, Chadiha, Proctor, & Morrow-Howell, 2008). Thus, the presence of these resources is related to overall caregiver well-being (physical and psychological) and acts as a buffer shielding the caregiver from negative outcomes (Rozario, Chadiha, Proctor, & Morrow-Howell, 2008). Irrespective of the situation, the experience of the caregiver and their assessment of their situation have implications for resource utilization. More importantly, cultural factors such as social background, values, and preferences of the caregiver frame the resource options. Thus understanding caregiving through the lens of cultural context can be illuminating. This is particularly noteworthy in the study of African American caregivers, where it is widely believed that resources available to them are very much a function of their socio-cultural history (Williams, 2005; Dilworth-Anderson et al., 2005).

The African American economic profile reflects a historically disadvantaged economic and social position (LaVeist, 1993, 2002; Jargowsky, 1997). It is generally

accepted that middle class incomes are between \$25,000 and \$49,999 and according to the 2000 United States Census Bureau⁶, the median income for Black families is \$33,255. Analyzing income⁷, occupation, and education data from the 2000 United States Census (U.S. Census) and the U.S. Census Population Surveys (1998-2002), Attewell and colleagues (2004) looked at recent African American economic progress over the years. Based on their findings, they estimate that between 25-50%⁸ of African American (Black) households are middle class. Though this subgroup shows steady growth, there remains overwhelming support which also suggests that as a group African American families are more likely to live at or near significant levels of poverty (James et al, 2007; Isaacs, 2007; Brisco et al, 2010). They are more likely to live in impoverished and polarized communities characterized by high rates of unemployment, illiteracy, crime, homicide, and unwed births (LaVeist, 1993; Jargowsky, 1997; Williams & Collins, 2001; Stafford, 2001). Thus chronic poverty is an issue which greatly affects their ability to access material resources, like medical insurance and formal medical and mental health care (Kingston & Smith, 1997; Smedley, Stith & Nelson, 2002; DeNavas-Walt, Proctor, & Mills, 2004; DeNavas-Walt, Proctor, & Hill, 2006; Brisco et al, 2010). This is evidenced in the caregiving literature where there is evidence that African American caregivers underuse services (Hargrave, 2006; Collins, Hall, and Neuhaus, 1999; Smedley, Stith, & Nelson, 2002; Pinguart & Sorensen, 2005; Williams et al 2005). This is of particular concern,

⁶ United States Census Bureau does not have an official definition of middle class, but it does look at income distribution and inequality. (United States Census Bureau, 2010). Income Inequality: Narrative (Middle Class) , <http://www.census.gov/hhes/www/income/data/inequality/middleclass.html> Retrieved 10.19.2010.

⁷ In analyzing income, the following factors were considered: marriage partner patterns, # of earners in the household, education, and wage levels (Attewell et al, 2004).

⁸ The average varies depending upon which measured is looked at (earnings, educational trends, and occupational trends)

because research suggests a negative relationship between income and physical health (Pinquart & Sorensen, 2007).

Despite the grim economic profile, African Americans have access to and utilize a number of resources, in the form of social supports that have emerged as a result of a worldview that focuses on collective functioning, collective responsibility, interdependence, cooperation, and group survival. Though there are other helpful resources such as material and financial resources that aid these families, social supports are accessed more often. Social support resources include: a strong sense of family and familial obligation, flexible family structure, flexible role assignment and a propensity toward self-reliance and mutual aid (Dilworth-Anderson, Boswell, & Cohen, 2007; Pinquart & Sorensen, 2005; Hill, 1999; McAdoo, 1998). As noted below, there are multiple references in the caregiving literature explaining how these resources have been utilized.

Flexible family structure and role assignment are extremely important in African American families (Hill, 1999; McAdoo, 2009). "As a consequence of low rates of marriage and high rates of non-marital child-bearing, (African American) families are often configured differently from families of other racial/ethnic groups." (LaVeist, 2005, p. 44-45). Single parent households are prominent (Marsh et al, 2007). Equally, multiple members often reside with each other. This helps to distribute responsibilities and extends resources. These kinship networks are common (Hatchett & Jackson, 1993; Chatters, Taylor, Lincoln, & Schroepfer, 2002; Caldwell-Colbert et al., 2003; Hill, 1999; McAdoo, 2009). They are relationships comprised of not only multi-generational

conjugal and blood relatives, but also (consanguineal) non-relatives as well (Chatters & Jayakody, 1995). The relationships are “characterized by intimate involvement and a set of unwritten obligations” (Wilkinson, 1993, p. 38) that inform members’ sense of obligation to each other (Chatters, Taylor, Lincoln, & Schroepper, 2002). Coined the “kin help-exchange network” by sociologist, this network provides material, psychological, emotional, spiritual, and social support (Hatchett & Jackson, 1993; Chatters, Taylor, Lincoln, & Schroepper, 2002; Caldwell-Colbert et al., 2003). Consequently, caregiving is not only limited to the immediate family members but the extended network and responsibilities are shared. The support provided by this network of extended family is instrumental in helping individuals cope with their responsibilities as caregivers (Becker, Gates, Newsom, 2004) and helps maintain well-being (Chatters, Hardison, Riley, 2001). For caregivers of older adults with chronic cognitive disorders, they receive both tangible and psychological help from family members and the extended family network (Dilworth-Anderson, Williams, & Cooper, 1999; Yeo & Gallagher-Thompson, 1996). This holds true for other African American caregiver subgroups, such as caregivers of adults diagnosed with serious mental illnesses and disabling chronic conditions.

Elasticity of family boundaries is also a resource. Family boundaries stretch to accommodate the various conditions in which the family finds itself (Hill, 1999; McAdoo, 2009). Role expectations and definitions are flexible and are not clearly and rigidly defined (McGoldrick, 1993). Thus in the face of chronic illness where family roles fluctuate and caregiver demands increase because of role accumulation, coping becomes a bit more bearable within African American households. Family members

participate in shared responsibilities to provide care for the ill member, especially if they co-reside with each other. The primary caregiver may find it easier to negotiate the multiple roles in which he or she finds themselves, when there are others in the household with whom he or she can share these responsibilities. Extended kin residing in the household may translate into shared caregiving, with the caregiver believing that his or her role is more manageable and less burdensome. This has implications for caregiver adaptation.

Vulnerabilities

Caregiving occurs in the context of other ongoing roles which create stress. Equally, a number of social factors can complicate the caregivers experience and add undue strain. These factors increase caregivers' vulnerability to stress and morbidity. The added effect of their presence complicates the caregiving experience. A number of studies have examined the extent to which caregiver vulnerabilities (e.g competing demands) shape the caregiving experience (Chou, LaMontagne, & Hepworth, 1999; Rozario & DeRienzi, 2008; Ory, Yee, Tennstedt, & Schulz, 2000). In particular, special attention has been paid to two key areas: (1) the caregiver's employment role and (2) the presence of other caregiving roles, such as supplementary family care. Available literature focuses on how these factors contribute to caregiving stress and well-being outcomes.

Individuals who assume the role of caregiver for someone with a chronic illness do so with the understanding that this new role will extend their familial responsibility

within the family. The role of caregiver becomes an added responsibility that must be balanced against any existing roles that the individual already holds. Thus there are increased demands, burdens, and strains. The ability of the caregiver to adapt to the compilation of roles can impact well-being. The most prolific of these pre-existing roles is that of a labor force participant. Though caregivers, in comparison to non-caregivers, are less likely to be employed, there are an estimated 16 million working age adults caring for a sick or disabled family member (Ho, Collins, Davis and Doty, 2005). Equally, nearly one third (32%) of all primary family caregivers are in the labor force (Center on Aging Society, 1999). Bullock, Crawford & Tennstedt (2003) suggest that African American employed caregivers deserve particular attention. As a result of several economic and social factors – including the high rate of single-headed households; limited financial resources that exist within African American families; growing numbers of both disabled and older African American persons- African American caregivers are likely to be labor force participants. These working caregivers are more likely to miss days of work, seek adjustments to their work schedule, and lack insurance coverage (MetLife, 2006; National Alliance for Caregiving & AARP, 1997; Arksey, 2002; Ho, Collins, Davis and Doty, 2005; Center on Aging Society, 1999). Particularly when their jobs are demanding or lack flexibility, these caregivers experience increased strain and demands as a result of their dual-role (Scharlach, Sobel, & Roberts, 1991; Stephens et.al, 1991; Arksey, 2002). Full-time employment equates to time constraints which limit the amount of time an individual can devote to caregiving. This can inform the extent and quality of caregiver services (informal and formal).

Evidence suggests that caregivers who juggle multiple roles have increased stress and poorer health (Commonwealth Fund, 2003), negatively impacting their overall well-being. Additionally, they are more likely to use more hours of paid and unpaid assistance to help manage both work-related time and their caregiving duties (Velkoff & Lawson, 1998; Doty et al, 1998). Sometimes, caregiving even reduces employment, as family members are forced to make the decision to leave their jobs or work fewer hours because of job strain related to the dual-role (Chang & White-Means, 1995; Stone & Short, 1990; Bullock, Crawford, & Tennstedt, 2003). A unique perspective has been put forth by Borg & Hallberg (2006). In their study of self-identified frequent caregivers, less frequent caregivers, and non-caregivers, they found a positive relationship between gainful employment and life satisfaction for the caregiver subgroups. It is suggested that this relationship may be due to personal caregiver needs, caregiver feelings of pride and self-worth, caregiver financial needs, or caregiver needs for social contact. Distinct in that these findings do not conform to the majority of published studies investigating employment and caregiving, this study extends the simplified perception that employment is a caregiver competing demand.

Regardless of whether they are employed, many caregivers are still accountable for multiple roles. Numerous studies report that African caregivers of adults with chronic illness are also providing care for others in their family and household, particularly young children and frail elderly (Hargrave, 2006; McCann et al., 2000). Probably related to their sense of family obligation and familial responsibility, this dual role has an additive effect on the pre-existing strain the caregiver might be enduring.

Based on findings from their study on cultural justification for caregiving among African American and White caregivers, Dilworth-Anderson et al (2005) suggest that higher rates of caregiving within African American families exists because of culturally-based perceptions around family care and lack of resources.

Coping

Caregiving can be difficult, time-consuming and overwhelming. It has the capacity to negatively affect the caregiver and increase morbidity and mortality. However, these negative consequences can be mitigated with coping techniques (Goode, Haley, Roth, & Ford, 1998). Thus coping is an essential mediator for adaptation to chronic disease (Madhu & Sridhar, 2001), for both the afflicted and their caregivers. For the caregiver, coping involves (a) appraisal of the situation, (b) learning new skills to deal with the stressors, and (c) engaging in adaptive tasks which reduce the stress. Behavioral responses may include sharing the responsibility with others, utilizing formal or informal supportive services, turning to spiritual resources for encouragement, taking care of one's health (participation in preventative health behaviors), and/or relinquishing caregiving duties. No matter the behavioral response chosen, coping with the responsibilities of chronic illness caregiving is a normative process that involves engaging in activities or behaviors that decrease perceived levels of burden, stress, and risk of negative life outcomes. This process is fairly standard across all caregiving family types, but culture can decidedly shape the accessibility and acceptability of the caregivers coping mechanisms and social supports (Aranda & Knight, 1997).

Due to a history of discrimination, racism, and oppression African Americans have adopted unique cultural coping techniques based on folk beliefs, cultural traditions, and available resources. The survival, stability, and advancement of the family is attributed to a number of enduring strengths (Hill, 1998), particularly strong family affect, flexible family roles, shared responsibility, strong kinship bonds, and deep religious orientation (Hill, 1998; Freeman & Logan, 2004). Family boundaries stretch to accommodate the various conditions in which the family finds itself (Nobles, 1988). Role expectations and definitions are flexible and are not clearly and rigidly defined (McGoldrick, 1993; Hill, 1999; McAdoo, 2009) and informal helpers such as the clergy and extended family frequently accessed (Taylor & Chatters, 1991; Hill, 1999; McAdoo, 2009). What has emerged is an indigenous support system based on interdependence, shared goals, and a collective nature (Poole, 1990). The core of this system being "The Family,"-both biological and extended, with the church playing a critical role (Caldwell-Colbert et al., 2003). Within this framework, families have relied on themselves and close social networks to function and maintain the emotional well-being of its individual members in spite of the wider society (Snowden, 2001). They engage in mutual sharing of knowledge and attempt to solve their own problems by tapping into familiar indigenous social support systems (e.g. the church) and engaging in group problem solving within their extended family. In their study of African American caregivers, Lawton, Rajagopoul, Brody & Kleben (1992) found strong identification with cultural-specific values that encourage family care provision. These caregivers demonstrate a high degree of familial obligation and responsibility, which aids them in justifying their

roles as caregivers (Dilworth-Anderson et al., 2005; Lawton et al., 1992). Furthermore, they have great communalistic tendencies identified by high family involvement and community leader consultation (Guarnaccia & Parra, 1996; Guarnaccia, 1998). They often turn to five different sources for assistance: family, friends and neighbors, co-workers, professionals, with the majority of their assistance coming from family (O'Brien, Osby, & Johnson, 2005; McAdoo 2009; Hill, 1999; Lum, 2005). Their extended family and kin network are instrumental in coping, providing caregivers with referrals, tangible resources, and psychosocial support. Thus, for African Americans, the family is seen as a critical source of social support that aids in coping and healthcare promotion (UDHHS, 2001).

Irrespective of racial background, religion and spirituality are often a key means of coping for caregivers (National Alliance for Caregiving & AARP, 2004). In African American populations religious supports have been identified as an important resource for coping with the struggles of everyday life (Taylor, Chatters, & Jackson, 2007; Wood & Parham, 1990; Segal & Wykke, 1999). The church has a long history of providing support to African Americans and assumes a positive influential role in shaping African American family life (Braithwaite, Taylor & Austin, 2000; Johnson & Staples, 2005; O'Brien, Osby, & Johnson, 2005). Religious instruction and prayer are one of the most common coping resources for dealing with personal problems (Taylor & Chatters, 1991). In their comparison of religious behavior among African American and Caucasian caregivers, The National Alliance for Caregiving & AARP (2005) found that African Americans are more likely to report religious supports, in the form of prayer, as a way of

coping with the strains of caregiving. Involvement in activities that improve the health of African Americans is a natural extension of the church's service to African American families (Braithwaite, Taylor, & Austin, 2000). Religious variables, such as church attendance, spirituality, utilization of clergy support, and prayer are important sources of support for African American caregivers (Sun et al, 2009; Connell & Gibson, 1997; Chadiha & Fisher, 2003; Chadiha, Rafferty, & Pickard, 2003; Taylor, Chatters, Jackson, 2007). A number of studies have documented the relationship that exists between African American religious involvement and health (Wimberly, 2001). Religious involvement is positively related to receipt of support (Taylor, Chatters, Jackson, 2007; Sun et al, 2009), use of health care services (Levin, Chatters, & Taylor, 2005), self-rated health (Musick, 1996), and well-being (Ellison, Boardman, Williams & Jackson, 2001; Chadiha, Rafferty, & Pickard, 2003; Levin, Chatters, & Taylor, 2005) and is inversely related to depression and distress (Brown, Ndubuisi, & Gary, 1990; Ellison et al, 2001; Sun et al, 2009). Thus, religious orientation is a social and personal resource that provides both instrumental and emotional support for African American caregivers and aids them in stress adaptation.

It is important to note and recognize the possible harmful effect of religious coping. Though there is limited research in this area, existing social science inquiry does suggest that religious coping for personal problems can often cause family turmoil and stress. A number of studies investigating religious coping in response to chronic illness found harmful effects associated with coping (Alferi et al, 1999; Ben-Zur, Gilbar, & Levy, 2001). In fact, in their study investigating how religious coping informed treatment for

chronic disease, Koenig (2001) and colleagues found that certain types of religious coping caused delays in seeking treatment for medical conditions. In the case of family caregiving, religious beliefs and coping strategies can inform ideas about illness manifestation, treatment possibilities, prognosis, and even caregiving role expectations. If a family member believes that an illness is attributed to spiritual retribution as a punishment for engagement in negative behaviors they may not be as likely to feel compassion for and/or be willing to help them family member access necessary medical treatment or interventions. If the family member does not believe in certain treatment modules because of their religious beliefs, then this could impact the ill member choice of treatment options. The choice not to access available medical assistance might result in a higher need for family caregiving services. Moreover, a family's religious beliefs about family caregiving roles might contradict with their personal beliefs and/or willingness to engage in caregiving. For the purpose of this study, the role that religious coping has on caregiving outcomes will be tested. Whether or not coping is a positive or negative mediating attribute will be considered.

Well-Being – Global happiness, Depression, & Health

There is no question that the act of providing care for someone with a chronic illness can be difficult, time-consuming, and overwhelming, yet discrepancies exist in the literature which examines the degree to which caregiving is related to well-being outcomes for African Americans. Studies that have examined caregiving in general

without giving consideration to ethnic variations find that the act of caregiving is generally associated with negative well-being outcomes. In fact in their study looking at the challenges presented to the healthcare system by the emergence of informal caregiving, Donelan and colleagues (2002) found evidence suggesting that caregivers commonly report that the act of caregiving has negative effects on their health. These findings were confirmed by Pinquart & Sorensen (2003). Based on their comparative study looking comparing depressed mood and burden among caregiver and non-caregiver groups, Pinquart & Sorensen (2003) found that caregivers are more stressed and show higher depressive symptoms. Additionally, caregivers were found to have lower subjective well-being, physical health, and self-efficacy (Pinquart & Sorensen, 2003). Other studies show similar findings - negative mental health outcomes (Beach et al., 2000; Bookwala, 2009; Redinbaugh, MacCallum, & Kielcolt-Glaser, 1995), negative physical health outcomes (Pruchno & Potashnik, 1989; National Alliance for Caregiving & AARP, 1997; Schulz & Beach, 1999; Wilcox, Bopp, Wilson, Fulk, & Hand, 2000; Borg & Hallberg, 2006; Vitaliano, Zhan, & Scanlan, 2003), increased burden (Annerstedt, Elmstahl, Ingvad, & Samuelsson, 2000), and decreased life satisfaction (Borg & Hallberg, 2006). Outcomes such as burden and life satisfaction are related to critical attributes such as caregiver social and demographic characteristics, caregiver resources, caregiver social supports, caregiver stressors, caregiving intensity, competing caregiver demands, and ill-member social and demographic characteristics (Chou, 2000; Borg & Hallberg, 2006; Lim & Zebrack, 2004). Mental health indicators, such as depression, distress, and anxiety show similar relationships to caregiver resources, vulnerabilities, and coping.

In contrast to the fore-mentioned findings, there exists a growing body of literature, particularly for African American caregivers who report less negative well-being and health outcomes. Despite the probability that they experience increased vulnerabilities, they experience less stress, anxiety, and burden when compared to non-caregiver and other ethnic-caregiver groups (Aranda & Knight, 1997; Knight et al, 2000; Janevic & Connell, 2001; Haley et al 2004; Rittman et al., 2006; Fredman, Daly, & Lazur, 1995; Magana, 2004; Pinqart & Sorensen, 2005; Roth et al, 2008; Kosberg, et al., 2007). Likely as a result of their lower stress appraisal, there is evidence that African American caregivers are less likely to be depressed in response to their caregiving roles (Aranda & Knight, 1997; Janevic & Connell, 2001). A classic study by Lawton and colleagues (1992) compared African American and White caregivers of older adults with dementia and found that African Americans report greater caregiving satisfaction and benefits. In fact, a number of more contemporary studies replicate these findings, reporting intrinsic rewards, such as pride in fulfilling familial responsibilities, enhanced closeness with the ill-member, and satisfaction with one's competence (Beach et al, 2000; Roff et al 2004; Haley et al, 2004). Particularly this tendency towards higher levels of life satisfaction is likely to be related to their feelings of empathy towards their loved one, sense of filial responsibility, appraisal of the situation, and use of coping strategies (Lee et al, 2001). Dilworth Anderson and colleagues (2005) even suggest that the construct of 'cultural justification' is involved as African Americans are more likely to have culturally justified reasons for providing care.

The literature does show inconsistent findings. Despite the evidence suggesting a more positive appraisal of caregiving, a recent study by Drentea & Goldner (2006) examining the effect of race on depression found a high degree of depression among African American caregivers. Similar results were found in other studies where depression levels among African Americans or other negative caregiver well-being indicators were found to be comparable to other ethnic groups or significantly higher (Haley et al, 2004; Young & Kahana, 1995). The results of the White, Townsend & Stephens (2000) study were also atypical. In their study of White and Black caregivers of chronically impaired older adults they found lower rates of stress and higher reports of intrinsic rewards among African American caregivers, but significantly similar levels of depression symptomology. Though, a plausible explanation for these divergent findings is methodological issues, such as sampling and measurement variations across the studies (White et al., 2000; Pinquart & Sorensen, 2005; Drentea & Goldner, 2006), Knight and colleagues (2000) contend that other aspects of ethnicity may be involved. They suggest that ethnic specific structural status variables, such as coping styles, pre-existing life stressors, problem appraisal, and socio-demographic background differences between the caregiver and ill-member, complicate the process of stress and coping and affect the relationship between the variables in multi-dimensional ways, influencing study findings. No matter the findings, scholars agree that the deleterious effects of being a caregiver are probably most often moderated by caregiver resources and coping mechanisms. For African Americans family networks, sense of familial

responsibility, and religiosity are key agents in shielding them from negative caregiving outcomes (Drentea & Goldner, 2006; Roff et al, 2004; White et al, 2002).

In respect to other caregiver health outcomes, research findings are more equivalent across ethnic racial groups. In general, a number of studies show decreased physical health among caregivers (Shaw et al, 1997; Schulz & Beach, 1999; Borg & Hallberg, 2006; Vitaliano, Scanlan, & Zhang, 2003; Schulz & Sherwood, 2008) and higher incidence of chronic health conditions (Pruchno & Potashnik, 1989; Schulz & Beach, 1999; Vitaliano, Scanlan, & Zhang, 2003), when caregivers are compared to non-caregivers, race notwithstanding. When ethnic-specific or race variables are considered no differences are found. Similar to other caregiver groups, African Americans caregivers show poor health outcomes. When based on objective measures, no significant differences in actual health status are observed across groups (Roth, Haley, Owen, Clay, & Goode, 2001; Knight et al, 2007), but when subjective measures of health are considered, the findings vary. In these instances, African American caregivers actually fare far worse. Their perceived symptoms and global self-reported ratings of health are less favorable compared to other ethnic caregiving groups, specifically Caucasian caregivers (Knight et al.2007; Pinquart & Sorensen, 2003, 2005; Bookwala, 2009). This trend may be related to the disproportionate amount of care they provide and their underutilization of formal services for their loved one and themselves. Additionally, since African American families tend to have limited financial resources and lack medical insurance, (DeNavas-Walt, Proctor, & Mills, 2004; DeNavas-Walt,

Proctor, & Hill, 2006) their ability to access formal medical services, to ensure their health, is greatly reduced.

Summary

Understanding the experience of African American caregivers of individuals with chronic illnesses is a much needed addition to the scientific knowledge base. Minimal attention has been paid to understanding the response these caregivers have to their caregiving role, particularly which resources benefit, which vulnerabilities compromise, and which coping strategies aid their well-being. Given the disproportionate numbers of African Americans afflicted with chronic illnesses and trends that suggest disparities in their use of healthcare and family support services, informal family caregivers are an ever-increasing group within the African American community. Evidence, based primarily on cross-cultural comparisons and research on older adult populations, suggests that African American caregivers provide an inordinate amount of care for their loved ones, yet demonstrate a unique resiliency. In the face of common vulnerabilities, such as additional caregiving roles and competing demands, these caregivers turn to material and social resources to help them endure. Moreover, evidence suggests that culturally informed help-seeking strategies and coping techniques (e.g. seeking family and friends in times of need, turning to religious supports, etc.) are critical agents in shielding these family caregivers from negative caregiving outcomes. Thus a study investigating the experience of African American caregivers is clearly warranted. A study that explores the relationships between caregiver resources, vulnerabilities,

coping, depression, health, and global happiness, can enhance social scientist and health care practitioners' understanding of variables that affect the well-being of African American caregivers. Such a study would also facilitate the development of family health and support programs tailored to address the unique challenges of specific African American subgroups of caregivers.

Chapter Three: Theoretical Framework

In this chapter, the theoretical framework underlying the proposed study will be summarized. The contributions of The Resiliency Model of Family Stress, Adjustment, and Adaptation will be explored. As a dynamic model drawn from the person-environment theories of stress and coping, this model has a rich history illuminating familial adaptation to stressful conditions. It is perfectly structured to help explain caregiver response to chronic illness (Kramer, 1993) and is particularly useful in illuminating the African American caregiving experience (Drentea & Goldner, 2006; Dilworth-Anderson, Goodwin, & Williams, 2004; Haley et al., 1996; Rozaria & DiRienzi, 2008; Kim, Longmire & Knight, 2007). The first section of this chapter will generally describe the model and its utility for understanding chronic illness caregiving, with special attention given to African American applications. The subsequent section will identify explanatory variables that will be tested in the proposed study. Finally, the chapter will conclude by delineating model-specific considerations that apply to the proposed study.

Overview - Model of Family Stress, Adaptation, and Resiliency

Developed by McCubbin & McCubbin (1988) to guide research, prevention efforts, and interventions with ethnic minority families, the Model of Family Stress, Adaptation and Resiliency (hereunto referred to as the Resiliency Model) is a derivative of family stress and coping frameworks (Kramer, 1993; Pearlin & Schooler, 1978; Pearlin, Mullan, Semple, & Skaff 1990), particularly the Double ABCX Model of Adjustment and

Recovery. The model focuses on the family as a unit and considers coping and adaptation processes of the family system and its individual members. Thus, it emphasizes the family's ability to recover from stressful events and crises by drawing on patterns of functioning, strengths, capabilities, appraisal processes, coping, resources and problem-solving to facilitate adaptation (DeMarco et al, 2000, p. 297). It considers the influence of family stressors on psychosocial, emotional, and health outcomes, whilst emphasizing the role that the family's environment (or ecosystem) and perceptions play in maladjustment and adaptation to the crises. The family's environment is comprised of external demands and resources which are both constraints and opportunities that inform family adaptation and creative functioning (Bubolz & Sontag, 1993; Hatfield, 1987). The family's perception of the crisis and the personal meaning they ascribe to the situation informs how they adapt to the stressor in light of these environmental resources and constraints. This adaptation process is marked by several stages: (1) The onset of the initial stressor, (2) The period of adjustment – the initial response to the stressor, and (3) The post-crisis or adaptation – attempts to deal with the stressor. Key variables that impact these stages are existing day-to-day vulnerabilities the family is navigating (pile-up demands), normative family transitional factors, existing family resources, the personal meaning the family ascribes to the situation (stressor appraisal), and family coping behaviors (McCubbin & Patterson, 1983). A dynamic model, it considers interactions (inside the family – individual to individual; individual to family system) and transactions (outside the family – family to social environment) over time as the family and its members attempt to

maintain and/or adjust to their situation (McCubbin & McCubbin, 1993; Saunders, 2003). Thus it is not just a model exploring internal family system issues but rather it is a framework for understanding the contextual nature of the family resilience by recognizing the social environment in which the family exists (McCubbin & McCubbin, 2001). In the study of family caregiving this is particularly important.

Relevance to African American Caregiving & Chronic Illness

The Resiliency Model is “a useful framework to identify and fortify key processes that enable families to surmount crisis and persistent stresses” (Walsh, 1996, p.261); thus it is applicable to the study of caregivers of persons with chronic illness, given the high level of presumed stress these families cope with (Marsh, 1998b). In the face of chronic illness, these caregivers strive for restoration and harmony in family interpersonal relations, structure, functioning, development, well-being, and spirituality (McCubbin, Futrell, Thompson, & Thompson 1998). The caregiver’s awareness of their loved one’s illness and the meaning they ascribe to the illness defines the assumed caregiving role. Additionally, the meaning ascribed to the caregiving role also shapes the context of the caregiving experience. If caregiving is seen as a burden then the ability to adjust and adapt is compromised. Conversely, if caregiving is perceived as a rewarding activity, then adaptation is more likely to occur. Family resources, demands, and coping mechanisms ultimately shape caregiver adaptation. This theory highlights the multitude of contextual variables involved in chronic illness caregiving, all of which directly influences the caregivers’ well-being and capacity to provide ongoing care for their ill loved ones.

An additional benefit of this theory is its utility as a guide in specifying factors that are thought to promote resilience in families impacted by chronic illnesses (Enns, Reddon, & McDonald, 1999; Saunders, 2003). The construct of “resilience” is related to the concept of protective factors. Borne in psychology, it originally applied to our understanding of individual behavior (McCubbin et al, 1998). In this sense, “resilience” focused on the ability of a single individual to withstand chronic stress or recover from traumatic life events. Though it has been traditionally viewed as an attribute of individuals, the Resiliency Model broadens the concept of resiliency to explain relations within a family system (e.g. the family unit and its individual members). Additionally it looks at relationships across the family system between the family and its external environment. Through the lens of this theoretical model resiliency is defined as those characteristics, dimensions, and properties of the family which help them be resistant to disruption in the face of changes and help them adapt to crisis (McCubbin & McCubbin, 1988; McCubbin & McCubbin, 2001). Whether passively or actively employed, family resources and coping mechanisms restore family adaptation in the midst of crises and assume the role of resiliency factors. In her discussion of the application of this model to chronic mental health conditions and family caregiving, Marsh (1998a) proposes that most families tap into existing personal and interpersonal resources, identify coping strategies, and ultimately adapt to the stressful demands of the illness. She provides the best description of this framework.

“Family adaptation involves acceptance of the ... illness and its meaning for the family, accommodation to the altered family circumstances, acquisitions of pertinent knowledge and skills,

and resolution of the emotional burden....The model includes four components: family life events, family resources, family appraisal, and family adaptation.” (Marsh, 1998a)

This approach acknowledges the unique strengths of all families and recognizes their resilience and tenacity. It is particularly advantageous for understanding the experience of African American caregivers, who use existing resources, such as religion, extended kin networks, self-reliance, and flexible role assignment to help them cope with adversity (Hill, 2003). Their ability to cope with adversities is therefore directly related to their collective strengths and ethnic-specific patterns of functioning. This theory has proven to be a useful guide in a number of studies highlighting the resilient nature of the African American family (McAdoo, 1998; McCubbin et al, 1993; McCubbin, 1998; McCubbin et al, 1998a; McCubbin et al, 1998b) and in a number of studies exploring the African American caregiving experience (Drentea & Goldner, 2006; Dilworth-Anderson, Goodwin, & Williams, 2004; Haley et al., 1996; Rozaria & DiRienzi, 2008; Kim, Longmire & Knight, 2007).

Specifications of the Model

Model Concepts & Their Relationships

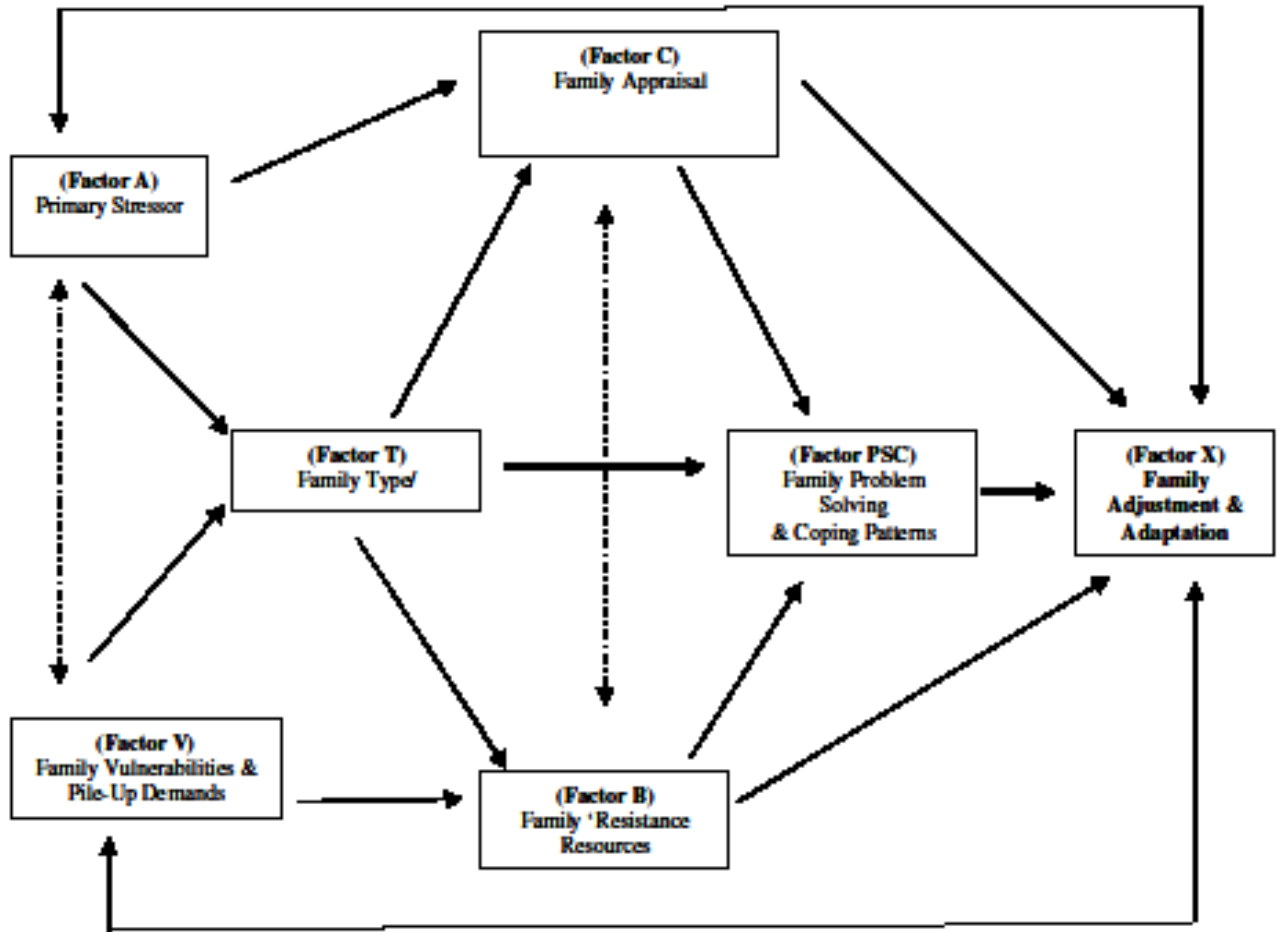
Rather than focusing on the objective and subjective dimensions of the family stressor and family pathology, this model identifies specific resources, vulnerabilities, patterns of coping, and stress appraisal, and competencies the family members can utilize in order to deal effectively with crisis. In the first stage, acknowledgement of the

initial stressor is critical and family member adjustment is the key outcome of interest. This component of the adjustment process is directly linked to the caregiver's appraisal of the situation, vulnerabilities to the stressor, residual problems with the stressor, role strain, and pile-up of competing demands, as shaped by their socio-demographic and psychosocial background characteristics and resources. The second stage involves the active process of adjustment. In this stage the family members use available resources and coping mechanisms to assist in functioning. Coping mechanisms that involve established patterns of functioning are key agents that inform resiliency and shape the adjustment process. For caregivers of persons with chronic illness this translates into their ability to adjust to their caregiving role, using problem solving strategies and available social supports. Ultimately this has an effect on adaptation. As the final stage of adjustment, adaptation involves a reaction to the stressing stimulus. For caregiving family members this reaction, whether conscious or subconscious, is directly linked to their cognitive, emotional, and physical well-being. In the best case scenario, caregivers acclimatize to their situation and demonstrate resiliency. Their coping patterns create protective factors and the outcome is bon-adjustment (McCubbin & McCubbin, 1988; McCubbin & McCubbin, 1991; McCubbin & McCubbin, 2001) or positive adaptation. In other cases, the stressors associated with the role become unbearable. When this occurs, problem solving is absent or futile; efforts at adjustment prove to be unsuccessful and the caregiver experiences maladjustment and has a maladaptive outcome (McCubbin & McCubbin, 1988; McCubbin & McCubbin, 1991; McCubbin &

McCubbin, 2001), which translates into negative health and well-being outcomes.

Figure 3 models the dynamic structure of this theory.

Figure 3: Resiliency Model of Family Stress, Adaptation, & Resiliency



This figure presents a generalized depiction of the model factors. According to the model, adjustment to the stress of caregiving results from the interaction of stressors (Factor A), with existing caregiver resources (Factor B), established patterns of caregiver functioning (Factor T) and caregiver appraisal of the situation (Factor C). Vulnerabilities and Pile-up demands (Factor V) are important because they can overwhelm the

caregiver’s resources (Factor B); they ultimately compromise adjustment (Factor X) and negatively impact perceived health, global happiness, and mental health.

Table 4: Model Abbreviations & Terms

Adjustment Phase	
Primary Stressors	(A)
Family Resistance Resources	(B)
Family Types and Established Patterns of Functioning	(T)
Appraisal of the Stressing Situation: Meaning & Schema	(C)
Family Vulnerability Due to Life Changes and Pileup Demands	(V)
Maladjustment Crisis Situation	(X)
Problem Solving and Coping Patterns	(PSC)
Bonadaptation	(*)

Regardless of the amount of resources (Factor B) which the caregivers have at their disposal, it is the extent to which they utilize these resources and engage in problem solving and coping (Factor PSC) that ultimately moderates the negative relationship that the stressor has on their health and global happiness. Using this model as a guide, it is possible to learn how caregiving, as an objective stressor adjusts functioning and shapes family member well-being.

Limitations of the Model

Before reviewing the specific applications of this model to the proposed study, it is important to discuss some of the broad limitations of this model in studying family processes. It is evident that the Resiliency Model is quite comprehensive in identifying critical factors that influence family adaptation. It covers a wide array of social, intrapersonal, and environmental constructs related to family functioning and suggests an interactive rather than a linear approach in explaining family adaptation to change

and stress. Though it is comprehensive and includes a large number of concepts, the extensiveness and complexity of the model make it quite difficult to test (DeMarco et al, 2000).

Another challenge posed by the model is its static time reference. Using this theoretical framework, it is only possible to look at family adaption at one point in time versus looking at adaption over the course of the life cycle unless longitudinal data is captured at different stages of the family life cycle or at different key time points (Perry, 2004). The success or lack thereof of family adaptation may change over time and may be related the family's stage in the life cycle. Perceived or real stressors, resources, and vulnerabilities may change over time and new coping patterns may also emerge.

Perry (2004) also describes an additional and one of the most important limitations posed by the model. Though the Resiliency model is guided by family systems perspectives it is really only designed to capture data based on individual response. Instead of considering family group interaction dynamics it only considers the characteristic of an individual. The family measures and coping resources are either inherently individual constructs or based on an individual's perspective of their family's life. Thus the unit of analysis is really the individual and not the family group and the individual's adaption is but a proxy for the adaptation of the entire family. The only way to avoid this limitation is to consider the additive adaptation processes of multiple family members. Thus, the Resiliency theory is not meant to directly inform understanding of family group behavior trends, instead it allows researchers to see how

individual family member functioning shape the larger family unit in which the individual respondent exists.

A final limitation of the model is related to its focus on family pathology. The family's strengths, coping, and adaption are all in relationship to the family's perceived stressors. Though it is based on a family strengths model, it only considers the family's strengths in relationship to their ability to competently function after exposure to significant risks or stressors. In essence the theory looks at how families utilize strengths to demonstrate resilience in face of stress. It does not consider everyday non-reactive family functioning in the absence of stressful conditions. This is a particularly salient issue in the study of caregiving among African Americans. In general the act of providing care to an ill member is perceived as a family stressor, but for African Americans this perception does not always hold true. It is evidenced in the literature African Americans often report intrinsic rewards as a result of familial caregiving. The act of providing care to family members is not necessarily seen as a stressor, but a filial role that results in personal satisfaction, enhanced closeness, and pride (Beach et al, 2000; Roff et al., 2004; Haley et al, 2004). In this way, adaptation to the caregiving role is less about stress and coping, but fulfillment of family responsibilities and enhancement in familial relationships. The Resiliency Model as proposed may not be the most suitable framework for mapping these caregiving gains. In the instance where the Resiliency Model is applied, intrinsic rewards in caregiving are considered ultimate adaptation.

Despite these limitations, the contextual nature of the Resiliency Model and its focus on family functioning variables make it a good candidate for testing the study constructs of interest. The model includes a multitude of both socio-cultural variables (stressors, schemas, resources, vulnerabilities, and coping patterns) that inform caregiving and considers the complex nature of how these constructs interrelate. Particularly, in the context of caregiving, the model has the capacity to consider circular transactions that occur between the caregiver, ill member, the family unit, and the larger environment in which the family exists.

Applications of Model to Proposed Study

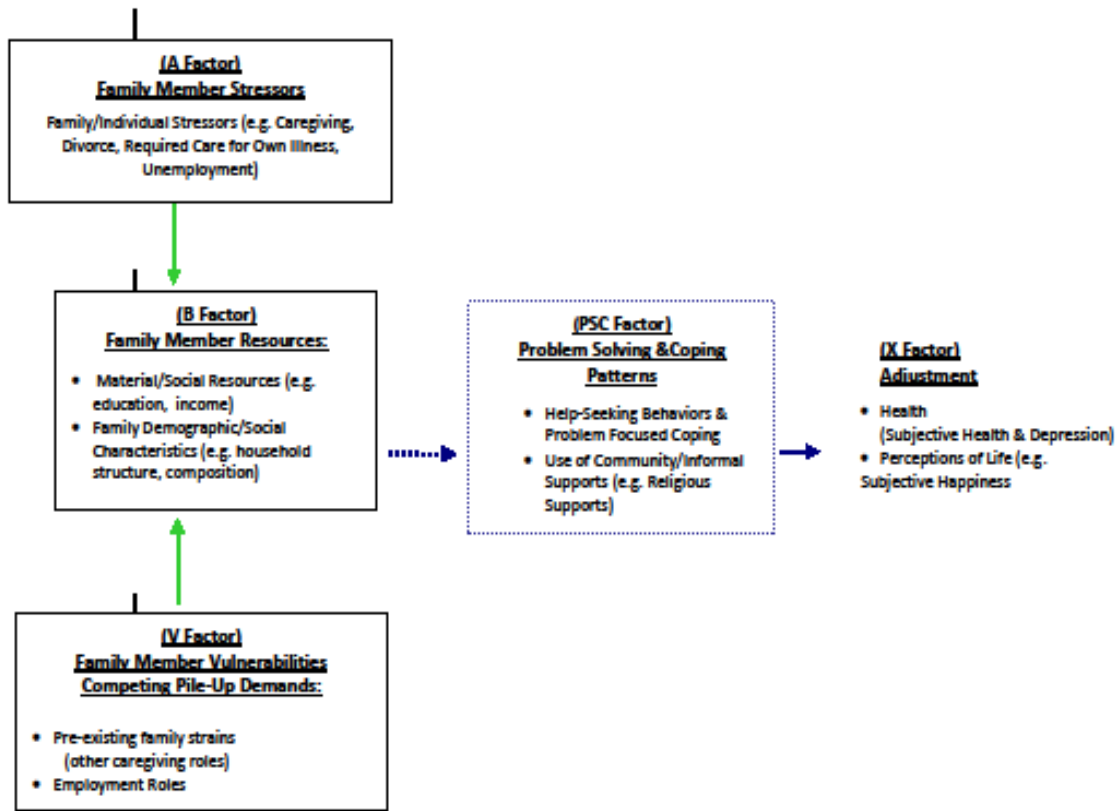
A complete test of the model in its entirety is beyond the scope of the available data, thus figure 4 depicts an abridged version of the theoretical model as it concerns the proposed study, given the research questions of interest. Specifically this study will address the relationship between the primary stressor (e.g. caregiving), resistance resources, competing demands, coping strategies, and adjustment factors, namely caregiver health and global happiness. It allows for the inclusion of positive cultural traits and coping mechanisms. Based on the model the assumptions are as follows:

1. Individual and family adjustment to chronic illness caregiving is influenced by the perceived stressors, resources, and coping strategies available to deal with the caregiving role;
2. Effective coping strategies have the potential to moderate negative responses and maladjustment;

3. Positive caregiver response and adjustment translates to well-being outcomes that are healthy and favorable.

On the surface this model is capable of incorporating the unique perspective of caregivers of persons with chronic illness, but the model assumptions need to be further explored with African American caregivers. Given the conflicting and limited research on African American caregivers, there is insufficient evidence to identify how the model assumptions best describe the experience of African American caregivers. The application of the model within the scope of this study will begin to address this gap in the knowledge base. In its totality, the model highlights cultural traditions, social context, schemas, resources and problem solving strategies and is quite complex and difficult to test (DeMarco et al, 2000). Using African American caregivers and families affected by chronic illness as the populations of interest this study will only test the relationships between a few of the constructs posed by the model (e.g. cultural traditions, resources, vulnerabilities, and problem solving). None-the-less applying the Resiliency Model to this study will enhance our understanding of the impact of chronic illness on African American families and caregivers. Moreover, it will shed light on the role that family deficiencies, such as imbalances in structure, lack of resources, and disorganization play on caregiver functioning. Consequently, applying this model to the proposed study will broaden our understanding of the African American family caregiving experience.

Figure 4: The Abridged Version of the Model Specific to Proposed Study



Model Constructs Tested in Study

In the proposed study, the stress of caregiving for African American family member caregivers will be investigated, with special attention paid to caregiver resistance resources, vulnerabilities, and coping patterns. Recognition will be paid to the presence of multiple stressors, specifically, normative and non-normative life stressors like unemployment, divorce, and receipt of care for a pre-existing chronic condition or disability, with the understanding that caregivers seldom experience the stress of caregiving within a vacuum. The extent to which these additive stressors

contribute to caregiver depression and perceptions of global health and happiness will be explored.

More in-depth analyses will look at the relationship between the model factors. With caregiving being the primary stressor of interest, the study will explore how family caregiver resources (Factor B) and vulnerabilities (Factor V) shape caregiver adjustment (Factor X). In the case of caring for someone with a chronic or disabling condition, the primary stressor (Factor A) is that which is brought on by the extent of care provision, as dictated by the ill-member's diagnosis, capacities, behaviors, and context of the condition. In the face of this stressor, the caregiver must utilize available resources (Factor B) to assist them in carrying out the responsibilities of their role (McCubbin, Thompson, & McCubbin, 1996). These resources are attributes or skills that the caregivers have at their disposal when adapting to the stress of caregiving. They are the psychological, social, interpersonal, and material characteristics of the family (McCubbin & Patterson, 1983). This includes demographic factors and material resources. It also includes their social context and social supports. Conversely, vulnerabilities and competing pile up demands (Factor V) compromise the caregiver's ability to adeptly respond to their role. In the case of caregivers of persons with chronic illness, these demands are any competing responsibility and strains that compromises their ability to provide comprehensive care. Pre-existing strains to be considered are financial strains and caregiver pre-existing personal illness strains. The strain of caregiving is also directly related to the ill-member's demographic profile, diagnosis, capacities, behavior, and relationship to the caregiver. Competing demands include other familial caregiving

roles and employment roles. The added responsibilities created by these additional role assignments limit the caregiver's capacity to provide care to the chronically ill member.

Finally, this study will investigate the role that coping and problem solving strategies (PSC Factor) have on caregiver adjustment and adaptation (X Factor). When caregivers are unable to cope with their role adequately using existing resources they turn to a number of adaptive coping skills to help them adjust. McCubbin and colleagues (1996) assert that coping strategies help family members maintain and restore balance between demands and resources, which decrease the intensity of family stressors, such as those created by chronic illness and long-term caregiving. According to the Resiliency Model, the family's coping and problem solving strategies regulate the depth of the relationship between the stressor and maladjustment (McCubbin & McCubbin, 1993). Utilization of problem solving strategies helps manage family member stress and are positively related to family adaptation (McCubbin & McCubbin, 1993). Consequently, the use of coping and problem solving strategies determines if and how caregivers cope. In the proposed study caregiver help-seeking behavior in times of crisis and church participation will be considered. According to the proposed model, existing family caregiver resources (Factor B) assist family members in dealing with caregiver stress (A Factor). Pile-up Demands (Factor V) are expected to amplify this stress and make coping much more difficult, but the use of coping and problem solving strategies (Factor PSC) have the capacity to buffer the effect of caregiving stress and moderate maladjustment (Factor X).

Specifying the Model to African American Caregivers

To understand the dynamics of how caregivers respond to stress within the family, it is important to take into account the social context of caregiver, which includes the cultural context of the family. Race, especially, has been shown to be related to caregiver perception, burden, and response (Picot, 1995). Cultural values such as familism, the extended family structure, indigenous social supports, and the frequent use of informal coping mechanisms can buffer caregiver stress (Lubkin & Payne, 1998). The Resiliency Model is perfectly structured to address this issue. Though applicable to all families, the Resiliency Model has been more widely used to describe the unique processes of ethnic minority families (McCubbin, Thompson, Thompson, Elver, & McCubbin, 1994). As one of the only theories that incorporates and highlights cultural traditions, social context, schemas, resources and problem solving strategies, this theory aptly enhances our understanding of African American family strengths, such as indigenous support systems, flexible role assignment, affectional ties, and self-reliance (McAdoo, 1998; McCubbin et al, 1998; McAdoo & Younge, 2009). In addition, it also sheds light on the role that family deficiencies, such as imbalances in structure, lack of resources, and disorganization play on family functioning.

One of the most salient issues that the model highlights is social context and available social supports, which is of particular importance when applying the model to African Americans. As previously mentioned in Chapter 2, African American families exist within a unique social context where family affect is strong, interdependence is the norm, and roles are flexible (Chatters et al 2002; Caldwell –Coldbert et al, 2003; McAdoo

& Younge, 2009). Consequently, other family members, the biological and extended, become a natural resource (B Factor). These individuals provide emotional, instrumental, and informational support (Taylor & Chatters, 1991). The extended family provides empathy; advice; physical, financial, and material assistance to caregivers. Thus, they are often called upon in times of distress (Factor PSC) and are critical in helping the caregiver function, which may reduce their stress and strain (Dilworth-Anderson, Williams, & Cooper, 1999). The extent to which African American extended family members contribute to adjustment is related to their presence and degree of involvement. Paradoxically, the extended family can also present challenges for African Americans. Their presence in the household may increase strains, particularly role and financial strain (Factor V). As a result, the proposed study will not only consider the household structure, but the presence of additional members in the household. Additionally, since research has shown that the extended family – including friends, co-workers, professionals, and lay leaders – is a critical resource for coping, the study will investigate the extent to which African American caregivers call upon these individuals and explore how this contributes to positive indicators of health and global happiness.

The role of religious resources is also important among African American families. There is evidence that African American caregivers call upon religious supports, such as clergy, prayer, church attendance, and meditation to help cope with everyday issues and difficult situations (Dilworth-Anderson, Williams, & Gibson, 2002; Picot et al, 1997). Faith and prayer act as a buffer to caregiving stress (Picot et al, 1997) and contribute to positive caregiver outcome, such as adaptive coping and adjustment.

Consequently, the availability and utilization of this resource is important to understanding African American caregiver stress. Because of the demonstrated significance of religion in African American caregiving and family coping, the moderating effects of church attendance and participation will be considered in the model.

Chapter Four: RESEARCH METHODOLOGY

Methods

Data Source

The study sample consists of respondents from the National Survey of Families and Households (NSFH). In particular it focuses on the subset of African American respondents to the survey. A longitudinal cross-sectional study, the NSFH has questions which cover a wide array of issues related to family life including household structural characteristics, household tasks, cohabitation, informal caregiving, economic profile, family relationships and social background, and family member subjective psychological and physical well-being. Its extensive coverage of household background and family member demographics and wellness allow for a more holistic analysis of family experience and life-history (Sweet, Bumpass, & Call, 1988).

Rationale for Choosing the NSFH

Comparison to Other Chronic Illness & Caregiving Surveys

Though similar to other surveys, such as the Behavioral Risk Factor Surveillance System (BRFSS) (1984-2008), Chronic Illness & Caregiving Study (Thamer, 2000), The Robert Wood Johnson Foundation & The Foundation of Accountability Survey (RWJF-FACCT) (2001), and The National Health Interview Survey (NHIS) (2005), which all look at varying aspects of family life, health, healthcare, and caregiving, the NSFH stands out as the best option to address the key research questions of interest. The NSFH holds several advantages such as its use of a large national probability sample, large number

of African American respondents, and its focus on family caregiving experiences. Table 5 and the following narrative show how the NSFH stands up against other comparative surveys and African American family life specific surveys.

Table 5: Characteristics of NSFH and other Family Life, Caregiving, and African American Specific Surveys

	Data Survey						
	NSFH	BRFSS	RWJ/ FACCT	Chronic Illness & Caregiving	NHIS	NSBA	Three Generation NSBAF
National Probability Sampling	✓		✓	✓	✓	✓	✓
Sufficiently Large N for Complex Multivariate Analyses	✓		✓	✓	✓	✓	✓
Adequate Number (N >100) of African American Respondents	✓				✓	✓	✓
Identifies Caregivers in Sample	✓	✓	✓	✓		✓	✓
Inclusion of Caregiver Experience Variables (e.g. coping, attitude, activities)	✓	✓	✓	✓			
Inclusion of Variables relating to Chronic Illnesses (incidence)	✓	✓	✓	✓	✓		

The BRFSS gathers information on health and health-related behaviors. It is administered annually by individual states (Remington et al 1988). The caregiving module is only administered within specially identified states⁹ that demonstrate interest and administrative capacity and thus the data source does not include a nationally representative sample of caregivers. Moreover, sample sizes in each of these states are

⁹ Use of the caregiving, and other modules of the BRFSS, is at the sole discretion of any individual state that demonstrates interest and administrative capacity. Thus, it is not administered annually in all 50 states and United States occupied areas. Over the past 10 years, the BRFSS caregiving module was only utilized in the years, 2009, 2002, 2001, and 2000. Over this time period a total of 30 states elected to use the module at one time or another.

small and generalizability is limited, which limit capacity for the research questions addressed in this study.

The RWJF-FACCT and Chronic Illness & Caregiving Study both employ national probability sampling and have larger sample sizes, but they are also limited. Their inclusion of African American respondents is inadequate to address the research questions addressed in this study. The numbers of African American caregiver respondents are 91 and 38 respectively, even after attempts at oversampling. Though the NHIS does include a substantial number of African American caregivers (over 300 in the 2005 survey) the survey does not include variables specific to the caregivers' perspective or consist of information on caregiver experiences, attitude, or coping – key constructs of interest for this study. Though, the NHIS is one the nation's largest annually compiled health care surveys and looks at broad health trends and aspects of family life, data on caregiving are limited. Caregiving questions in the NHIS mainly focus on the type of caregiving (e.g. paid or unpaid) persons with disability require (Doty & Marton, 2007).

Comparison to African American Family Life Surveys

There exist other recognized surveys, particularly the National Survey of Black Americans (NSBA) (Jackson & Gurin, 1979, 1987, 1988, 1992) and the Three Generation of National Survey of Black American Families (NSBAF) (Jackson & Tucker, 1997) that include sufficiently large numbers of African American respondents. As a result they circumvent concerns with sampling posed by the previously mentioned data sources. The NSBA and the Three Generation NSBAF address African American family life,

household structure, social life, coping, and well-being, but do not have comprehensive measures on family caregiving, chronic illness, or health care. Thus both of these data sources are unsuitable for addressing the research agenda posed by this study.

Rationale for Choosing Wave 1 of NSFH

Ultimately, the NSFH is the best data source for this research study. It is advantageous as it includes measures of chronic illness, multiple dimensions of caregiving, and family life. Moreover, it explores the issue of caregiving from the caregiver's perspective. Wave 1 of the NSFH (1987-1988) is used for analysis in this study. Though it is 20 years dated, and chronic illness care and caregiving has changed dramatically in the past 20 years, this wave includes the most complete and largest number of African American caregiver respondents (N= 369), which allows for greater within-group analyses. NSFH is a panel study and subjects were re-interviewed in multiple waves (Wave 2 – 1992/1994; Wave 3 – 2001/2002) following the initial wave in 1987-1988.

Though questions about informal caregiving are reintroduced in subsequent waves, wave 1, which has a larger N (N=13,017), is the preferred data for this study. The overall response rate for Wave 2 is considerably high (82%) and the number of African American respondents is sizeable (N =1721 compared to N = 2390 in Wave 1), but the number of African American respondents who identified as caregivers is much smaller (N = 268) in Wave 2. The same holds true for Wave 3 which has even fewer African American respondents (N=113). Table 7 provides a cross comparison of waves. Such

small sample sizes do not allow for adequate analysis, particularly structural modeling, used to explore the study’s research questions. Thus the baseline data (Wave 1), which has a larger N (N = 369) is the preferred data for this study.

Table 6: African American Caregiver Samples across NSFH Waves 1-3.

NSFH Panel Data			
*same subjects were interviewed at three different time points.			
	Wave 1 (1987-1988)	Wave 2 (1992-1994)	Wave 3 (2001-2002)
<i>Main Respondent</i> Total N	13017	10007	4600 ¹⁰
Response Rate (of original Wave 1 respondents)	---	81.7%	59%
African American Respondents	2390	1721	653
African Americans who met 'Caregiver Criteria'	369	268	113

Description of Sample

NSFH includes data collected from a nationally representative sample of individuals, age 19 and over, as well as a double sampling of minorities and households containing single-parent families, stepfamilies, recently married couples, and cohabiting couples. Individuals came from households that were randomly selected from households in the 48 contiguous states. Multi-state probability area sampling was employed. In order to correct for sample selection probabilities and non-response, data

¹⁰ The total number of respondents for Wave 3 was 7277, but this included both the primary respondents from previous waves and their spouses. The subset of just primary respondents was only 4600 individuals; the remainders were their spouses and were not computed in the analysis presented in the comparison table above.

were weighted using a weighting variable constructed by NSFH so that the sample would approximate the demographic distribution of the United States population (Sweet, Bumpass, & Call, 1988). 13,017 individuals comprised the total sample for an initial wave of data collected in 1987-88 (Sweet, Bumpass, & Call, 1988). In this initial wave 9,643 respondents were in the primary sample and 3,374 were in the oversampled group.

The NSFH offers some unique advantages because caregiver reports are made from the perspective of the primary caregiver. The reports of the caregivers included in the NSFH are made in relation to the person for whom they provide the most care, particularly if they provide care for more than one individual. As such, it provides an opportunity to explore the caregiving experience of family members who provide care for relatives and friends with chronic illness.

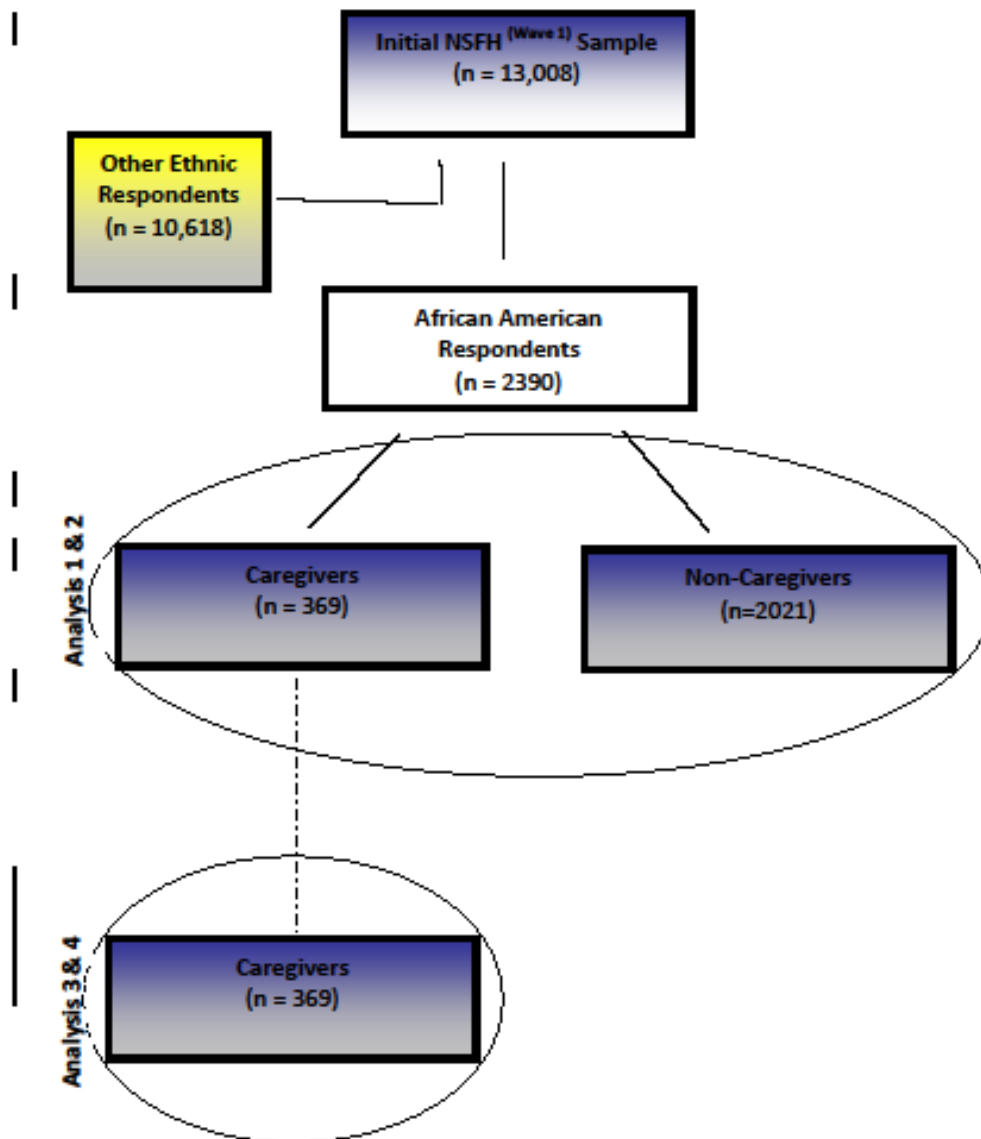
To address the gap in the caregiving knowledgebase and to shed much needed light on the unique caregiving experience of African Americans, only the sub-sample of African-American respondents are analyzed in this study. The total sample of African American respondents consists of 2390 household members¹¹. The primary (independent) variable of interest to this dissertation study is caregiving. Thus, respondents from the NSFH who responded to the criteria set forth by the following screeners are identified as caregivers:

- (a.) Does anyone living here require care or assistance because of a disability or chronic illness?*
- (b.) Sometimes people take care of relatives who are seriously ill and disabled who do not live with them. Have you provided such care at any time in the past 12 months?*

¹¹ The term "household member" will be abbreviated in the sampling flow chart and other related figures as "HHM" and the term 'household' will be abbreviated as "HH."

In following, the trend set forth by the other caregiving studies which used NSFH data, (Marks, 1996; Marks & Lambert, 1999), an affirmative response to either of these questions identifies the respondent as a caregiver. A “yes” response to either of these questions indicates the provision of instrumental help due to a functional impairment of the care recipient. Conversely, those respondents who responded “no” to both of these screener questions are identified as non-caregivers. Additionally, if the respondent indicates that he or she was in fact the person who was living in the household that required care and if he or she is the *only person* who requires that care in the household, then that individual is also excluded and considered a non-caregiver. Thus, respondents are only considered caregivers if someone in the household other than themselves requires care or if they provide care to someone else outside of the household. The number of African Americans who met the criteria for caregiving in the sample is 369 (15.44%). (See Sampling Flowchart, Figure 5). As further discussed in the Data Management and Analysis section below, the first stage of analysis which focuses on research questions 1 and 2 involves the larger sample of both caregivers and non-caregivers, and the last set of research questions (3 and 4) includes just the subset of caregivers in the sample.

Figure 5: Study Sampling Flowchart



Data Collection

NSFH data were obtained by both interviews and self-administered questionnaires. One adult per household was selected as the primary (main) respondent and this individual responded to a structured interview and self-administered questionnaire. In addition, the spouse or cohabitating partner was also asked to respond to a shorter self-administered questionnaire. The average length of an interview was about an hour and a half. For the purposes of this study, only the primary respondent data is analyzed. As only one adult in the household responded to the questions and is considered the primary respondent, it is important to note that all responses to family related measures are based on only this individual's (the primary respondent) personal perspective¹². Thus application of this dissertation using the Resiliency Theory focuses on an individual level analysis.

Study Measures

Demographic Variables

Demographic variables of interest include age, gender, and residential living status. Age was measured in years. Gender was measured by a designation of male or female. Co-residence was measured by caregiver reports indicating whether or not their ill-loved one stayed in the caregivers' household or not. Because studies have found all three of these variables to be associated with caregiver well-being (Pinquart & Sorensen, 2007) their inclusion might confound analytic results thus they are used as

¹² It is important to note that the NSFH also solicits information from the main respondent's spouse in a separate interview. Data from this supplementary interview is not included in this study. The NSFH does not solicit data from any other related or non-related family members.

controls in all multivariate analyses. A more detailed breakdown of variable coding, sub-construction, precise wording, and response alternatives are provided in Tables 7 – 12.

Table 7: Description of Family Member Caregiver Demographic Variables

Concept	Constructs	Empirical Indicators	Operational Definition (Precise Wording)	Measurement Level	Coding
Caregiver Demographics & Social Characteristics	Age	Age of respondent <i>(In years)</i>	What is the date of your birth?	Ratio/Continuous	Actual Year
	Gender	Gender of respondent	Sex of Respondent	Nominal	(0) Male (1) Female
	Residential Living Status of Caregiver & Ill Member	Co-Residence between Caregiver & Ill Member	<p><i>Caregiver & Ill Member Lived Together</i> "Yes" response to the following question – Does anyone living here require care or assistance because of a disability or chronic illness?</p> <p><i>Caregiver & Ill Member Do Not Live Together</i> "Yes" response to the following question – Sometimes people take care of relatives who are seriously ill and disabled who do not live with them. Have you provided such care anytime in the past 12 months?</p>	Nominal	(0) Caregiver & Ill Member do not Co-reside (1) Caregiver Co-Reside with Ill Member

Family Stressors

A number of family stressors are considered in this study, particularly in research question #2, where the stressors of caregiving, divorce, unemployment status and the receipt of care for a disabling condition are analyzed. Caregiving is a dichotomous variable and is measured by a positive or negative response to questions inquiring about care provision to a family member with chronic illness. Divorce is measured by a response to a marital status question. Response options were married, single, cohabiting, widowed, divorced. A self selected response of "divorce" indicated a respondent was divorced. Individuals who were divorcees from a first, second, or subsequent marriage and who were still not currently remarried at the time of questioning are considered "1-currently divorced." Conversely, individuals who had never divorced and who were currently married, single, cohabitating, or widowed are coded as "0-not currently divorced." Unemployment is measured by the question "Are you currently working for pay in any job?" in the employment module of the NSFH. Responses of yes are coded as "0- employed" and responses of no are coded as "1- not employed." The variable 'Receipt of care for a disabling condition' is measured by the question "Do you require care or assistance because of a disability or chronic illness?" Responses of yes are coded "1- receives care for a preexisting chronic condition or disability" and responses of no are coded "0- does not receive care for a preexisting chronic condition or disability."

Table 8: Description of Family Member Stressor Variables

Concept	Constructs	Empirical Indicators and/or Instrument	Operational Definition (Precise Wording)	Measurement Level	Coding
Stressors	Caregiving	Respondent lives with someone who requires care and assistant due to a chronic illness or disability and/or Respondent cares for someone with chronic illness or disability who does not live in household.	Respondent answered "yes" to any of the following conditions: Do you have a household member who requires care or assistance because of a disability or chronic illness During the past 12 months, did anyone (else) who lived here require care or assistance because of disability or chronic illness? Sometimes people take care of relatives who are seriously ill and disabled who do not live with them. Have you provided such care any anytime in the past 12 months?	Nominal	(0) No – did not meet criteria for any condition (1) Yes – did meet criteria for one of the 3 conditions
	Divorce	Divorce Status	"Divorce" response to the question- What is your marital status? <i>Married, Separated, Divorced or Never Married</i>	Nominal	Recoded into a 2-part dummy variable (0) Not divorced (1) Currently Divorced
	Receipt of Care for Pre-existing Chronic Condition or Disability	(Respondent) Presence of a medical condition	Do you require care or assistance because of a disability or chronic illness?	Nominal	(0) Does not receive care (1) Receives Care
	Unemployment	Respondent employment status	Now let's talk about your fulltime and part-time work experience. Are you currently working for pay in any job?	Nominal	(0) Yes, Currently Employed (1) No, Currently Unemployed

Family Resource Variables

Family resource variables include measures of caregiver demographic and social characteristics, specifically educational attainment, household income, and household structure. Educational attainment is a measure of high school and college completion. This variable is recoded as a 3-part dummy variable. Less than high school education is coded “0”, high school degree is coded “1” and some college or more is coded “2”. Household income, a variable constructed by NSFH, is a measure of the combined income of all household members and includes wages, salaries, self-employment, social security, pension, survivor benefits, public assistance, government benefits, child support, investment income and any other income as reported by the respondent. Household income is measured in dollars. Household structure is specifically measured by the variable ‘Household Type’. Household type is a NSFH constructed measure assessing whether or not the household is headed by a spouse/partner, single parent, extended family, or other non-household members. Responses of single-parent are coded “0-single parent” and other responses are coded “1-other”.

Table 9: Description of Family Member Resources

Concept	Constructs	Empirical Indicators	Operational Definition (Precise Wording)	Measurement Level	Coding
Family Member Resources	Material Resources	Education al Attainment	NSFH constructed variable (COMPLED) which indicates highest grade/education level completed <i>(Ranges from no formal education to doctorate degree)</i>	Nominal	Recoded as a 2-part dummy variable – 0) Less than high school 1) High school degree or more
		Household Income	NSFH constructed variable (IHTOT2) that considers the total income of all householders. Includes all types of earned and unearned income (including wages, salaries, self-employment, public assistants, government programs, child support, pension, interest, investments, social security, and other sources of income)	Ratio/Continuous	in Dollars
	Household Structure	Household Type - Single Headed Household	NSFH constructed variable (HHTYPE) that identifies spouse/partner, single parent, extended family, and other non-family households.	Nominal	Recoded as a 2-part dummy variable 0) Single (Parent) Headed 1) Other

Family Vulnerability Variables

Family Vulnerability variables include measures denoting other competing caregiving responsibilities. For the purposes of this study this is assessed by two measures: employment roles and other caregiving roles. Both of these measures have the capability to additively contribute to the caregiver's responsibilities. As previously mentioned, employment is measured by a yes or no response to the question "Are you currently working for pay in any job?" Having other caregiving roles is measured by two separate questions. The first question is "Who else do you provide care for?" If a respondent indicated they provided care for another person then the response is coded "0-yes" and if the respondent indicated they did not provide care for anyone else then the response is coded "1-no". The second question assessing other caregiving roles inquires about the presence of children in the household. Young children (under the age of 18) in the household translates into additional responsibilities and demands, thus their presence has the capacity to intensify pre-existing presumed caregiving strains. The measure is a NSFH constructed variable denoting the number of children under the age of 18 on the household roster. This constructed variable includes biological, adopted, foster, and other related and non-related children age 18 and under. If children are present then the item is coded "0-yes" and if there are not children under 18 in the household then the item is coded "1-no".

Table 10: Description of Family Member Vulnerabilities

Concept	Constructs	Empirical Indicators	Operational Definition (Precise Wording)	Measurement Level	Coding
Family Member Vulnerabilities	Competing Roles	Presence of Employment Role	Now let's talk about your fulltime and part-time work experience. Are you currently working for pay in any job?	Nominal	(0) Yes (1) No
		Other Caregiving Roles (for other family members/friends – adults/children)	Who else do you provide care for? If respondent states they provide care for another person in or out of the household, then they are presumed to have another caregiving role. .	Nominal	(0) Yes (1) No
	Other Competing Time Demands	Presence of children under age 18	NSFH constructed variables (K1, K3, K4, K5, K6A, K7A) which denote the presence of children under the age 18 on the household roster. Includes biological, adopted, foster, step, other related, and non-related children)	Nominal	(0) Yes (1) No

Family Coping Variables

It is expected that coping mediates caregiving well-being, thus two dimensions of coping are examined: Help-Seeking and Church participation. The first dimension, Help-seeking is measured by two single-item questions: “Who would you call in the middle of the night in an emergency?” and “Who would you ask for help if depressed or confused?” For each of these questions, respondents indicate, who, if anyone, they would rely on for help in times of distress. NSFH response options are (a) friends, neighbors, co-workers; (b) children over age 19; (c) parents; (d) siblings; (e) other relatives; (f) no one. Previous research using NSBA data exploring African American help-seeking patterns found trends indicating high use of informal resources in times of need. Results suggest key areas of help: family members, friends, neighbors, coworkers, and church members (Hatchett & Jackson, 1993; Taylor, Chatter, Hardison, Riley, 2001). Based on these results and following precedent research exploring help-seeking among African Americans, responses to help-seeking for this study are recoded as follows. Children, parents, siblings, and other relatives are recoded into a category called ‘Family Members’ and coded 1; Friends, neighbors, and co-workers are recoded into a category called ‘Non-Family Friends’ and coded 2. If the respondent indicated he or she received help from no one, then this response is coded 0.

The second dimension of coping is Church Attendance. NSFH uses a two-part question which explore attendance. It first asks respondents to state “How often they attend religious services” and then it asks them for the unit of time (in days, weeks, or months). Given the high variability of response possibilities, this two-part question was

reconstructed into a 4-part dummy variable item that measures weekly attendance (0 not at all, 1 =less than weekly, 2 = weekly attendance, 3 = more than weekly).

Table 11: Description of Family Member Coping Variables

Concept	Constructs	Empirical Indicators	Operational Definition (Precise Wording)	Measurement Level	Coding
Family Member Coping & Problem Solving Patterns	Help-Seeking Behaviors	<i>Crisis Management</i> How respondent responds in emergency	Suppose you had an emergency in the middle of the night and needed help, Who would you call?	Nominal	3-part dummy variable (0) No one (1) Family Member (2) Non Family Friends
		<i>Emotional Coping</i> How respondent responds to being overwhelmed	Suppose you had a problem and you were feeling depressed or confused, Who would you ask for help or advice?	Nominal	3-part dummy variable (0) No one (1) Family Member (2) Non- Family Friends
	Religious Coping	Church (Religious Service) Attendance	How often do you attend religious services? (Original measure reconstructed to assess yes/no did person ever attend religious services)	Nominal	2-part dummy variable (0) No (1) Yes

Family Member Well-Being Variables

In keeping with the 2-factor model of family stress by Lawton et al (1997) this study examined caregiver well-being in terms of positive (global happiness and health) and negative (depression) indicators. Consequently, three measures of well-being are used – depressed affect, health and global happiness. These outcome variables are considered distinct dimensions of psychological well-being (Ryff & Keys, 1995).

Depression is a common indicator of well-being and has been explored in many caregiver studies (MacCallum & Kielcolt-Glaser, 1995; Young & Kahana, 1995; Beach et al, 2000; White, Townsend, & Stephens, 2000; Pinquart & Sorensen, 2003; Haley et al., 2004; Drentea & Goldner, 2006; Bookwala, 2009). The depression measure is from Radloff's (1977) depression scale. It is a modified version of the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). The original 20-item scale developed for use with large scale community based studies has been shown to have good concurrent validity, acceptable test-retest reliability, and good internal consistency (Radloff, 1977; Devins & Orme, 1985). The original 20-item self-report measure was modified to include only 12 items which explore key negative affect and somatic indicators that have occurred with the respondent in the past week, namely feelings of general depression, sadness, loneliness; appetite changes, behavior changes, and sleep disruptions (Kessler, Foster, Webster, & House, 1992). The 12-items are described in Appendix 2. Respondents reported the number of days in the past week (7 days) that each symptom occurred.

This 12-item version of the original 20-item CES-D scale has been used extensively in epidemiological research. The 12-item scale is a product of factor analytic work conducted by Mirowsky & Ross (1992) and has a .88 correlation with the full CES-D (Fuller-Thomson, 1995). For the shorter version, when the number of days is used as the measurement indicator, the index ranges from 0 through 7, with “0” indicating that a person experienced no days of the week with that depressive symptom and “7” indicating daily experiences. Thus the summed scores (across the 12-items) range from 0 to 84, with higher values representing greater depressive symptomology. The summed response is calculated and entered into the models as predictors of depression. Scores that are at the highest 20th percentile or lower are deemed more predictive of clinical depression (Ensel, 1986). Thus a score of 17 through 84 indicates clinical depression. This criterion is used for this study. All cases are included for the purposes of this analysis.

The NSFH used one-item self-reported, subjective measures to assess satisfaction with one’s life and health. Satisfaction with one’s life is assessed by a standard assessment of the respondent’s global happiness by asking the question: “Taking things all together, how would you say things are these days?” where 1 denotes “very unhappy,” 7 denotes “very happy,” and intermediate values are not defined. This global measure is taken from the Global Positive Affect Measure from the Quality of Life Survey (Staines, 1973), developed by the Institute for Social Research at Michigan.

Similarly, global self-assessed health is measured by a single-item question: “Compared with other people your age, how would you describe your health? (1-Very

Poor, 2-Poor, 3-Fair, 4-Good, 5-Excellent). This item is also taken from the Quality of Life Survey (Staines, 1973), particularly the section dedicated to health and integrated into the NSFH. Though only one item, previous research by Idler & Benjamini (1997) finds this measure to be a strong predictor of mortality across a variety of adult populations. Additionally, this measure has also been shown to be correlated with more objective health indicators (Ferraro and Farmer 1999).

Table 12: Description of Family Member Health & Life Satisfaction Variables

Concept	Constructs	Empirical Indicators	Operational Definition (Precise Wording)	Measurement Level	Coding
Family Member Adaptation Health & Life Satisfaction Outcomes	Subjective Health	1-item Standard Measure of Respondent Perceived Health Status	Compared with other people your age, how would you describe your health?	Ordinal	(1) Very Poor (2) Poor (3) Fair (4) Good (5) Excellent
	Depression Level	Radloff's CES-D 12-Item Depression Index	On how many days during the past week did you: Feel bothered by things that usually don't bother you?; Not feel like eating; your appetite was poor?; Feel that you could not shake off the blues, even with help from your family or friends?; Have trouble keeping your mind on what you were doing?; Feel depressed?; Feel that everything you did was an effort?; Feel fearful?; Sleep restlessly?; Talk less than usual?; Feel lonely?; Feel sad?; Feel you could not get going?	Ratio/Continuous	Number of days (0-7) Depression Index is the sum of the answers to these questions
	Subjective Happiness	1-item standard measure of Positive Affect and Global Happiness	Next are some questions about how you see yourself and your life. Taking things all together, how would you say things are these days?"	Ordinal	Scale Response Range (1-7) (1) very happy to (7) very unhappy * Values in between do not have explicit labels.

Data Management

Analysis Software

Data were analyzed using SPSS 15.0 and Muthén's M-Plus 4.2 software.

Statistical significance for all analyses was defined as a two tailed p level of .05 or under ($p < .05$). Since M-Plus does not support data manipulation and coding, data was initially cleaned and coded with SPSS prior to entry into the correlation and regression analyses. Fit was evaluated using Comparative Fit Index (CFI), the chi-square values, the root mean square residual (RMSR), and the root mean square error of approximation (RMSEA). M-Plus (Muthén & Muthén, 1998) was chosen because of its ability to both handle missing data¹³ and conduct multivariate analyses with complex sampling structure and probability weights. In regards to missing data, M-Plus uses full information maximum likelihood (FIML) estimation. This assumes that observed data, rather than data that are missing (e.g. missing at random and missing completely at random¹⁴), better informs the probability of data being missing. Cases with full and partial information are consequently included in the analyses. Thus, direct estimation information is borrowed from cases where information is available. For more complex analytic techniques such as path analysis and structural equation modeling, FIML has been shown to provide better model fit and parameter estimates (Enders, 2001; Schlomer, Baumer & Card, 2010).

¹³ The amount of missing for most variables was moderate (less than 15%). The exception was Household Income. For this variable 32 percent of the data was missing.

¹⁴ In the case where data is missing at random (MAR) the probability of the data being missing depends on the available data. Contrary to this is the case where the probability of missing data is constant across all cases, in which case data is considered missing completely at random (MCAR).

Descriptive statistics on factors that test the Family Resiliency Model, particularly, individual demographic & social characteristics, family member stressors, family member resources, family member vulnerabilities, family coping patterns, and family well-being factors of African American caregiver and non-caregiver subsamples were computed using the SPSS software. This descriptive data is based on weighted responses¹⁵. A descriptive table of all study variables by caregiver type is presented.

¹⁵ Reported sample sizes and frequency counts are unweighted.

Table 13: Frequency Distribution of Study Variables¹⁶

Study Variables		All (N=2390)		Caregivers (N = 369)		Non-Caregivers (N = 2021)	
		Weighted	Actual Unweighted N (response rate ratio)	Weighted	Actual Unweighted N (response rate ratio)	Weighted	Actual Unweighted N (response rate ratio)
Demographic & Social Characteristics	Age, M (SD)	40.4 (16.3)	41.8 (16.3)	41.6 (16.2)	41.7 (16.1)	40.3 (16.6)	41.8 (16.6)
	Female, n (%)	53.3	63.6(+ 1520/2390)	63.9	71.3(+ 264/369)	53.9	62.1(+ 1254/2021)
Stressors	Divorced, n (%)	10.1	13.6(+ 325/2390)	11.9	14.1(+ 52/369)	9.7	13.3(+ 273/2021)
	Respondent requires Care for own illness	6.4	6.2(+ 148/2390)	3.4	0.7(+ 16/369)	6.3	3.6(+ 133/2021)
	Employment Status, n (% no)	38.0	40.3(+ 963/2390)	42.1	44.0(+ 162/369)	37.2	39.9(+ 801/2021)
Resources	Less than HS, n (%)	32.9	32.9(+ 782/2390)	30.3	29.8(+ 110/369)	33.4	29.4(+ 592/2021)
	HS, n (%)	36.2	36.8(+ 875/2390)	34.4	34.4(+ 127/369)	36.6	37.2(+ 748/2021)
	> HS, n (%)	30.3	30.3(+ 722/2390)	33.3	33.8(+ 132/369)	29.3	33.4(+ 673/2021)
	Household Income, M (SD)	\$22, 576.80 (34,209.35)	\$22,563.11 (27,136.15)	\$21,544.63 (21,985.56)	\$19,763.12 (21,317.48)	\$22,990.79 (15,906.51)	\$20,200.30 (28,012.51)
Vulnerabilities	Single-Headed HH, n (%)	15.8	22.1(+ 527/2390)	14.8	22.0(+ 81/369)	16.0	22.1(+ 444/2021)
	Employment Status, n (% yes)	61.4	59.1(+ 1412/2390)	57.3	56.0(+ 206/369)	62.2	60.1(+ 1206/2021)
	Children under 18 in HH, n (% yes)	46.3	30.8(+ 1213/2390)	43.4	49.6(+ 183/369)	46.3	49.2(+ 994/2021)
Coping/Social Support	Never Attend Religious Services, n (%)	16.0	13.6(+ 374/2390)	13.0	14.4(+ 53/369)	16.8	13.9(+ 321/2021)
	Attend Less than Weekly	47.3	46.8(+ 1118/2390)	47.4	43.8(+ 169/369)	47.3	47.0(+ 943/2021)
	Attend Weekly	24.3	24.3(+ 585/2390)	21.3	22.8(+ 84/369)	24.8	24.48(+ 501/2021)
	Attend More than Weekly	12.3	13.1(+ 313/2390)	16.2	17.1(+ 63/369)	11.3	12.4(+ 252/2021)
	Call in Emergency, n (% yes)						
	Family Members	59.4	59.6(+ 1424/2390)	59.4	58.8(+ 217/369)	59.4	59.7(+ 1207/2021)
	Non Family/Friends	23.4	23.4(+ 606/2390)	22.8	24.7(+ 91/369)	23.9	23.3(+ 513/2021)
	No one	3.3	4.0(+ 95/2390)	3.3	4.1(+ 15/369)	3.6	4.0(+ 80/2021)
Call when depressed, n (% yes)							
Family Members	50.2	50.0(+ 1195/2390)	48.2	48.2(+ 178/369)	50.6	50.3(+ 80/2021)	
Non Family/Friends	30.3	29.8(+ 713/2390)	28.3	29.3(+ 109/369)	30.9	30.0(+ 80/2021)	
No one	8.4	9.1(+ 218/2390)	8.9	9.3(+ 35/369)	8.3	9.1(+ 80/2021)	
Health & Global Happiness Outcomes	Depression Index, M (SD)	18.33(18.42)	18.42(18.98)	20.72 (20.26)	21.39(20.17)	17.87 (18.83)	17.83 (18.60)
	Self Report Health, n (%)						
	Excellent	24.9	23.1(+ 552/2390)	19.1	21.6(+ 73/369)	26.1	23.3(+ 479/2021)
	Good	44.0	44.4(+ 1061/2390)	49.6	52.8(+ 179/369)	42.9	46.7(+ 882/2021)
	Fair	18.1	19.7(+ 471/2390)	16.1	19.8(+ 67/369)	18.4	21.4(+ 404/2021)
	Poor	3.9	3.7(+ 88/2390)	3.4	3.2(+ 11/369)	4.0	4.1(+ 77/2021)
	Very Poor	2.1	2.4(+ 57/2390)	2.1	2.7(+ 9/369)	2.1	2.3(+ 48/2021)
	Global Happiness Scale, n (%)						
	Very Happy (7)	20.9	21.3(+ 514/2390)	13.6	21.1(+ 61/369)	21.9	23.9(+ 453/2021)
	(6)	17.8	18.2(+ 436/2390)	19.4	22.8(+ 66/369)	17.3	21.2(+ 370/2021)
(5)	21.8	20.3(+ 490/2390)	21.9	24.6(+ 71/369)	21.7	24.0(+ 419/2021)	
(4)	16.2	16.6(+ 396/2390)	14.4	20.1(+ 58/369)	16.6	19.3(+ 338/2021)	
(3)	4.1	4.4(+ 106/2390)	4.9	6.2(+ 18/369)	3.9	3.0(+ 88/2021)	
(2)	1.7	1.8(+ 43/2390)	1.1	1.7(+ 5/369)	1.8	2.2(+ 38/2021)	
Very Unhappy (1)	1.9	2.2(+ 52/2390)	2.0	3.3(+ 10/369)	1.8	2.4(+ 42/2021)	

¹⁶ The variable “Employment Status” is reflected twice in the table. This variable takes on a dual role according to the tested model. The lack of employment is considered a family stressor and conversely active employment is considered vulnerability.

Weighting

As previously mentioned in the Data Source section, NSFH data is weighted. The case weight is inversely proportional to an individual's likelihood of being selected into the sample. NSFH computes the case weight by taking the product of the basic sampling weight, a screening non-response adjustment, an interview non-response adjustment, and a post-stratification adjustment¹⁷. Individual weighted responses were used for bivariate and multivariate analyses. This corrected for oversampling, ensured that the results represent national population rates, and correctly estimated the model. As aforementioned, SPSS is not as apt at dealing with complex sampling structure and sampling weights. M-Plus (Muthén & Muthén, 1998), on the other hand, is much more capable of dealing with the issue of sample weights and thus was preferred for all multivariate analyses.

Data Preparation

Assessing Variable Distributions

In regards to the continuous measures of age and income, it is important to note that tests for univariate normality revealed deviations from normality. Age and Household Income are both skewed (*Skewness = .77 and 8.13, respectively*). Shapiro-Wilk's test statistics for both age (*S.W. = .927, $p < .001$*) and household income (*S.W. = .538, $p < .001$*) confirmed that these univariates are not normally distributed. Given that

¹⁷ More detailed explanation of NSFH weighting can be found in NSFH Codebook, Appendix L.

age was not highly skewed it was not transformed for analyses. On the other hand, the household income variable was highly skewed, so it was log transformed which resulted in less skewness and a more normally distributed univariate curve (*Skewness* = $\bar{1}.39$).

Data on all outcome variables (e.g. depression index, self-report health, and global happiness) were also examined to determine if they met multivariate test assumptions for normality, linearity, and homoscedasticity. Histograms, skewness and kurtosis tests, and Shapiro-Wilk's Tests for normality revealed that the dependent variables of interest are not normally distributed. The depression index variable is highly skewed (*Skewness* = 1.31 ; *S.W.* = $.836$, $p < .001$) and the self-report health and global happiness variables are moderately negatively skewed (*Skewness* = $\bar{.868}$, *S.W.* = $.843$, $p < .001$ and *Skewness* = $\bar{.709}$, *S.W.* = $.898$, $p < .001$, respectively). Table 15 details these findings. Due to the moderate level of skewness of both self report health and global happiness, these variables were not altered and the actual values were used in all multivariate analyses. Conversely, the depression variable was highly skewed so it was log transformed. The log transformation of these variables resulted in more normal distribution. Consequently, the original values on the depression variables were replaced with the log transformed values for all subsequent multivariate analyses. Linearity was assessed by investigating whether or not linear combinations of the dependent variables were correlated and normally distributed. Multivariate normal distribution was assessed with bivariate scatterplots and correlation tests. As seen in Intercorrelation Table presented in Appendix 2 there was strong correlation between the dependent variables at a significant level less than .001.

Caregiver Outcomes Variables of Interest	Outcome	Initial Values				Log Transformed Values			
		M(SD)	Skew	Standard Error of Skewness	Shapiro-Wilk's Statistic	M(SD)	Skew	Standard Error of Skewness	Shapiro-Wilk's Statistic
	Depression Index	17.28 (18.42)	1.31	.050	.836, $p < .001$	4.07 (.57)	-.461	.054	.910, $p = .000$
	Self-Report Health	3.89 (.915) ^a	-.868	.052	.843, $p < .001$	-	-	-	-
	Global Happiness	5.27 (1.45) ^a	-.709	.054	.898, $p < .001$	-	-	-	-

Table 14: Tests for Normality of Outcome Variables

^a Values not log-transformed because of low or moderate skewness.

Testing Bivariate Correlations

As previously mentioned, prior to conducting the multiple regressions, multivariate assumptions of normality were investigated. In particular, for the purposes of testing regression equations bivariate correlations were performed on the stressor, resource, vulnerability, and coping variables to assess for a high degree of collinearity between the proposed predictors. A correlation matrix can be found in Appendix 2. Examination of the correlation matrix revealed that none of the independent variables were highly correlated ($r > .50$) thus multicollinearity is not an issue. In respect to the stressor variables of interest (e.g. divorce, unemployment, and caregiving) a very small, but significant correlation was only observed between divorce status and unemployment ($r = -.075, p < .001$). An association was then confirmed between the stressor variables unemployment and caregiving and well-being indicators (e.g.

depression, health, and global happiness). Unemployment was positively correlated with depression level ($r = .114, p < .001$) and negatively correlated with self-reported health ($r = -.255, p < .001$). Caregiving was associated with the depression indicator ($r = .045, p < .01$) and gender ($r = .075, p < .01$). Thus caregivers were more likely to be women and report more depression symptoms. The variable caregiving status did not significantly correlate with any other family stressors, resources, vulnerabilities, or well-being indicators.

In regards to the key study concepts of interests (e.g. family stressors, resources, vulnerabilities, and coping strategies) a number of associations also exists. All resource variables (education, household type, and household income) were related to employment status and the presence of young children in the household. There were no significant correlations between resource variables and coping strategies. A relationship was observed between one of the vulnerability variables of interest (caregiving for more than one individual) and religious attendance ($r = .107, p < .001$). Caring for more than one ill family member was associated with lower levels of religious attendance. Religious attendance was the only coping variable associated with well-being outcomes. It was marginally associated with depression and global happiness. There was a negative relationship between depression level and religious attendance ($r = -.072, p < .001$) and a positive correlation between global happiness and religious attendance ($r = .105, p < .01$).

A more in-depth look at the relationship between caregiving demographic variables and resource and vulnerability variables of interest revealed more interesting

findings. Coresidence patterns between the ill member and the caregiver was significantly related to income ($r = .149, p < .01$), education ($r = .010, p < .05$), providing care to multiple persons ($r = -.302, p < .01$), and caregiver self reported health ($r = .228, p < .05$). Thus family caregivers who lived with their ill loved ones were likely to have higher incomes, be more educated, provide care for only one person in their household, and have better health than caregivers who did not live with their ill loved ones. Providing care for more than one ill family member was related to caregiver age ($r = .188, p < .05$), employment ($r = .134, p < .01$). Conversely, providing care to more than one ill family member was negatively associated with education ($r = -.047$) and religious attendance ($r = -.107$). The more educated the caregiver was the less likely they were providing care for more than one ill member. Equally, the higher their level of religious attendance the less likely they were providing care for more than one ill member.

Analytic Approach by Research Question

Research Question #1 investigates the differences between caregivers and non-caregivers on social and demographic characteristics, family member resources, family member vulnerabilities, family member coping patterns, and family member well-being variables. It provides basic descriptive data and frequency reports. Additionally, it tests group differences using chi-square and T-tests bivariate analyses.

To address research question #2, which explores whether caregiving, as an independent family member stressor irrespective of other possible objective caregiver

stressors, is negatively related to well-being indicators, a multiple linear regression model was used. The basic model representing this analysis is as follows:

Equation 1: Research Question #2 Analytic Equation

$$Wb = a + b_1FS_{\text{Care}} + b_2FS_{\text{Divorce}} + b_3FS_{\text{Emp}} + b_4FS_{\text{Ill}} + b_5FS + z_i$$

Where Wb represents Well-being Indicators (e.g. the independent measures of Depression Index, Self Report Health, and Global happiness), b_1FS_{Care} stands for caregiving, b_2FS_{Divorce} stands for divorce stressor and b_3FS_{Emp} stands for unemployment stressor and b_4FS_{Ill} stands for receipt of care for pre-existing illness stressor.

Additionally, “a” is the intercept, “ b_i ” is regression coefficients, and “ z_i ” represents the effects of the control variables known to be related to well-being (e.g. educational attainment, age, income, and gender). Separate models were tested using the depression index, self report health and global happiness measures as dependent variables.

For this analysis caregiving is coded as a binary measure (1 = yes, 0 = no) and is the primary independent variable of interest. The well-being indicators of interest are depression level, subjective health and global happiness. Other family stressors that are entered into the model and controlled for are respondents’ experience with divorce and unemployment. Though not stated in the regression equation, the variable ‘Receipt of care for disability or chronic condition’ is also considered a possible caregiver stressor. A review of the univariate statistics revealed that the numbers of respondents who

identified as having their own illness for which they required care was minimal (caregivers, n = 16 and non-caregivers, n = 133). These numbers were too small and not adequate for inclusion in multivariate analyses. The included indicators, divorce and unemployment, were coded as binary measures (*e.g. yes or no*).

Research question #3 ascertained whether the relationship between caregiving and well-being outcomes (e.g. depression, health, and global happiness) are attenuated or explained by model-specific family stress and adjustment factors. Ordinary Least Squares Regression (OLS) with progressive adjustment was used to examine main interaction effects. Well being variables (depression index, global happiness, and perceived health) were regressed on resource variables (particularly household structure and material resources) and vulnerability variables (e.g. competing caregiving roles and employment roles) whilst controlling for key contextual social and demographic predictors (e.g. age and gender) to determine if a relationship exists between these independent variables and the outcome variables of interest (e.g. Well-being indicators). The model simultaneously considers both resources and vulnerabilities.

Equation 2: Research Question #3 Analytic Equation

$$Wb = a + b_1FR_{HS} + b_2FR_{Inc} + b_3FR_{Educ} + b_1FV_{CCR} + b_2FV_{CHD} + b_3FV_{Emp} + b_4FRV + Z_i$$

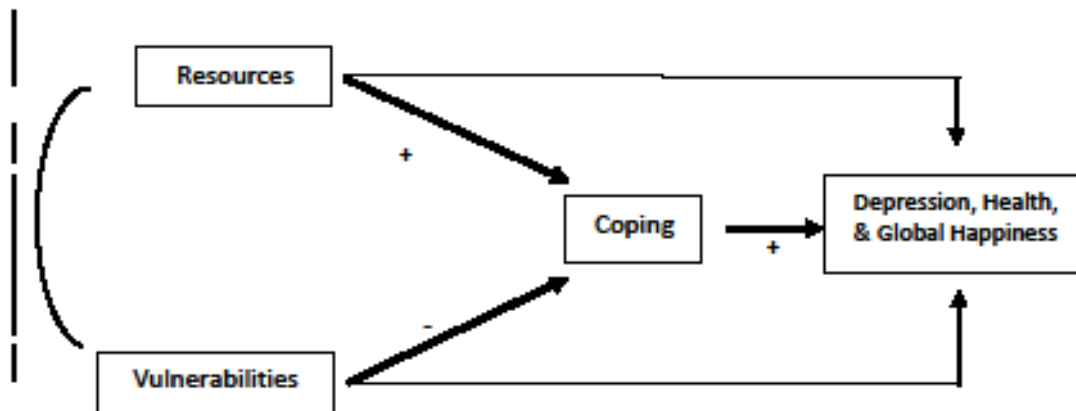
Where Wb represents Well-being Indicators (e.g. the independent measures of Depression Index, Global happiness, and Perceived Health), b_1FR_{HS} , b_3FR_{Educ} , and b_2FR

inc represent family member resource variables, namely household structure, education, and available material resources (e.g. household financial resources), respectively. Vulnerability variables considered are competing caregiving roles (b_1FV_{CCR}), the presence of children in the household (b_2FV_{CHD}), and employment roles (b_3FV_{Emp}). In the equation “ a ” is the intercept, “ bi ” is regression coefficients, and “ z ” represents the effects of the control variables of age and gender. Separate models were tested using the depression index, self report health and global happiness measures as dependent variables.

The final stage of the analysis expands on the previous analyses and tests the indirect path of the multiple independent and outcome variables via identified mediators in the measurement model. This analysis addresses the final research question (question #4) in the study. It is assumed that the relationships between resources and vulnerabilities on well-being indicators are mediated by coping behaviors (e.g. Help-seeking and church participation). The hypothesized relationship among these variables is based on the conceptual model and corroborating research evidence described in the introduction. To perform a test of mediation, causal modeling is exemplified by the path analysis technique (Baron & Kenny, 1986; Loehlin, 1987), which test for both direct and indirect effects, particularly those created by mediating variables (Baron & Kenny, 1986). The path analysis is an extension of the regression analysis which allows for a joint analysis of the association between (1) resource and vulnerability variables and coping preferences and (2) coping preferences and caregiver well-being outcomes. Key contextual demographic variables (e.g. age and gender) were

controlled for in all analyses. Path models were conducted on just the data from the caregiver subgroup. The proposed path analysis is depicted by the following diagram:

Figure 6: Research Question #4- Path Analysis Diagram



Each arrow or series of arrows represent a hypothesis about the relationship among variables in the model. Thus, it is hypothesized that the caregiver’s well-being (e.g. depression level, health, and global happiness) are related to their resources and vulnerabilities indirectly by way of their relation to family coping. As much of the data is normally distributed the path model uses a maximum likelihood estimator (ML), which is the recommended estimator for multivariate normal data. Additionally, since most of the predictor variables are non-normal dichotomous, ML is also a preferred estimator since with its standard errors and chi-square statistic it is robust to non-normality. As aforementioned, goodness-of-fit was evaluated using multiple indices, namely chi-square test of model fit, Comparative Fit Index (CFI), Root mean square residual (RMSR), and Root-mean-square error of approximation (RMSEA). According to current convention, adequate fit was defined as a non-significant model fit chi-square (Barrett, 2008; Muthén & Muthén, 1998), CFI above 0.90, RMSR less than .08, and a RMSEA value less than 0.10 (Hu & Bentler, 1995, 1999). MPlus version 4.2 uses a test statistic that

functions as a z-score to determine significance. The path coefficient divided by its standard error (β/SE) greater than 1.96 ($p<.05$) is used to determine whether the observed variables are significantly associated with well-being outcomes.

Chapter Five: STUDY RESULTS

This chapter begins with an overview of the demographic characteristics of the larger African American sample, presenting descriptives of both caregivers and non-caregivers. This is followed by a discussion of bivariate analyses and tests for normality results. Comparisons of caregiver and non-caregiver attributes are then tested and presented. Finally, the findings pertaining to regression and path analyses are reported. The narrative will be organized around the research question of interest. Thus for all bivariate and multivariate analyses results the corresponding research question will precede study findings.

Sample Description & Demographic Profile

As previously mentioned, the total sample size for the study includes 2390 African American respondents. The average age of these respondents is 40. Over a half, 55.5% (n = 1520) are female. Only a third of these respondents reported being married (33.7 %) and a little more than two thirds (67%) report having greater than a high school education. In general, most respondents were employed at least part-time (61.4%), yet the overall household income was modest (\$22,577¹⁸).

From the total sample of African Americans, 369 (15.44%) are caregivers. The majority (n = 349, 94.5%) of caregivers only provide care for one chronically ill relative. Their relationships to the ill members were varied. The majority of caregivers provide care for a chronically ill parent (n =163, 44.17%). Fifty caregivers (13.5%) provide care

¹⁸ Using The Bureau of Labor Statistics' inflation calculator (http://www.bls.gov/data/inflation_calculator.htm) it is possible to translate 1988 household incomes to 2010 figures. Accordingly, a household income of \$22,576.80(1988) translates into a household income of \$41,606.01 (2010).

for an ill child and forty-one caregivers (11.11%) provide care for a spouse/partner. Caregivers also report providing care for other relatives such as grandparents (n=51), grandchildren (n=2), siblings (n=35), and other biological relatives and in-laws (n =62). Additionally, they report providing care for non-relatives (n = 19). In regards to the illnesses afflicting these individuals, the NSFH only solicits this information from caregivers who live with their chronically ill loved ones (n=150). When a caregiver reports that they live with their ill loved one, they are then asked “What was your (ill-loved ones) major illness or disability?” The responses are diverse (Table 15). The most predominant chronic conditions were Circulatory illnesses, Musculoskeletal illnesses, Diabetes, and Mental Health disorders.

Table 15: List of Care Recipient Illnesses¹⁹

Chronic Condition (by type)	(N)	Specific conditions
Circulatory	29	Stroke, Heart Attack, High Blood Pressure, other unspecified heart trouble or circulatory conditions
Diabetes	14	
Musculoskeletal	21	Arthritis, Rheumatism, other
Neurological	13	Lumbar/Spinal condition, Seizures, other unspecified neurological disorders
Cancers	11	Cancer related conditions
Respiratory	10	Asthma, TB, Bronchitis, other unspecified Chronic Conditions
Mental Health	16	Psychological Problems, Mental Retardation, Brain Damage, Senility
Digestive	1	Kidney, unspecified digestive system disease
GenitoUrinary	2	Kidney, Prostrate, Bladder, Reproductive
Other	27	Residual Acute Conditions, Blood Disorders, Infectious, Parasitic, Ear, Eyes, Skin, Injury or operative induced condition
No Response	6	
Total N	150	

¹⁹ This information was not reported by all caregivers. It was only reported by caregivers who live with their chronically ill family members. Caregivers who provided care to loved ones they didn't live with were not asked about the ill members' illness diagnosis.

As just mentioned, among the caregiver subgroup, 150 (41%) respondents reside with their ill loved one and 218 (59%) respondents do not live with their ill loved one. The average age of both caregivers and non-caregivers is 41 (16.1) and 40 (16.6), respectively. It is interesting to note that the youngest caregiver is 19 years of age and the oldest caregiver is 85 years of age. Caregivers who are currently living (e.g. coresiding) with someone who requires care or who had lived with someone who required care in the past year are a few years older, averaging 46 years of age ($SD = 18.3$). The average age of caregivers who did not co-reside with their chronically ill loved ones is lower. These caregivers have a mean age of 38 years ($SD = 14.4$). The majority (63.9%) of caregivers are female, not married (63.7%), and at least high school graduates (69.7%). In respect to marital status, though some respondents were divorced (11.9%), the majority of caregivers were married ($n = 134$, 36.3%). Only 41 (11.1%) were widowed and a third ($n = 111$) reported they were never married. Non caregivers had a similar profile. About a third of non-caregivers were currently married ($n = 671$, 33.2%) and about a third of them were never married (30.3%). A review of marital disruption and divorce reports indicated that a quarter ($n = 503$, 24.9%) of the non-caregiver subsample reported being divorced or separated due to marital problems and only 11.6% were widowed.

At least half of all caregivers are employed (57.5%) either full-time or part-time and their household incomes are economically modest²⁰. With respect to their household structure, most caregiver households are not single-headed, but instead are

²⁰ The average caregiver income was \$18,826.94. According to The Department of Labor Statistics CPI index this is synonymous to an inflated income of \$34,696 in the year 2010.

dually or multiply headed, they include an average of three or more occupants in the household, and at least half of them include children under the age of 18. Non-caregivers have a similar demographic profile as caregivers. They are predominantly female (54%), likely to be at least high school graduates, and not married. They are likely to be employed (62.2%), have multiple headed households, with young children present and live with moderate incomes.

In respect to well-being, caregivers and non-caregivers reported similar outcomes. In regards to their scores on the CES-D depression scale, on average, caregivers' depression score is 20.72, which is considered a moderately high CES-D score, compared to a depression score of 17.87 for non-caregivers. When asked how they would describe their health, 68.7% (n = 252) and 79% (n =1361) of caregivers and non-caregivers, respectively, reported their health was at least good. When asked to rate their global happiness on a non-discriminate 7-point Likert scale ranging from very unhappy (score of 1) to very happy (score of 7), 80% of caregivers gave a score of 4 or better, which suggest moderate to high levels of happiness. Non-caregivers ratings were similar, with 87% of them rating their happiness as a 4 or greater.

Analyses Results, by Research Question

Research Question 1: Caregiver & Non Caregiver Differences

The demographic profile and life experiences of caregivers and non-caregivers could be different due to the role differences brought on by caregiving duties. Thus,

research question 1 seeks to explore possible differences that may exist between the two groups. The research question is restated below:

- (1) *Do African American caregivers and non-caregivers differ on*
 - a. *Individual demographic & social characteristics,*
 - b. *Illness and non-illness related stressors,*
 - c. *Illness and non-illness related resources,*
 - d. *Vulnerabilities. in the form of competing roles and pile-up demands,*
 - e. *Illness and non-illness related family coping patterns, and*
 - f. *Well-being, in the form of depression, subjective health, and subjective happiness*

Chi square analyses and Independent sample T-Tests were performed to test for differences between the caregiver and non-caregiver subgroups. A two-tailed p level of .05 and under was considered statistically significant in all analyses. The following table (Table 16) details the findings. Similar to correlation analyses, tests reveal two significant differences between the groups. Caregivers were more likely to be female ($\chi^2(1, 2390) = 8.95, p = .002$). Additional analyses reveal that there were no other significant differences found between the groups across all other demographic and social characteristics, stressors, resources, vulnerabilities, family coping patterns, and well-being factors.

Table 16: Caregiver & Non-Caregiver Group Differences, Significance Testing

		Caregivers (N = 369)	Non- Caregivers (N = 2021)	Test Statistics
<i>Demographic & Social Characteristics</i>	Age, M (SD)	41.7 (16.1)	41.8 (16.6)	t(2390) = .609, p = .435
	Female, n (%)	264 (71.5)	1256 (62.1)	$\chi^2(1, 2390) = 8.95, p = .002^{**}$
<i>Stressors</i>	Divorced, n (%)	52 (14.1)	273 (13.5)	$\chi^2(1, 2390) = 1.20, p = .272$
	Respondent requires Care for own illness	16 (0.7)	133 (5.6)	
	Unemployed, n (% yes)	162 (44.0)	801 (39.9)	$\chi^2(1, 2375) = 2.21, p = .157$
<i>Resources</i>	Less than HS, n (%)	110 (29.8)	590 (29.4)	$\chi^2(2, 2379) = 2.69, p = .101$
	HS, n (%)	127 (34.4)	748 (37.2)	
	> HS, n (%)	132 (35.8)	672 (33.4)	
	Household Income, M (SD)	\$18,826.94 (21,317.48)	\$19,378.67 (28,012.51)	t(2390) = 3.06, p = .090
<i>Vulnerabilities</i>	Single-Headed HH	81 (22.9)	446 (22.1)	$\chi^2(1, 2390) = .349, p = .555$
	Employed, n (% yes)	206 (56.0)	1206 (60.1)	$\chi^2(1, 2375) = 2.21, p = .157$
	Children under 18 in HH, n (% yes)	183 (49.6)	994 (49.2)	$\chi^2(1, 2390) = .115, p = .734$
<i>Coping/Social Support</i>	Never Attend Religious Services, n (% yes)	53 (14.4)	321 (15.9)	$\chi^2(3, 2390) = 1.427, p = .232$
	Attend Less than Weekly	169 (45.8)	949 (47.0)	
	Attend Weekly	84 (22.8)	501 (24.8)	
	Attend More than Weekly	63 (17.1)	250 (12.4)	
	Call in Emergency, n (% yes)			$\chi^2(2, 2390) = .625, p = .429$
	Family Members	217 (58.8)	1207 (59.7)	
	Non Family~Friends	91 (24.7)	515 (25.5)	
	No one	15 (4.1)	80 (4.0)	
	Call when depressed, n (% yes)			$\chi^2(2, 2390) = .225, p = .635$
Family Members	178 (48.2)	1017 (50.3)		
Non Family~Friends	109 (29.5)	604 (30.0)		
No one	35 (9.5)	183 (9.1)		
<i>Health & Global Happiness Outcomes</i>	Depression Index, M (SD)	20.51 (20.17)	16.76 (18.07)	t(.2388) = 2.19, p = .139
	Self Report Health, n (%)			
	Excellent)	73 (21.6)	479 (25.3)	$\chi^2(1, 2227) = .465, p = .435$
	Good	179 (52.8)	882 (46.7)	
	Fair	67 (19.8)	404 (21.4)	
	Poor	11 (3.2)	77 (4.1)	
	Very Poor	9 (2.7)	48 (2.5)	
	Global Happiness Scale, n (%)			
	Very Happy (7)	61 (21.1)	453 (25.9)	t(2350) = .843, p = .358
	(6)	66 (22.8)	370 (21.2)	
(5)	71 (24.6)	419 (24.0)		
(4)	58 (20.1)	338 (19.3)		
(3)	18 (6.2)	88 (5.0)		
(2)	5 (1.7)	38 (2.2)		

Research Question 2: The Role of Caregiving, Divorce, Receipt of Care for Pre-existing Chronic Condition, & Unemployment

Multiple regression analysis was utilized to explore whether the role of caregiving, as an independent life stressor, is associated with negative well-being. To determine if just caregiving by itself can be related to negative life outcomes, caregiving is considered a binary measure with response options 'yes' or 'no.' Additionally other family stressors are entered into the model (e.g. divorce and unemployment). The research question of interest is:

(2) Controlling for other objective stressors (e.g. divorce, unemployment, and receipt of care for pre-existing chronic condition or disability) is caregiving associated with depression, health and global happiness?

It is important to note that the presence of an illness can also be a confounding factor that has a high likelihood to be related to a respondent's well-being. Though data on this respondent stressor was available for analysis and the initial intent was to control for this stressor, the numbers of individuals in the sample that met this criteria was extremely low. The number of caregivers who received care for their own pre-existing chronic condition or disability was 16 (less than 1%) and the numbers of non-caregivers were 133 (5.6%). These low numbers precluded using this data in the model or final analyses.

As previously mentioned each outcome (dependent) variable was tested separately. After simultaneously entering the block of predictor variables in each well-being model, a significant overall relationship between the predictors and the well-being outcomes of interest was found. An adjusted R was obtained for depression and the overall fit is significant (*adjusted R² = .042, F = 15.31, p < .001*), thus 4% of variability is accounted for by the variables in the model. For self reported health the adjusted R² was .138 (*F = 47.38, p < .001*), which suggests that 14% of variability is accounted for by model variables. With respect to the final outcome of interest global happiness, the variables account for 19% of variability in the model (*Adjusted R² = .019, F = 5.27, p < .001*). In order to assess whether or not the act of being a caregiver is significantly more compromising to a family member's well-being than other stressors, the contribution of each independent variable was explored. Table 17 details these findings. As the ultimate purpose of this study is to understand caregiving, it is important to note that correlation analyses did find a significant relationship between caregiving and depression (*r = .045, p < .001*). There was no significant correlation between caregiving and self-report health or global happiness.

Results of regression analyses reveal that after controlling for age, gender, education, and household income only unemployment ($\beta = .107, p = .000$) is significantly associated with depression. Caregiving ($\beta = .047, p = .152$) and divorce ($\beta = .047, p = .172$) did have a positive relationship to depression outcomes but these relationships were not significant. Additional regression analyses revealed caregiving status is not an individual predictor of the respondent's health ($p = .969$) or global happiness ($p = .495$),

when the other independent variables are held constant. These findings suggest that caregiving alone is not related to family member well-being (e.g. depression, health, or happiness). In a vacuum, a relationship may exist between caregiving and depression, but when other stressors are controlled for the relationship disappears. These findings replicate the findings of bivariate analyses that revealed no significant differences between caregivers and non-caregivers on health and global happiness outcomes.

Table 17: Examining the relative influence of family stressors (caregiving, divorce, and unemployment) on well-being (N =2390)

Predictor	Depression Index				Self Reported Health				Global Happiness			
	R ²	B	SE B	β	R ²	B	SE B	β	R ²	B	SE B	β
<i>Stressors</i>	.042**				.138**				.019**			
Caregiving (1 = yes)		.038	.033	.047		-.002	.053	-.002		-.017	.098	-.067
Divorce (1 = yes)		.031	.035	.047		.012	.060	.000		-.022	.107	-.104
Unemployed (1 =yes)		.101	.031	.096***		-.223	.056	-.126***		-.005	.091	-.016
<i>Demographic Controls</i>												
Age		-.135	.001	-.004***		-.013	.001	-.168***		.058	.002	.005*
Gender (1 = female)		.017	.025	.016		-.067	.045	-.041*		.009	.076	.026
Education		-.086	.027	-.086***		.158	.049	.145***		-.008	.084	-.025
Income		-.068	.028	-.055*		.187	.056	.042***		.128	.086	.323**

*p<.05, **p<.01, ***p<.001

Research Question 3: Caregiving as a Family Stressor

To further understand within-group variability that exists among just African American caregivers, research question 3 explores the extent to which contextual factors, such as family member resources and family member vulnerabilities (e.g.

competing demands) are associated with caregiver well-being. The specific research question of interest is:

(3) Among African American caregivers, are family member resources and vulnerabilities related to depression, health and global happiness?

Ordinary Least Squares regression was run to test the relationships between the variables. As there are three well-being variables of interest (depression level, self-report health, and global happiness), separate analyses was conducted on each outcome. The first model (Model A) considers family resources, the second model (Model B) considers family vulnerabilities, and the third model (Model C) considers all preceding variables with the addition of age and gender as controls. Two of the models were statistically significant at the .05 alpha level for the depression outcome (Table 18). In Model A where well-being outcomes were regressed on resource variables, statistical tests revealed that caregivers who lived in a single headed household were more likely to experience depression symptoms ($\beta = .184$) compared to caregivers who lived in a household headed by multiple persons. There is an increase in depression of .184 units for caregivers who live in single-headed household. The adjusted R^2 indicates that 2.5% of the variance in depression is explained by family resources. Model B, which accounted for the effect of family member vulnerabilities was also statistically significant. According to this model, household structure was still a significant contributor to depression outcomes, even when vulnerabilities are considered. None of

the vulnerability factors were significantly associated with depression in caregivers. In this model 3 percent of the variance in depression is explained. With the addition of the control variables age and gender (Model C), the model is no longer significant. Thus resource and vulnerability factors are not significantly related to depression in this model.

Table 18: OLS Regression of Depression on Resources, Vulnerabilities, & Demographics

	Variable	Model A β (SE B)	Model B β (SE B)	Model C β (SE B)
Resources	Education	-.074 (.070)	-.075 (.069)	-.100 (.068)
	Household Income	.009 (.060)	.019 (.067)	.011 (.066)
	Household Structure	-.184 (.071)**	-.168 (.074)*	-.135 (.076)
Vulnerabilities	Employed		.003 (.069)	.003 (.074)
	Children in Household		.052 (.061)	.025 (.066)
	Multiple Care Provider		.082 (.073)	.106 (.080)
Demographics	Age			-.004 (.002)
	Gender			.020 (.075)
Adjusted R ²		.025*	.030*	.044*

(N = 369), * $p < .05$, ** $p < .01$, *** $p < .001$, 2-tailed tests

Table 19 examines the effects of resources and vulnerabilities on self-reported health. All three models were statistically significant at the .01 level. In the first model

(Model A) which looks at the effect of family resources, education and income both have a statistically significant effect on caregiver perceived health ($\beta = .230$ and $.329$, respectively). The adjusted R^2 suggests that a very small percentage (8.0%) of the variance is explained by this model. With the addition of family vulnerabilities in Model B, the effect of education is still statistically significant, but the effect of income is not significant any more. A relationship is also revealed between each of the three vulnerability variables and self report health. Being employed is related to more positive reports of health. On the other hand, caring for more than one ill family member is related to lower reports of health. While employment status and the presence of children in the household have a comparably strong effect on health, they only marginally contribute to the variance explained. According to the standardized beta coefficients, caring for more than one ill member had the strongest effect on self-reported health and contributes significantly more to the model. Model B indicates that 24.7% of variance is explained by resources and vulnerabilities. According to F-change statistic (37.72, $p < .001$) this increase in variance is statistically significant. Model C which includes control variables explains 28.5% of variance in depression. Accounting for control variables, the presence of children in the household and education are no longer statistically significant. Employment and caring for more than one ill member continue to have statistically significant effects. The control variable age is also associated with negative reports of health. For every one year increase in age, health decreases by .011 units. There was no significant relationship observed between gender and health.

Table 19: OLS Regression on Self-Report Health on Resources, Vulnerabilities, & Demographics

	Variable	Model A β (SE B)	Model B β (SE B)	Model C β (SE B)
Resources	Education	.230 (.111)*	.263 (.117)*	.188 (.113)
	Household Income	.329 (.140)*	.010 (.169)	-.002 (.167)
	Household Structure	-.060 (.140)	.221 (.145)	.287 (.150)
Vulnerabilities	Employed		-.243 (.104)*	-.210 (.103)*
	Children in Household		.265 (.100)**	.182 (.106)
	Multiple Care Provider		-1.226 (.254)***	-1.145 (.235)***
Demographics	Age			-.011 (.003)***
	Gender			-.059 (.105)
Adjusted R ²		.080*	.247*	.285*

(N = 369), *p<.05, **p<.01, ***p<.001, 2-tailed tests

The last well-being variable examined was global happiness. Regression analyses revealed no significant relationship between model variables and global happiness in any of the three models of interest.

Research Question 4: The Role of Coping Mediators in Predicting Caregiver Well-Being

Research question 4, specifically looked at how coping strategies mediate the proposed relationships. The direct and indirect effects of family member resources and

vulnerabilities on well-being outcomes were tested. The specific research question of interest is

(4) Among African-American caregivers, do two forms of coping – help-seeking and church participation – mediate the associations of family member resources vulnerabilities on depression, health and global happiness?

As there are three dependent variables of interest (depression level, self-report health, and global happiness), separate models will be run on each outcome. Initially, the bivariate relationship between the predictor variables (family member resource variables and family member vulnerability variables) and each of the endogenous or outcome variables (e.g. depression, self-report health, and global happiness) were examined. Correlation analyses revealed no significant correlations between resource variables and coping strategies, but a relationship was observed between one of the vulnerability variables of interest (caregiving for more than one individual) and religious attendance ($r = .107, p < .001$). More details on these bivariate relationships were previously addressed in Chapter Four 'Methods' in Data Preparation, Testing Bivariate Correlations section.

Using path analysis, three mediational relationships were assessed, namely how coping behaviors mediate the relationship between family member resource and vulnerability factors and the three outcome measure of interest: (1) depression, (2) self-reported health, and (3) global happiness. All the models considered the control

variables, age and gender and freely estimated all unidirectional paths. For estimated models of interest the unstandardized path coefficients (β), and standard errors (SE) as reported by M-plus are included in the table. The ratio (z) of the path coefficient (β) and standard error (SE) is also reported.

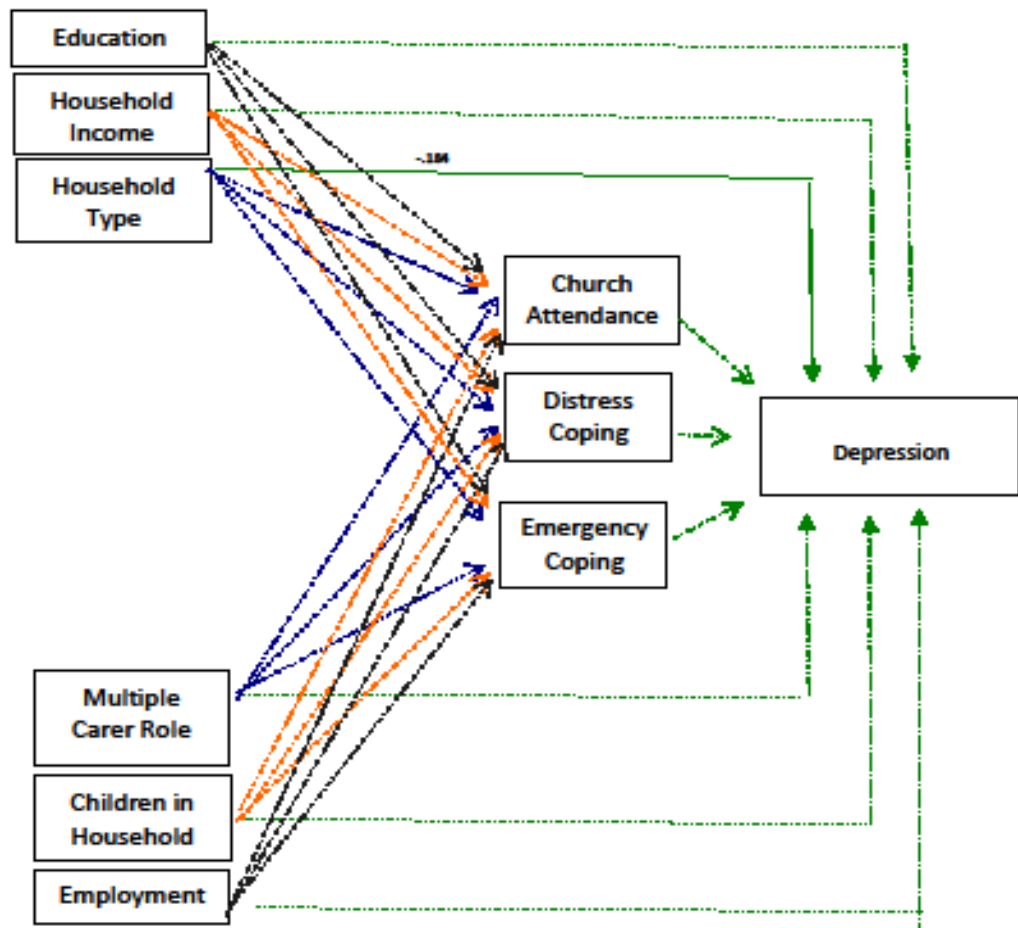
The first model examined the mediating role of coping on caregiver depression. Table 20 details model findings. The path diagram (Figure 6) illustrates the path analysis model after model reduction. The proposed full model yielded several insignificant paths and an unacceptable fit ($\chi^2 (3, N = 369) = 85.30, p < .001; CFI = .000, RMSEA = .273, SRMR = .059$). After reduction of non-significant paths, the reduced model was a good fit, as indicated by the following chi-square, CFI, and RMSEA values ($\chi^2 (10, N = 369) = 9.862, p = .453; CFI = 1.00, RMSEA = 0.00, SRMR = .027$). In the reduced model only a very small percentage ($R^2 = .022; 2.2\%$) of the variance is explained by the model. The model demonstrates that there is no significant direct relationship that exists between any of the coping measures and depression. In keeping with the findings of the regression analysis, the path analyses of depression revealed that the only variable that was directly associated with depression was household structure ($\beta = -.184, p < .01$). This variable contributed a very small amount of variance to the model. To properly fit the model, several insignificant paths were dropped. All paths from the coping in distress and coping in times of emergency to family member resource and vulnerability predictors were insignificant, thus they were dropped from the model. It is interesting to note, that in respect to the multiple caregiving roles in particular the effect sizes of the path coefficients, in the full models, indicate a large effect

Table 20: Path Analysis of Family Member Resources, Family Member Vulnerabilities and Coping Measures on Caregiver Depression

		Full Mediation Model			Reduced Mediation Model		
		β	SE	z	β	SE	z
Resources	Education	-.07	.07	-.08	—	—	—
	Household Income	.02	.07	.02	—	—	—
	Household Structure	-.17	.07	-.13*	-.18	.07	-.14*
Vulnerabilities	Employed	.00	.07	.00	—	—	—
	Multiple Carer Role	8.53	.08	.04	—	—	—
	Children in Household	-.87	.06	.06	—	—	—
Coping	Church Attendance	-.01	.03	-.02	-.02	.03	-.03
	Emergency Help	.00	.06	.00	.00	.06	.00
	Distress Help	-.02	.06	-.02	-.02	.06	-.03

* P < .05

Figure 7: Significant Direct and Indirect Pathways of Family Member Resources, Family Member Vulnerabilities, Coping Measures, and Depression.



Note: dashed lines indicate non-significant paths

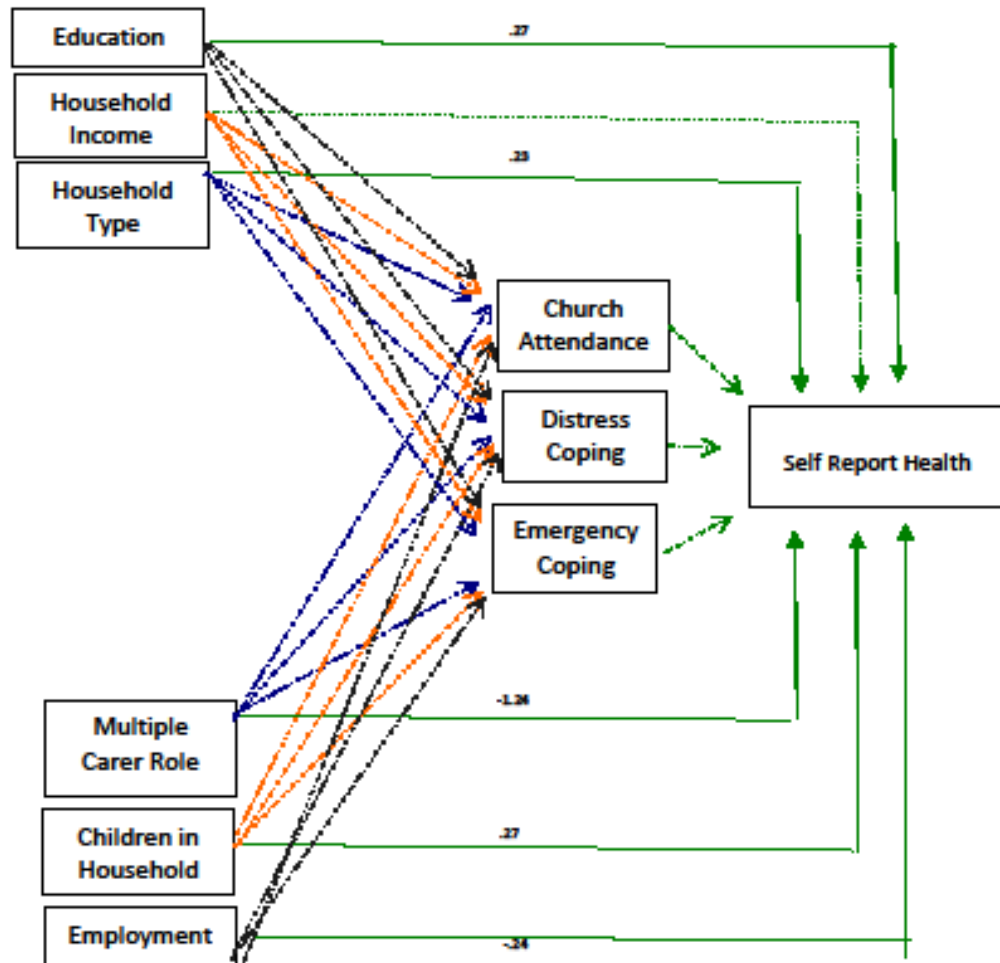
The second model examined the mediating role of coping on caregiver self-report health. Once again variables that were found not to be related significantly or marginally to the dependent outcome in question were removed successively until a final 'best fit' model could be derived consisting of only significant predictors. The reduced model showed improvements in model fit (Full model: $\chi^2 (3, N = 369) = 85.05, p = .000; CFI = .325, RMSEA = .272, SRMR = .059$); Reduced model: $\chi^2 (6, N = 369) = 3.95, p = .684; CFI = 1.00, RMSEA = .000, SRMR = .014$). In the reduced model 25.1% of variance is explained by the model. The reduced model suggests that none of the coping measures are directly related to self-report health, but the following family member resource and vulnerability factors are directly related: education ($\beta = .271, p < .01$), household structure ($\beta = .232, p < .05$), employment ($\beta = -.240, p < .05$), having children ($\beta = .270, p < .01$) and caring for more than one ill member ($\beta = -1.237, p < .001$). None of the coping measures mediated these relationships.

Table 21: Path Analysis of Family Member Resources, Family Member Vulnerabilities and Coping Measures on Caregiver Self Report Health

		Full Mediation Model			Reduced Mediation Model		
		β	SE	z	β	SE	z
<i>Resources</i>	Education	.27	.12	2.35	.27	.10	2.77
	Household Income	-.00	.17	-.01			
	Household Structure	.23	.14	1.62	.23	.12	1.95
<i>Vulnerabilities</i>	Employed	-.24	.10	-2.33	-.24	.10	-2.50
	Multiple Carer Role	-1.24	.25	-5.02	-1.24	.24	-5.06
	Children in Household	.27	.10	2.67	.27	.10	2.67
<i>Coping</i>	Church Attendance	-.04	.05	-.84	-.04	.05	-8.40
	Emergency Help	-.03	.11	-.24	-.02	.11	-1.23
	Distress Help	.07	.09	.81	.06	.09	.71

* P < .05

Figure 8: Significant Direct and Indirect Pathways of Family Member Resources, Family Member Vulnerabilities, Coping Measures, and Self-Report Health.



Note: dashed lines indicate non-significant paths

The final model tested for the direct and indirect effects of family member resources and vulnerabilities on coping items and global happiness. Initial estimation of the full model indicate that the model was not fitted for the data ($\chi^2(3, N = 369) = 84.89, p = .000; CFI = .000, RMSEA = .272, SRMR = .059$). After removal of all insignificant

paths, the reduced model was an improved fit ($\chi^2 (5, N = 369) = 3.43, p = .634$), $CFI = 1.00$, $RMSEA = .000$, $SRMR = .016$). According to the model results, none of the three coping measures mediated global happiness. Moreover, there was no indirect or direct relationship observed between any of the model factors and global happiness. The path coefficients are presented in Table 22.

Table 22: Path Analysis of Family Member Resources, Family Member Vulnerabilities and Coping Measures on Caregiver Global Happiness

		Full Mediation Model			Reduced Mediation Model		
		β	SE	z	β	SE	z
Resources	Education	-.18	.19	-.97	-.24	.19	-1.27
	Household Income	.27	.22	1.25	.35	.19	1.85
	Household Structure	-.20	.27	-.72	—	—	—
Vulnerabilities	Employed	-.13	.21	-.63	—	—	—
	Multiple Carer Role	.04	.34	.12	—	—	—
	Children in Household	-.24	.20	-1.18	—	—	—
Coping	Church Attendance	.15	.10	1.60	.15	.09	1.65
	Emergency Help	.27	.21	1.29	.26	.20	1.28
	Distress Help	-.07	.17	-.45	-.07	.16	-.40

* $P < .05$

Chapter Six: DISCUSSION

Overview

The aims of this dissertation were four-fold: (1) To investigate the differences between adult caregivers of persons with chronic illnesses and non-caregivers on demographic and social characteristics, family member resources, family member vulnerabilities, and coping patterns using a national probability sample of African American caregivers; (2) To ascertain if caregiving has a negative impact on well-being when other common family member stressors (e.g. divorce and unemployment) are controlled for; (3) to investigate the extent to which family member demographics, resources, and vulnerabilities are related to caregiver well being, specifically depression symptomology, health, and global happiness; (4) to explore whether coping behaviors mitigate negative well-being.

Bivariate analyses of caregiver and non-caregiver groups revealed quite a bit of homogeneity between the two subgroups. African Americans who were caregivers were more likely to be adult females and have a higher depression index than non-caregivers. Further exploration of just the subset of caregivers revealed a demographic profile of the African American caregiver that has yet to be put forth in the literature. Based on descriptive analyses of this national sample, a profile emerges which suggests that African American caregivers are likely middle-aged, predominantly female, married, employed, and have at least a high school education. Though the population studied for this dissertation includes a dataset that is dated by almost 20 years, a comparison of this

study's findings to studies that include more contemporary African American samples reveal that not much has changed over time. Consequently, the findings of this study are consistent with other caregiving studies investigating African Americans (Pinquart & Sorensen, 2003; Haley et al 1996; Dilworth-Anderson, Goodwin, Williams, 2004; Roff et al, 2004; Knight et al, 2000) that used non-probability convenience samples. Moreover, these data are based on national probability sampling, which cannot be said of more contemporary studies. Thus the findings of this study are much more generalizable, which is an asset to the current knowledge base.

The second aim of this study was to ascertain if caregiving, as an independent family life stressor, was associated with negative well-being when all other common stressors, namely divorce and unemployment, are considered. Using regression analyses, the act of being a caregiver was compared to other life stressors, namely divorce status and unemployment status. The extent to which well-being outcomes are related to these stressors was then examined. Model results suggest that unemployment is the only stressor that is significantly associated with family member well-being. The act of caregiving, though significantly linked to depression, does not contribute to the likelihood of depression symptoms as much as lack of employment. Choi-Kwon et al (2005) reported similar findings in their study of caregivers of stroke survivors. Their main outcome variable of interest was the well-being variable 'burden', but they also considered caregiver's depression and anxiety. According to their findings, unemployment is significantly related to caregiver burden, depression, and anxiety. Individuals who were unemployed were more likely to report being burdened, have

depression symptoms and have anxiety symptoms. As suggested by Choi-Kwon (2005) the relationship between unemployment and negative well-being may be due to a number of underlying conditions that may make the caregiver more susceptible to depression, burden, and anxiety. Unemployed persons may be more likely to suffer from lower self-image because of the loss of employment and/or may have increased personal and financial stress. At its essence, unemployment literally translates into a reduction of financial resources for which an individual can call upon to help them secure basic necessities and material resources, such as housing, food, clothing, transportation, and healthcare. Consequently, a state of unemployment could have a drastic impact on family life. It can create an intense sense of uncertainty and loss within an individuals' life, which inevitably negatively alters an individuals' well-being. A number of review studies have been conducted that attest to the negative influence unemployment has on well-being, including depression, physical health, self-esteem, and life satisfaction (McKee-Ryan et al, 2005; Wanberg, Kammerer-Mueller, & Shi, 2001). Even though finding out your loved one has a chronic illness and assuming the arduous role of their care provider can also create a sense of uncertainty and loss, the role of caregiver may differentially impact well-being less than unemployment because it doesn't diminish access to basic needs. Unemployment places a family at an increased risk for poverty and there is overwhelming evidence that among African Americans unemployment is related to poor well-being (Rodriguez, Allen, Frongillo, Chandra, 1999) and that poverty places this ethnic group at increased risk for poor physical and mental health outcomes (Brisco et al, 2010).

Unemployment and divorce aside, the findings of this study suggest that caregiving does not have as much a deleterious effect on family member well-being as has been reported by some in the literature. Though correlation tests suggest that caregiving is inversely related to well-being, depression in particular. The relationship between the outcomes, depression, self-report health, and global happiness are not related to caregiving when other stressors are considered. Though there exist a number of studies that have reported a negative relationship with well-being outcomes and caregiving, the literature is not consistent. For African Americans in particular, though there are studies that suggest a negative relationship; others suggest either no significant relationship at all or a positive relationship. It has formerly been suggested that these divergent findings might be related to sampling or measurement concerns. It is also likely that the true relationship between caregiving and well-being cannot be fully understood without considering the additive effect of the caregiver's social life experiences, like his or her experience with other life stressors. As is evidenced by the findings of this study, the contribution of other stressors might be masking the true relationship between caregiving and well-being outcomes. Thus, social scientists should continue to explore these phenomena. Such work could unravel some of the inconsistencies that are common in the literature and help practitioners better understand the experience of African American caregivers.

The next aim of this study was to test the relationship between family member demographics, resources, and vulnerabilities on well-being outcomes. According to the analytic findings, household structure is related to depression. Caregivers who live in

single-headed households are more likely to be depressed. Other studies also report a relationship between household structure and depression among African American caregivers (Williams, 2005; Drentea & Goldner, 2006). Within single-headed households, there are less human resources and family support to share caregiving and household responsibilities. Caregivers within these households face increased financial and personal strains. When a household is headed by multiple persons and includes a large social network the responsibilities of caregiving are shared across these family members, thus alleviating some of the strains of the primary caregiving. It is important to note that given the relatively small amount of variance being explained by this resource (e.g. household structure) it is possible other important variables which are not available in this dataset or captured in this study might better explain depression in African American caregivers. As will be further discussed in the limitations, a number of other model factors, such as other family resources or caregiving appraisal might contribute more to caregiver well-being.

With respect to health, employment and caring for more than one ill-loved one, is related to health reports. Caregivers who were employed reported better health, perhaps because they had better access to resources as a result of the financial sustenance that was available to them from their job. This finding is identical to prior research which suggests that employment is related to more positive health outcomes and well-being factors. Caregivers who cared for multiple persons reported worse health. Providing such extensive care to multiple persons can greatly extend the caregivers resources (e.g. time and money) and can add undue strains to an already

overwhelming role. When controlling for demographics, no other family resources or vulnerabilities were related to health. It is worthy to note that prior to controlling for family member vulnerabilities and demographics, a negative relationship was observed between education, income and health. Those significant relationships disappeared in the full model. A possible explanation for this trend might lie in the compounding affect that vulnerabilities have on caregiving. Despite the contributions that family member resources make to ameliorating caregiver well-being, the enhanced stress brought on by other vulnerabilities may prove to be more related to overall well-being. Moreover, when the primary caregiver has to provide care for multiple chronically ill individuals, their time and attention is greatly compromised. Inevitably, this will lead to greater stresses which exceed the contribution of available resources.

The global happiness outcome was not related to family member resources or vulnerabilities. In a comparative study of White and African American caregivers using the NSFH, Drentea & Goldner (2006) found similar results. Though the African American caregivers in their study were significantly depressed, according to the CES-D, the sample reported more positive well-being (e.g. reduced burden) using subjective self-report measures. An explanation for these findings is best summed up in the words of Drentea & Goldner (2006) "...while African American caregivers are more depressed on average, they are not as stressed overall about their caregiving role" (p. 52). In other words, while the act of caregiving is related to poor health and mental health outcomes via objective measures, the opposite is likely when subjective self-report measures of distress are utilized. Due to culturally informed filial obligations about family care,

caregiving is seen as normative family process rather than a disruption (Haley et al, 1996 Dilworth-Anderson et al, 2005). African Americans tend to have a positive appraisal of caregiving (Haley et al, 1996; Haley et al, 2004; Roff et al, 2004; Lee et al, 2000) and consequently would not report caregiving outcomes in a negative fashion. Self-reports are more likely to be positive. Thus differences might be observed in how caregiving is experienced when objective and subjective measures are used. Objective measures of depression and physical health, such as the CES-D and measures of physiological functioning reveal deleterious effects of caregiving among African Americans, but when asked how they are doing subjectively African American caregivers tend to report positive outcomes. This trend is observed across a number of studies (Knight et al.,2007; Drentea & Goldner 2006; Pinquart & Sorensen, 2003, 2005), and raises concerns about the reliance of self-report measures for assessing psychosocial and health outcomes (Knight & Sayegh, 2010). This may explain why global happiness was not a significant factor in this study.

The final aim of this study was to look at the role that specific coping behaviors play on caregiver well-being. Based on the Resiliency Model, it was expected that coping behaviors would mediate the relationship between family member resources, vulnerabilities, and well-being outcomes. It was expected that coping would contribute to the caregiving experience and mediate adaptation. A number of caregiving studies have evidenced how coping can mitigate the stress brought on by family caregiving. Active coping in particular has been shown to be particularly helpful. Active coping involves seeking social support or other resources (both informal and formal) in an

attempt to adapt to a perceived family stressor. In caregiving, this type of coping is related to improved physical health functioning, depression outcomes, and greater life satisfaction (Kim, Knight, Longmire, 2007; Haley et al., 1996, Kosberg et al, 2007; Rozario et al, 2008; Knight et al 2000; Pinquart & Sorensen, 2005; Drentea & Goldner, 2006). It is agreed upon in the literature that for African Americans this type of coping often involves the use of religious supports and other family members. Using path analyses, the mediating effects of three types of caregiver coping (e.g. church attendance, receiving support from family in times of distress, receiving support from family in times of emergency) were examined. No coping measures mediated the relationship between family member resources, vulnerabilities, and well-being outcomes. An interesting finding, which was duplicated also in the regression analyses, was the relationship between outcomes and household structure. According to the path analyses, household structure (measured as single-headed household or not) was directly related to depression and self-reported health. Coping did not mediate this relationship. A possible explanation for these findings lie in the fact that within single-headed households caregivers have limited material and human resources to provide care, so their sense of being overwhelmed might be naturally heightened. Other family members in the home and heading the home allow responsibilities to be shared and reduces burden, particularly when care is needed for multiple ill members. African Americans have a rich tradition of calling upon family and extended kin in times of need and there is overwhelming evidence that this trend maintains in the face of family caregiving (Dilworth-Anderson, Williams, & Cooper, 1999; Becker, Gates, Newson, 2004;

Yeo & Gallagher-Thompson, 1996). Family reliance and the willingness of other family members to bend to accommodate those in need are cultural traits that aid in ameliorating the effects of family stress. The results of this study provide more evidence to support this supposition.

According to study findings, the vulnerabilities posed by the competing demands of employment, caring for young children in the household, and caring for more than one chronically ill individual are also significantly related to caregiver well-being outcomes in particular the caregiver's self-reported health. It is interesting to note, that in respect to the caregiver who provides care for more than one person (e.g. multiple caregiving roles) in particular the effect sizes of the path coefficients, in both the full and reduced models, indicate a large effect. The increased demands created by these vulnerabilities are likely to result in a number of objective burdens, such as financial and time constraints. Moreover, there is evidence that high intensity caregiving roles that involve complex care, large number of hours of care, or increased demands are related to poor health outcomes for the caregiver, in the form of poorer self-reports (Navaie-Waliser et al, 2002; Commonwealth Fund, 2003), negative health behaviors (Son et al., 2007; Brown et al., 2004), and physical health complications, such as cardiovascular problems (Lee et al., 2003). These caregivers may have less time and energy to engage in preventative health care behaviors. Moreover, they might also have reduced financial resources and time to attend to their own health conditions, thus they might be more apt to perceive their health as poor.

The results of these path analyses suggest that the context of caregiving (e.g. family resources and vulnerabilities) more so than coping behaviors, has a much more direct role in informing coping behaviors and how caregiver well-being outcomes manifest. Specifically, this study suggests that resources such as household structure inform available supports to aid the caregiver and vulnerabilities, in the form of competing demands, may result in additional caregiving strain. Similar ideas have been posited and investigated by other researchers (Chappell & Reid, 2002; Chatters et al, 2002; Taylor et al 2001).

Limitations

While the findings of this study are important for advancing knowledge on African American caregiver wellness, a few caveats should be considered in accepting study findings. The most salient issues are related to methodological limitations. Use of the NSFH presents a number of concerns. Wave1 of the NSFH, which was used for this study, is over 20 years old. This fact withstanding, it is important to note that the NSFH was the best available data for addressing the research questions of interest, even when compared to more contemporary caregiving and chronic illness surveys, as stated in Chapter 5: Methods. Moreover, demographics of the sample of African American caregivers used in this study and other findings are comparable to those in more recent studies as noted in the Discussion section. Never-the-less, there is a need for additional research using contemporary probability-based samples to improve generalizability

concerns , especially since family resources and vulnerabilities are also likely to be much different in this modern age.

Inherent in studies using secondary data are the methodological limitations presented by measurement confounds (Hofferth, 2005). In using secondary data, social scientists are forced to use the best available measures to measure the concept of interest. This was the case in this study. Though the measures chosen were the most appropriate for answering the research questions of interest, more elaborate measures would have provided a more thorough analysis. In particular, the NSFH coping variables (help-seeking and religious supports) are one-dimensional single-item measures. There is an abundance of evidence in the research that suggest that both of these constructs (religious coping and active behavioral help-seeking) are much more complex and have multiple dimensions. The NSFH variables are unable to tap into these latent constructs and thus may not measure family coping in the most comprehensive way. A similar concern is raised with the health and global happiness outcome variables. They are also single-item measures with only good face validity. Thus they may not be the best items to measure the outcomes of interest. Especially since multiple items scales are much more stable measures of a construct.

Compounding this measurement limitation is the fact that all the coping measures and both the health and global happiness measures are self-report measures. The subjective nature of these measures inherently questions their validity. In respect to coping, an individual's memory about coping and problem solving strategies may not accurately reflect their behavior. They may have recollection difficulties, may report

socially desirable coping strategies, or they may feel discomfort in reporting actual coping behaviors or lack of coping. For example, when asked who they turned to for help, the respondent may not actually report or remember all persons who they turned to for help, they may turn to different individuals for different stressors, or may only recall the last person they turned to for help in their most recent need. Moreover, given how this question is asked in the NSFH (e.g. it is not in direct reference to caregiving); it is possible that respondents are not considering their caregiving needs at all. The same logic holds true for self-reported responses to health and life satisfaction.

The final limitation of this study is a limitation that is common among many caregiver studies – the absence of data documenting family member well-being or personal history of health prior to the onset of caregiving. There is evidence that family history is related to caregiving outcomes (Dura, Stukenberg, & Kielcot-Glaser, 1991). A caregiver’s health history and pre-existing mental health prior to the onset of caregiving is related to their health and mental health outcomes during caregiving. In particular, Dura and colleagues (1991) found that caregivers who had a lifetime history of depression were much more likely to report depressive symptoms in relationship to providing care for their loved ones with dementia. Their findings argue for a need to consider caregiver health history. As is the case with this study, most caregiving studies are based on a cross-sectional design or a longitudinal design that only considers changes in caregiver well-being after the role of caregiver has been assumed. A prospective study of family members, that looks at life before a person assumes the role of caregiver and after they assume the role is much needed. In the present study,

causality cannot be inferred. It is only apparent that a relationship exists between the variables of interest, but the mechanisms by which they are related is impossible to ascertain. Consequently, the results of this study must be interpreted with caution. One cannot assume that being a caregiver leads to depression. Instead it may be that some underlying issue related to depression caused the person to consider or even unwillingly find themselves in the role of caregiver.

Strengths

Despite the limitations, there were several strengths associated with this research study, the most notable being its sampling structure. Lawton et al (2000) argue that to get a clearer understanding of caregiving and its impact on well-being it is important that social scientists use probability-based samples, a prospective study design, and a study duration that spans a sufficiently long period of time to observe family and individual life changes over time. Though this study is limited as it is cross-sectional and does not use a panel design, as was discussed in the Limitations section, the study does employ a national probability sample. Moreover, due to oversampling of certain subgroups, it also includes a relatively large sample of African Americans which is an anomaly, compared to other similar chronic illness and caregiving studies (e.g. Caregiving and Chronic Illness Survey and RWJ-FACCT). Social scientists (Dilworth-Anderson et al, 2005; Rozario & DeRienzi, 2009; Wilcox et al, 2005) have called for a study that addresses African American caregiving using a large nationally representative sample of diverse African American caregivers and this study aptly answers that call.

Though it is specified to explore the experience of African American caregivers, this study extends the caregiving literature in general. Though it is a well-documented fact that caregiving is a family stressor for the family caregiver, there is limited research that explores the extent to which other family stressors contribute to or mask the true relationship between caregiving and caregiver well-being. Examining other well-known family member stressors, namely divorce and unemployment, this study attempts to disentangle whether or not caregiving has an independent effect on caregiver well-being or whether it only results in deleterious outcomes when it is paired with other stressful situations.

Finally, and perhaps most importantly, this study fills an important gap in the understanding of caregiving among African Americans. Though the numbers of caregivers continue to grow nationally and family care is known as a core cultural value among members of this ethnic group, little is known about the unique experience of African American caregivers. Through its descriptive analyses this study takes on the very necessary steps of presenting a demographic and social profile of the African American caregiver. Moreover, since the caregivers in this sample provide care for a wide age range of afflicted individuals, the study improves upon the current profile describing the African American caregiver, which is primarily based on studies of chronically ill older adults.

It is important to note the within-group analytic approach which further advances knowledge specific to African Americans. One of the most important goals of this study was to engage in study that explored the within-group variability that might

exist among African American caregivers of persons with chronic illness. Even though there is merit in cross-cultural comparisons, as is demonstrated by the number of studies that have chosen this approach, a within-group analysis enhances awareness of the varying contextual factors that shape family member well-being in the face of caregiving. This study focuses on intra-group differences that could not have been captured by cross-ethnic analyses. In using this approach this study prohibits a conclusion that suggests that findings are culturally based or specific to just African Americans. As there is no other ethnic comparison group, this assumption cannot be made. However, it does offer the opportunity to investigate heterogeneity that exists within the African American caregiver population. This is crucial in that the results will highlight key contextual factors that differentiate the caregiving experience for one African American versus another. This is crucial in dispelling myths about ethnic commonalities and in aiding practitioners in designing appropriate interventions for families, not based on ethnicity but based on family need. In respect to caregiving research, in general, the findings of this study could be used to explore similar relationships in broader caregiving populations.

Conclusions

Future Research

Though this study addresses a gap in the knowledge base on African American caregiving, there remains a need for additional research. Future studies should continue to examine the contextual nature of caregiving as it relates to African Americans. The Resiliency Model is a multi-faceted dynamic model which seeks to

explain family response to stress and family coping processes. In its entirety, the model addresses family stressors, family resources, family vulnerabilities, family appraisal, family coping, and adaptation. Though it is possible to explore most of the key factors proposed by this theory using the NSFH dataset, it is not possible to explore one of the key factors of interest – ‘caregiving appraisal’. The NSFH has no variables on appraisal. The family’s views on and attitude toward their caregiving role shapes their well-being outcomes. If caregiving is perceived as a filial responsibility, then the response may be one of frustration or emotional acceptance, which has implications for perceived levels of burden. On the other hand, if caregiving is perceived to be rewarding, caregivers are less likely to report negative well-being. There are a number of studies that show that the meaning the family ascribes to caregiving contributes to (1) their willingness to give care, (2) the scope of the care they are willing to provide, and (3) their perceived needs as a caregiver. In addition, to the meaning ascribed to the role of caregiving, caregiving appraisal also deals with the justification that surrounds the decision to assume the role of caregiver. According to Dilworth-Anderson (2004), there are cultural justifications for caregiving among African American caregivers. Some caregivers may unwillingly approach the role due to a sense of obligation or responsibility and thus they are more likely to experience a sense of emotional dissonance and lower psychosocial well-being. So appraisal, both how caregivers view their role and the circumstances that influenced their accepting that role, has implications for the caregiver’s ability to cope and adapt. Thus caregiving appraisal could account for a substantial variance in the models. Future research should further explore this model factor.

There are a number of other family member stressors, resources, and vulnerabilities that deserve additional attention, such as extended family in the household, household responsibility sharing, access to formal services, ill-member needs, the availability or lack of other material resources, other than financial resources. Particularly in respect to African American families, there is a need to further test the role that coping mechanisms such as family reliance and religious support play in aiding adaptation. These informal agents are known to play a significant role in health and wellness among African Americans and investigations that utilize comprehensive measures that are capable of aptly testing the role these factors have in caregiving is essential.

The act of coping is a context-dependent behavior, which is influenced by a number of variables related to not only the family and its household, but also environmental factors. These environmental factors could present as either family resources or vulnerabilities. Such factors would include the social environment, in which the family exists, neighborhood characteristics, and community resources. For African Americans, these environmental factors and the family's perception of them would be greatly influenced by a socio-cultural history of racism, discrimination, and oppression. Future studies should further examine these variables and their relationship to caregiver well-being. Qualitative research might prove useful in this endeavor. Such exploratory analyses would allow for more accurate identification and deeper understanding of the specific stressors, resources, and vulnerabilities that confront African American caregivers.

There is yet another interesting aspect of coping that deserves more attention in the family stress literature. Though, a number of studies using family stress and coping frameworks have considered the moderational affects of coping mechanisms on family well-being, there is an ever-increasing trend to also consider the mediational affects of coping. Mediation and moderation are often terms used interchangeably in the social work literature, yet they are distinctly different. Mediation describes the mechanism by which a given effect occurs. Moderation, on the other hand, describes how one variable or set of variables interacts with a primary variable to affect outcomes. If these definitions are applied to family stress and adaptation frameworks the process by which coping could influence adaptation would vary. If coping mechanisms are considered to be mediators, they would function in an additive way to mediate family stress. It might increase the family's ability to adapt or it might increase the likelihood that they seek supportive services. On the other hand, if coping mechanisms are considered moderators in the model, they would interact with the stressor variables to produce variations in adaptational outcomes. The magnitude of adaptation might vary depending on the type of coping mechanism employed and the stress the family is facing. Given its varied application as both a mediator and moderator, coping is a variable that can be examined in multiple ways via multiple conceptual pathways. There exists no universal consensus among social science researchers on how coping should be measured; whether they should be considered moderators or mediators. Moreover, in their development of the Model of Resiliency McCubbin and McCubbin do not make this distinction clear. In her discussion of how moderators and mediators are

considered in Alzheimer's disease caregiving, Morano (2003) asserts that "the majority of caregiving literature has an a priori assumption that appraisal and coping are mediators of stress" (p. 116). There are a number of chronic illness and caregiving studies that take this approach (Haley et al, 1996;Ekwall et al, 2007; Knight et al , 2000; Sun et al, 2009; Connell & Gibson, 1997) . For the purposes of this study, two coping indicators (e.g. church attendance and help-seeking behaviors) were presumed to mediate the relationship between family caregiving stress and well-being. This approach was taken, because the study sought to understand how caregiver adaptation happens and given the pre-existing literature that suggests that coping has a role in caregiver well-being, coping factors were considered mediators. As was presented in Chapter Five "Findings," the results of this study suggest that these variables of interest do not mediate the relationship between caregiving and well-being. Consequently, it is possible that coping is not a mediator, but instead a moderator. Though it was assumed in this study that the stress of caregiving precedes and influences coping and therefore affect family well-being outcomes, this may not be the case. A moderational relationship between the variables might exist, where coping patterns might interact with and thus affect the relationship that exists between the stress of caregiving and well-being. Coping mechanisms might then work as protective factors against the stress of caregiving and influence outcomes. Future research should test these relationships.

Finally, using the findings of this research as a building block, researchers should replicate this study with other caregiver subgroups (e.g. other ethnic groups, gender specific groups, illness- specific groups, etc.). Dissecting the unique family resources,

vulnerabilities, and coping factors that contribute to or mitigate caregiver well-being is an important contribution to the literature and to social work practice. Such research would help pinpoint specific caregiver characteristics that contribute to healthy adaptation and resilience. This has direct implications for intervention development and policy.

Implications for Practice & Policy

At the most basic level this study quantifies African American caregivers and provides a basic social and demographic description of this sample. Though basic in content, this information will aid practitioners in developing service needs assessments. The more complex analyses that looked at health and well-being consequences of providing care are also important and will be beneficial in health policy and decision-making, particularly as it concerns caregiver health, caregiver service use, and caregiving policy initiatives.

How families cope with family stressors is very much a function of their social resources, vulnerabilities, socio-cultural background, and help-seeking behaviors. This is no different in the face of chronic illness. Caregivers of persons with chronic illness have increased family responsibilities and strains. Accordingly, they must figure out ways to cope and adapt to their situation. But, the unique experiences and social context of each family varies greatly and accordingly so does the adaptation process. Thus there is a need for interventions that consider a family's unique background, stressors, and coping patterns (Saunders, 2003). This presents a unique challenge for practitioners,

particularly with the current body of research that has informed practice standards thus far.

This research study has the capacity to inform practice standards. By using within-group analytic approaches (and holding constant ethnic variations) this research study helps distinguish particular family demographic and social factors, norms, and patterns of functioning that practitioners must consider in designing tailored comprehensive family support interventions. Based upon study findings, it is now clear that household structure and multiple role assignment matter in family caregiver well-being. Given this knowledge, there is a need for practitioners to work with family caregivers on developing strategies to alleviate role strains.

Disparities exist in the use of family based self-help support and education services. For African American caregivers, in particular, there is limited use of these models of care (Williams & Barton, 2003; Scharlach, Giunta, Chow, Lehning, 2008). It has been suggested that this lack of service use is related to both accessibility and acceptability concerns (Barton, 2003; Scharlach, Giunta, Chow, Lehning, 2008). With the knowledge obtained from this study practitioners can now begin to develop family-based psycho-education and/or family support interventions that consider not just the full-range of presumed supportive resources, but instead target specific contextual factors (e.g. additional life stressors, family member resources and family member vulnerabilities). Incorporating these dynamics into existing service options ensures a multi-systems approach which reinforces the existing adaptive structure of the family and brings in support congruent with their needs (Hines-Martin, 2002). This has great

implications for increasing service use and eliminating disparities. An example of this is demonstrated by exploring the relationship between household structure and caregiver health. From this study it is evident that for African Americans in particular, having more people in the household is related to positive health reports. Multiple-headed households can dissipate presumed caregiver responsibilities and increase financial and material resources. Caregivers in these household have increased strains and negative well-being outcomes and thus attention should be given to the provision of more support for these individuals. Specifically for practitioners, future family support programs should consider models that provide more or improved service options for members of single-headed households, such as in-home care assistance. This has obvious implications for policies. In particular, given the demography statistics that suggest that many African American households are single-headed, the results of this study suggests that advocates revisit the depth of the impact that marriage, out of wedlock birth rates, household structure, and household member participation have on the well-being and social welfare of African American family members.

Summary

The findings of this dissertation provide a framework for understanding caregiving as it exists within African American families coping with chronic illness. Thus, this study fills a necessary gap in the knowledge base. As a result of study findings, social scientists have more information on the profile and experience of African American caregivers. Complementing research that suggests lower self-reports of

caregiving burden and strain among African Americans, findings of this study suggest that the act of caregiving is not a definitive family stressor for African Americans. When stacked up against other family stressors, such as unemployment and divorce, the presumed negative effects of caregiving disappears. In most respects, according to study findings, caregivers and non-caregivers are demographically similar. They share the same resources, vulnerabilities, and coping patterns, which suggests some sense of cultural homogeneity. Yet, as was suggested in the subchapter “Directions for Future Research”, additional research with more defined measures is needed to further explore or test this conclusion. Within-group analyses yielded results that suggest that context matters. Household structure, education, employment, multiple carer roles, and coping patterns all inform caregiver well-being. This duplicates the finding of other research studies and provides support for the idea that context (e.g. environmental, social, cultural, and ecological) influences caregiving (Magana, 2004; Dilworth-Anderson, Goodwin, Williams, 2004; Rozario & DiRienzi, 2008). African Americans have a rich tradition and history of providing family care. In the words of Carlton-Laney (2006) in her discussion of caregiving trends among African American

“Caregiving is an essential part of African American mutual aid and self-help that has historically permeated the community, providing much-needed service where gaps existed.” (p.382)

This study is important because it directs attention to the factors that contribute to caregiving resilience, an important aspect of African American family life.

Appendix 1: 12-Item CES-D Measure of Depressed Mood.

The variable index of depression is created by adding the 12 items of the Center for Epidemiological Studies- Depression Scale -D (CES-D).

National Survey of Families and Households (NSFH) Depression Screening Question

“Next is a list of the ways you might have felt or behaved during the past week. On how many days, during the past week did you:

- a) Feel bothered by things that don’t usually bother you;
- b) Feel like not eating; appetite was poor;
- c) Feel that you could not shake off the blues even with help from your family or friends;
- d) Have trouble keeping your mind on what you’re doing;
- e) Feel depressed;
- f) Feel that everything you did was an effort;
- g) Feel fearful;
- h) Sleep restlessly;
- i) Talk less than usual;
- j) Feel lonely;
- k) Feel sad;
- l) Feel you could not get going?”

8-point Response Scale: 0 days, 1 day, 2 days, 3 days, 4 days, 5 days, 6 days, 7 days

Appendix 2: Intercorrelation of Study Variables

Intercorrelation of Study Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Caregiving	1.00	.019	.075	.027	.046	.012	.037	-.038	-.008	.002	.030	-.012	-.023	.045	-.011	-.022
Age		1.00	.022	.070	-.194	.217	.264	-.050	-.206	.188	.181	-.032	-.019	-.090	-.288	.054
Gender			1.00	.054	-.025	-.262	.152	.122	.197	-.059	.161	.011	.035	.049	-.075	-.013
Divorce				1.00	.030	-.176	-.075	.009	.016	.019	-.009	.015	.016	.015	-.003	-.015
Education					1.00	.033	-.183	.215	.030	-.047	-.004	.057	.058	-.088	.171	.005
Household Type						1.00	.070	.276	.083	.011	-.005	.027	-.095	-.012	.074	
Employment							1.00	-.456	.249	.004	-.043	-.002	.114	-.255	-.045	
Income								1.00	.114	-.134	.020	.007	.008	-.130	.197	.116
Children									1.00	.026	.011	-.056	.085	.031	.055	-.033
Caregiver for 1+										1.00	-.107	-.063	.077	.042	-.440	-.040
Church Attendance											1.00	.022	-.036	-.072	.034	.105
Distress Coping												1.00	.375	.015	.058	.000
Emergency Coping													1.00	-.023	.029	.036
Depression														1.00	-.193	-.296
Health															1.00	.202
Happiness																1.00

REFERENCES

1. AHRQ (Agency for Healthcare Research and Quality) (2003). National Healthcare Disparities Report: Summary. Rockville, MD.
<http://www.qualitytools.ahrq.gov/dispariteisreport/archive/2003/documents/Report%207.pdf>
2. Amato, P.R. (2000). Consequences of divorce for adults and children. *Journal of Marriage and the Family*, 62, 1269 – 1287
3. Anderson, G.F. (2002). Chronic Conditions: Making the Case for Ongoing Care. *Partnership for Solutions*, Baltimore, MD: John Hopkins University Press..
Available at: www.partnershipforsolutions.org/DMS/files/chronicbook2002.pdf
[Accessed January 12 2009](#).
4. Anderson G & Horvath J. (2004). The Growing Burden of Chronic Disease in American. *Public Health Reports*, 119, 263-270.
5. Anderson, G.F. & Knickman, J.R. (2001). Changing The Chronic Care System to Meet People's Needs. *Health Affairs* 20(6):146-160.
6. Annerstedt, L., Elmstahl, S., Ingvad, B., & Samuelsson, S.M. (2000). Family caregiving in dementia – an analysis of the caregiver's burden and the “breaking-point” when home care becomes inadequate. *Scandinavian Journal of Public Health*, 28, 23-31.
7. Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist*, 37, 342-354.

8. Arno, P. S., Levine C., & Memmott M. M. (1999). The Economic Value of Informal Caregiving. *Health Affairs, 18*(2), 182-188.
9. Arksey, H. (2002). Combining informal care and work: supporting carers in the workplace. *Health Social Care Community, 10*, 151-161.
10. Artazcoz, L., Benach, J>, Borrell, C. & Cortes, I. (2004). Unemployment and Mental Health: Understanding the Interactions Among Gender, Family Roles, and Social Class. *American Journal of Public Health, 94*(1), 82-88.
11. Attewell, P., Domina, T., Lavin, D. & Levey, T. (2004). The Black Middle Class: Progress, Prospects, and Puzzles. *Journal of African American Studies, 8*(1), 6-19.
12. Bach, P. (1999). Racial Differences in the Treatment of Early-Stage Lung Cancer. *New England Journal of Medicine 341* (16), 1198-1205.
13. Baron, R.M. & Kenny, D.A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(6), 1173-1182.
14. Barrett, P. (2007). Structural Equation Modeling: Adjudging Model Fit. *Personality and Individual Differences, 42*(5), 815-824.
15. Bartley, M. (1994). Unemployment and ill health: understanding the relationship. *Journal of Epidemiology and Community Health, 48*,333-337.
16. Beach, S.R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging, 15*, 259-271.

17. Becker G., Beyene Y., Newsom E.M., Rodgers D.V. (1998). Knowledge and care of chronic illness in three ethnic minority groups. *Family Medicine*, 1998, 30, 173–178.
18. Biegel, D.E., Sales, E., Schulz. R. (1991). *Family caregiving in chronic illness*. Newbury Park, CA: Sage.
19. Borg, C. & Hallberg, I.R. (2006). Life Satisfaction among informal caregivers in comparison with non-caregivers. *Scandinavian Journal of Caring Science*, 20, 427-438.
20. Bookwala, J. (2009). The Impact of Parent Care on Marital Quality and Well-Being in Adult Daughters and Sons. *Psychological Sciences*, 64B (3), 339-347.
21. Bowen, M.E. & González, H. M. (2008). Racial ethnic differences in the relationship between the use of health care services and functional disability: the health and retirement study (1992–2004). *Gerontologist*.,48, 659–67
22. Braithwaite, R., & Taylor, S. (2001). *Health issues in the black community*. San Francisco: Jossey-Bass.
23. Braithwaite, R.L., Taylor, S.E. & Austin, J.N. (2000). *Building health coalitions in the black community*. Thousand Oaks, CA: Sage.
24. Brisco, R., McClain, G., Nesman, T., Mazza, J., & Woodside, M. (2010). The strengths and challenges facing African Americans: Building Culturally Competency Practices with Communities and Families. In R.L. Hampton, T.L. Gullotta, & R.L. Crowel (Eds). *The Handbook of African American Health*, (pps. 3-9) New York: Guilford Press.

25. Brown, S.L., Smith, D.M., Schulz, R., Kabeto, M.U., Ubel, P.A., POulin, M., Yi, J., Kim, C., Langa, K.M. (2004). Caregiving Behavior is Associated with Decreased Mortality. *Psychological Science*, 20(4), 488-94.
26. Brown, D.R., Ndubuisi, S.C., & Gary, L.E. (1990). Religion and psychological distress among blacks. *Journal of Religion and Health*, 29, 55-68.
27. Bubolz, M. M. & Sontag, M. S. (1993). Human Ecology Theory. In P.G Boss, W.J. Doherty, R. LaRossa, W.R. Schumm, & S. K. Steinmetz (Eds) *Sourcebook of Family Theories and Methods: A Contextual Approach*, (pp. 419-447). Plenum Press: New York
28. Bullock, K., Crawford, S. L., & Tennstedt, S.L. (2003). Employment and Caregiving: Exploration of African American Caregivers. *Social Work*, 48, 150-162.
29. Burton, L., Kasper, J., Shore, A., Cagney, K., LaVeist, T., & Cubbin, C., et al (1995). The structure of informal care: Are there differences by race? *The Gerontologist*, 35, 744-752.
30. Caldwell-Colbert, A.T., Daniel, J.H., & Dudley-Grant, G.R. (2003). The African Diaspora: Blacks in the therapeutic relationship. In Robinson, J.D., & James, L.C (eds.), *Diversity in Human Interactions: The Tapestry of America*, Oxford University Press, NY.
31. Cano, A. & O'Leary, K.D. (2000). Infidelity and separations predict major depressive episodes and symptoms of non-specific depression and anxiety. *Journal of Consulting and Clinical Psychology*, 68, 774-481.

32. Carlton-Laney, I. (2005). Rural African American Caregiving. In B. Berkman and S. D'Ambruso (Eds) *Handbook for Social Work in Health and Aging*, New York: Oxford University, pps 381-389.
33. Centers for Disease Control and Prevention (2000). Chronic disease overview. *National Center for Chronic Disease Prevention and Health Promotion*. Available from <http://www.cdc.gov/nccdphp/overview.htm>. Accessed 1/3/2009.
34. Chadiha, L. A., & Fisher, R. H. (2003). Contributing factors to African American women caregivers' mental well-being. Retrieved October 10, 2009 from <http://www.rcgd.isr.umich.edu/prba/perspectives/springsummer2002/chadiha.pdf>
35. Chadiha, L.A., Rafferty, J., & Pickard, J. (2003). The influence of caregiving stressors, social support, and caregiving appraisal on marital functioning among African American wife caregivers. *Journal of Marital and Family Therapy*, 24(4), 479-490.
36. Chappell, N.L. & Reid, R.C. (2002). Burden and Well-being Among Caregivers: Examining the distinction. *Gerontologist*, 42(6), 772-780.
37. Chatters, L. M., Taylor, R. J., Lincoln, K. D., & Schroepfer, T. (2002). Patterns of informal support from family and church members among African Americans. *Journal of Black Studies*, 13(1), 66-85.
38. Chernoff, N.N. (2002) NIMH Study: Blacks mentally healthier. *American Psychological Society Observer*, 15, 21-36.

39. Chou, K. (2000). Caregiver Burden: A Concept Analysis. *Journal of Pediatric Nursing, 15*(6), 398-407.
40. Chou, K., LaMontagne, L.L, & Hepworth, J.T. (1999). Burnout experienced by caregivers of relatives with dementia in Taiwan. *Nursing Research, 48*(4), 206-214.
41. Christian-Herman, J.L., O'Leary, K.D., & Avery-Leaf, S. (2001). The impact of severe negative events in marriage on depression. *Journal of Social and Clinical Psychology, 20*, 25-44.
42. Choi-Kwon, S., Kim, H., Kwon, S.U., & Kim, J.S. (2005). Factors Affecting the Burden on Caregivers of Stroke Survivors in Korea. *Archives of Physical Medicine and Rehabilitation, 86*(5), 1043-1048.
43. Collins, K.S., Hall, A., & Neuhaus, C. (1999). U.S. Minority Health: A Chartbook. *The Commonwealth Fund*: New York.
44. Collins, K.S, Hughes, D.L., Doty, M.M., Ives, B.L., Edwards, J.N. & Tenney, K. (2002). Diverse Communities, Common Concerns: Assessing health care quality for minority Americans. Finding from the Commonwealth Fund 2001 Health Care Quality Survey. *The Commonwealth Fund*, New York, Publication #523.
45. Collins, K.S., Tenney, K., & Hughes, D.L. (2002) Quality of Health Care for African Americans: Findings from The Commonwealth Fund 2001 Health Care Quality Survey, *The Commonwealth Fund*, New York, Publication #524.
46. Connell, C. M. & Gibson, G. D. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist, 37*, 355-364.

47. Corbie-Smith G, Thomas SB, Williams MV, et al (1999). Attitudes and beliefs of African Americans toward participation in medical research. *Journal of General Internal Medicine*, 14(9):537-546.
48. Crewe, S.E. (2005). Ethnogerontology: Preparing culturally competent social workers for the diverse faces of aging. *Journal of Gerontological Social Work*, 43(4), 45-58.
49. Davis, S. K., Liu, Y., & Gibbons, G.H. (2003). Disparities in trends of hospitalizations for potentially preventable chronic conditions among African American during the 1990s: Implication and Benchmarks. *American Journal of Public Health*, 93(3), 447-455.
50. DeFries, E.L., McGuire, L.C., Andresen, E.M., Brumback, B.A., & Anderson L. A. (2009). Caregivers of Older Adults with Cognitive Impairment. Preventing Chronic Disease *Public Health Research, Practice, & Policy*, 6(2), http://www.cdc.gov/pcd/issues/2009/apr/08_0088.htm. Accessed [July 2009]
51. DeMarco, R., Ford-Gilboe, M., Friedemann, M., McCubbin, H.I., & McCubbin, M.A. (2000). Family stress, coping, and family health. In V.H. Rice (Eds.) *Handbook of Stress, Coping, and Health: Implications for Nursing Research, Theory, and Practice* (pp. 295-332). Thousand Oaks, CA: Sage.
52. Demirovic J., Prineas R., Loewenstein D., Bean J., Duara R., Sevush S., & Szapocznik, J. (2003). Prevalence of dementia in three ethnic groups. The South Florida program on aging and health. *Annals of Epidemiology*, 13(6), 472-478.

53. DeNavas-Walt, C., & Proctor, B.D., & Mills, R.J. (2004). Income, Poverty, and Health Insurance Coverage in the United States: 2003, *U.S. Census Bureau, Current Population Reports (P60-226)*. U.S. Government Printing Office, Washington, D.C.
54. DeNavas-Walt, C., & Proctor, B.D., & Lee, C.H. (2006). Income, Poverty, and Health Insurance Coverage in the United States: 2005, *U.S. Census Bureau, Current Population Reports (P60-231)*. U.S. Government Printing Office, Washington, D.C.
55. Devins, G.M. & Ormes, C.M. (1985). Center for Epidemiologic Studies Depression Scale. In D.J. Keyser & R.C. Sweetland (Eds). *Test Critiques Vol II*, pp. 144-160. Kansas City, Missouri, Test Corporation of America.
56. Dilworth-Anderson, P., Brummett, B.H., Goodwin, P., Williams, S.W., Williams, R.B., & Siegler, I.C. (2005). Effect of Race on Cultural justifications for Caregiving. *Journal of Gerontology, 608(5)*, S257-S262.
57. Dilworth-Anderson, P., Boswell, G. & Cohen, M.D. Spiritual and Religious Coping Values and Beliefs among African American Caregivers: A Qualitative Study. *Journal of Applied Gerontology, 25(4)*, 355-369.
58. Dilworth-Anderson, P. Goodwin, P.Y., & Williams, S.W. (2004). Can culture help explain the physical effects of caregiving over time among African American Caregivers? *Journal of Gerontology, 59B(3)*, S138-S145.

59. Dilworth-Anderson, P., Williams, S. W., Cooper, T. (1999). Family caregiving to elderly African Americans: Caregiver types and structures. *Journal of Gerontology: Social Sciences, 54B*, 237-241.
60. Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000). *The Gerontologist, 42*, 237–272.
61. Donelan, K, Hill, C., Hoffman, C., Scoles, K., Feldman, P., Levin, E., et al (2002). Challenged to care: Informal caregivers in a changing health system. *Health Affairs, 21*, 222-231.
62. Drentea, P. & Goldner, M.A. (2006). "Caregiving Outside of the Home: The Effects of Race on Depression." *Ethnicity and Health 11*(1), 41-57.
63. Dura, J.R. Kiecolt-Glaser, J.K., & Stukenberg, K.W. (1991). Anxiety and Depressive Disorders in Adult Children Caring for Demented Parents. *Psychology and Aging, 6*(3), 467-473.
64. Ekwall, A.K., Sivberg, B., Hallberg, I.R. (2007). Older caregivers' coping strategies and sense of coherence in relation to quality of life. *Journal of Advanced Nursing, 57* (6), 584-596.
65. Ellison, C.G., Boardman, J.D., Williams, D.R., & Jackson, J.S. (2001). Religious Involvement, Stress, and Mental Health: Finding from the 1995 Detroit Area Study. *Social Forces, 80*(1), 215-249.

66. Enns, R.A., Reddon, J.R. & McDonald, L. (1999). Indications of Resilience among family members of people admitted to a psychiatric facility. *Psychiatric Rehabilitation Journal*, 23(2) , 127-135
67. Ensel, W.M (1986). Measuring Depression: The CES-D Scale. In N. Lin, A. Dean, & W.M. Ensel (Eds.). *Social Support, Life Events, and Depression*. Orlando: Academic Press
68. Evans, M. D. R. & Kelley, J. (2004). Effect of Family Structure on Life Satisfaction: Australian Evidence. *Social Indicators Research*, 69, 303-53.
69. Ferraro, K.F. & Farmer, M.M. (1999). Utility of Health Data from Social Surveys: Is There a Gold Standard for Measuring Morbidity? *American Sociological Review*, 64(2), 303-315
70. Fiscella, K., Franks, P. Gold, M.R. & Clancy, C.M.(2000). Inequality in Quality: Addressing Socioeconomic, Racial, and Ethnic Disparities in Health Care. *Journal of the American Medical Association*, 238 (19), 2579-2584.
71. Fredman, L., Daly, M. P., & Lazur, A. M., (1995). Burden among White and Black caregivers to elderly adults. *Journal of Gerontology: Social Sciences*, 50B, S110-S118.
72. Gallo, W.T., E.H. Bradley, M. Siegel, and S.V. Kasl (2000). Health Effects of Involuntary Job Loss: Findings from the Health and Retirement Survey. *Journal of Gerontology: Social Sciences*, 55B (3): 131–140.
73. Gallo, W.T., Bradley, E.H., Dubin, J.A., Jones, R.N., Falba, T.A., Teng, H., & Kasl, S. (2006). The Persistence of the Persistence of Depressive Symptoms in Older

- Workers Who Experience Involuntary Job Loss: Results from the Health and Retirement Survey. *Journal of Gerontology: Social Sciences, Series B*, 61(4), S221-S228.
74. Goode, K. T., Haley, W. E., Roth, D. L., & Ford, G. R. (1998). Predicting longitudinal changes in caregiver physical and mental health: A stress process model. *Health Psychology*, 17, 190-198.
75. Grant, E.N., Lyttle, C.S., & Weiss, K.B. (2000). The relation of socioeconomic factors and racial/ethnic differences in US asthma mortality. *American Journal of Public Health*, 90(12), 1923-1925.
76. Groger, L & Mayberry, P.S. (2001). Caring too much? Cultural lag in African American perceptions of filial responsibilities. *Journal of Cross-Cultural Gerontology*, 16, 21-39.
77. Guarnaccia, P.J. (1998). Multicultural Experiences of Family Caregiving: A Study of African-American, European-American and Hispanic-American Families. In: H. Lefley, (Ed). *Families Coping with Mental Illness: The Cultural Context*. (pp. 45-61) New Directions in Mental Health Services. San Francisco: Jossey-Bass.
78. Guarnaccia, P.J., & Parra, P. (1996). Ethnicity, social status, and a families' experience of caring for a mentally ill family member. *Community Mental Health Journal*, 30(3), 259-269.
79. Gurland, B., Wilder, D., Cross, P., Lantigua, R., Teresi, J., Barrett, V. et al (1995). Relative rates of dementia by multiple case definitions: Over two prevalence

- periods in three socio-cultural groups. *American Journal of Geriatric Psychiatry*, 3(1), 6-20.
80. Gurland B., Wilder D., Lantigua R., Mayeux R., Stern Y., Chen J., Cross P., Killeffer E., 1997. Differences in rates of dementia between ethno-racial groups. (In Martin L. G & Soldo B. J Eds). *Racial and ethnic differences in the health of older Americans* 233-269. National Academy Press, Washington, DC.
81. Haley, W., Gitlin, L., Wisniewski, S., Mahoney, D., Coon, D., & Winter, L., et al. (2004). Well-being, appraisal, and coping in African American and White dementia caregivers: Finding from the REACH study. *Aging & Mental Health*, 8, 316-329.
82. Haley, W.E., Roth, D.L., Coleton, M.I., Ford, G.R., West, C.A.C., Collins, R.P., & Isobe, T.L. (1996). Appraisal, Coping, and Social Support as Mediators of Well-Being in Black and White Family Caregivers of Patients with Alzheimer's Disease. *Journal of Consulting and Clinical Psychology*, 64(1), 121-129.
83. Hargrave, R. (2006). AGS Position Paper: Caregivers of African American elderly with dementia – A review and analysis. *Annals of Long Term Care*, 14(10), 36-40.
84. Hatchett, S.J. & Jackson, J.S. (1993). African American extended kin systems: An assessment. In H.P. McAdoo (Ed.) *Family Ethnicity: Strength in Diversity* (pp.90-108). Newbury Park, CA: Sage.
85. Hatfield, A.B. (1987) Families as caregivers: A historical perspective. In A.B. Hatfield & H.P. Lefley (Eds). *Families of the Mentally Ill: Coping and Adaptation* (pp. 3-29). Guilford Press, New York, New York.

86. Hayward, M.D., Miles, T.P., Cummins, E.M. & Yang, Y (2000). The Significance of Socioeconomic Status in Explaining the Racial Gap in Chronic Health Conditions. *American Sociological Review*, 65(6), 910-930.
87. Heyman, A., Fillenbaum, G., Prosnitz, B., Raiford, K., Burchette, B., Clark, C. (1991). Estimated prevalence of dementia among elderly black and white community residents. *Archives of Neurology*, 48,594-598.
88. Hill, J. (2003a). The hidden patient. *The Lancet*, 362, 1682-1684.
89. Ho, A. Collins, SR, Davis, K, and Doty, M. (2005). *A Look at Working-Age Caregivers' Roles, Health Concerns, and Need for Support*. New York, NY: The Commonwealth Fund, August 2005
90. Hoffman, C., Rice, D., & Sung, H. Y. (1996). Persons with chronic conditions. Their prevalence and costs. *JAMA* 276, 1473-1479.
91. Hofferth, S.L. (2005). Secondary data analysis in family research. *Journal of Marriage and Family*, 67, 891-907.
92. Hu, L.T. & Bentler, P.M. (1995). Evaluating Model fit. In R.H. Hoyle (ed) *Structural Equation Modeling-Concepts, Issues, and Applications*. Thousand Oaks, California: Sage Publications, pp 76-99.
93. Hu, L.T. & Bentler, P.M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*, 6(1), 1-55.
94. Huang, C.Y. (2004). Informal Female Care Givers of Older Adults with Dementia in Taiwan. *California Journal of Public Health Promotion*, 2(3), 53-66.

95. Husaini, B.A., Sherkat, D.E., Moonis, M., Levine, R., Holzer, C., & Cain, V.A. (2003). Racial differences in the diagnosis of dementia and in its effects on the use and costs of health care services. *Psychiatric Services, 54*, 92-96.
96. Idler, E. L., & Benjamini, Y. (1997). Self-rated health and mortality: A review of twenty-seven community studies. *Journal of Health and Social Behavior, 38*, 21–37.
97. Isaacs, J.B. (2007). *Economic Mobility of Black and White Families*, The Brookings Institution.
98. Jackson, J.S. & Gurin, G. (1987-1992). *National Survey of Black Americans: 1979-1992*. Inter-University Consortium for Political and Social Research.
99. Jackson, J. S. & Tucker, M.B. (1997). *Three-Generation National Survey of Black American Families, 1979-1981* [Computer file]. ICPSR09288-v2. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor], 1997. doi:10.3886/ICPSR09288
100. Jackson, J.S., Torres, M., Caldwell, C.H., Neighbors, H.W., Neese, R.M., Taylor, R.J. Trierweiler, S., & Williams, D.R. (2004). National Survey of American Life: A Study of Racial, Ethnic, and Cultural Influences of Mental Disorders and Mental Health. *International Journal of Methods in Psychiatric Research, 13*(4), 196-207
101. James, C., Thomas, M., Blanton, L.M., Rushing, O.E., & Ruiz, S (2007). Key Facts: Race, Ethnicity & Medical Care, 2007 Update. . *The Henry J. Kaiser Family Foundation*: Menlo Park. Available at:

<http://www.kff.org/minorityhealth/upload/Key-Facts-Race-Ethnicity-Medical-Care-Chartbook..pdf>.

102. Janevic, M.R., & Connell, C.M. (2001). Racial, ethnic and cultural differences in the dementia caregiving experience: Recent findings. *The Gerontologist*, 41, 334-347.
103. Jargowsky, P.A. (1997). *Poverty and Place: Ghettos, Barrios, and the American City*. New York: Russell Sage.
104. Johnson, E. (2000). Differences among families coping with serious mental illness: A qualitative analysis. *American Journal of Orthopsychiatry*, 70(1), 126-134.
105. Johnson, L.B. & Staples, R. (2005). *Black families at the crossroads: Challenges and prospects*. San Francisco, CA: Jossey-Bass.
106. Johnson, D.R. & Wu, J. (2002). An empirical test of crisis, social selection, and role explanation of the relationship between marital disruption and psychological distress: A pooled time-series analysis of four wave panel data. *Journal of Marriage and Family*, 64, 211-224.
107. Kessler, R.C., Berglund, P., Demler, OI, Jin, R., Koretz, D., Merukangas, K.R. et al. (2003). National Comorbidity Survey Replication. The epidemiology of major depressive disorder: Results from the National Comorbidity Survey Replication (NCS-R). *Journal of American Medical Association*, 289, 3095-3105.
108. Kessler, R.C., Foster, C., Webster, P.S., & House, J.S. (1992). The relationship between age and depressive symptoms in two national surveys. *Psychology and Aging*. 7(1), 119-126

109. Kessler, R.C., McGonagle, K., Zhao, S., Nelson, C., Hughes, M., Eshleman, S., Wittchen, H., & Kendler, K. (1994). Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States: Results from the National Comorbidity Survey. *Archives of General Psychiatry*, 51(1): 8-19.
110. Kessler, R. C., Berglund, P. A., Zhao, S., Leaf, P. J., Kouzis, A. C., et al. (1996). The 12-month prevalence and correlates of serious mental illness (SMI). In R. W. Manderscheid & M. A. Sonnenschein (Eds.), *Mental health, United States*. Rockville, MD: Center for Mental Health Services
111. Kim, H.K. & McHenry, P. (2002). The Relationship between marriage and psychological well-being. *Journal of Family Issues*, 23(8), 885-911.
112. Kingston, R.S. & Smith, J.P. (1997). Socioeconomic status and racial and ethnic differences in functional status associated with chronic disease. *American Journal of Public Health*, 87(5), 805-810.
113. Knight, B.G., Flynn Longmire, C.V., Dave, J., Kim, J.H., & David S. (2007). Mental health and physical health of family caregivers for persons with dementia: A comparison of African American and White Caregivers. *Aging and Mental Health*, 11, 538-546.
114. Knight, B.G. & Sayegh, (2010). Cultural values and Caregiving: The updated Sociocultural Stress and Coping Model. *Journal of Gerontology: Psychological Sciences*, 65B(1), 5-13.
115. Knight, B. G., Silverstein, M., McCallum, T. J., & Fox, L. S. (2000). A sociocultural stress and coping model for mental health outcomes among African American

- caregivers in Southern California. *Journal of Gerontology: Psychological Sciences*, 55B, P142–P150.
116. Kosberg, J., Kaufman, A.V., Burgio, L.D., Leeper, J.D., & Sun, F. (2007). Family Caregiving to those with dementia in rural Alabama: Racial similarities and differences. *Journal of Aging and Health*, 19(1), 3-21
117. Kramer, B.J. (1993). Marital history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. *Family Relations*, 42, 367–375.
118. LaVeist, T.A. (2002) Ed., *Race, Ethnicity, and Health: A Public Health Reader*, San Francisco: Jossey-Bass.
119. LaVeist, T.A. (2005) *Minority Populations and Health: An Introduction to Health Disparities in the United States*. Jossey Bassey
120. LaVeist T.A., Nickerson K.J., Bowie J.V. (2000). Attitudes about Racism, Medical Mistrust, and Satisfaction with Care among African American and White Cardiac Patients. *Medical Care Research and Review*. ;57(1):146–61
121. Lawton, M. P., Moss, M., Kleban, M. H., Glicksman, A., & Rovine, M. (1991). A 2-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology: Psychological Sciences*, 46, P181-P189.
122. Lawton, M. P., Rajagopal, D., Brody, E., & Kleban, M. H. (1992). The dynamics of caregiving for a demented elder among Black and White families. *Journal of Gerontology*, 47, S156-S164.

123. Lee, S., Colditz, G.A., Berkman, L.F., Kawachi, I. (2003). Caregiving and Risk of Coronary Heart Disease in U.S. Women: A Prospective Study. *American Journal of Preventative Medicine*, 24(2), 113-119.
124. Lester, L.A., Rich, S.S., Blumenthal, M.N., Togias, A., Murphy, S., Malveaux, F., Miller, G.M., Dunston, J., Solway et al (2001). Ethnic differences in asthma and associated phenotypes: Collaborative Study on the Genetics of Asthma, *Journal of Allergy and Clinical Immunology*, 108, 357-362
125. Liao Y., Tucker P., Giles W.H. (2004). Health status among REACH 2010 communities, 2001-2002. *Ethnicity & Disease*, 14(3), S9-13.
126. Loehlin, J.C. (1987). *Latent Variable Models*. Baltimore: Lawrence Erlbaum.
127. Lubkin, I. & Payne M.E. (1998). "Family Caregivers." In Lubkin, I. M. and Larsen, P. D. (Eds.), *Chronic Illness: Impact and Interventions*. (pp. 258-282). Massachusetts: Jones and Bartlette Publishers.
128. Lum, T.Y. (2005). Understanding the racial and ethnic differences in caregiving arrangements. *Journal of Gerontological Social Work*, 45(4). 3-21.
129. Maciejewski, P.K>, Prigerson, H.F., Mazure, C.M. (2001). Sex differences in event-related risk for major depression. *Behavioral Neuroscience*, 117, 195-201.
130. Magana, S. (2004). African American Families Who Care for Adults with Developmental Disabilities or Mental Illness: A Call for Research. *African American Research Perspectives*, 10, 129-139.
131. Marks, N. F. (1996). Caregiving across the lifespan: National prevalence and predictors. *Family Relations*, 45, 27-36

132. Marks, N.F. & Lambert, J.D. (1997). Family Caregiving: Contemporary Trends and Issues. In T.H. Brubaker (Eds), *Family Relationships in Later Life*. Newbury Park, CA: Sage.
133. Marks, N.F. & Lambert, J.D. (1998). Marital Status Continuity and Change Among Young and Midlife Adults. *Journal of Family Issues*, 19(6), 652-686.
134. Marks, N.F. & Lambert, J.D. (1999). Transitions to Caregiving, Gender, and Psychological Well-Being: Prospective Evidence from the National Survey of Families and Households. In T.H. Brubaker (Eds), *Family Relationships in Later Life*. Newbury Park, CA: Sage.
135. Marsh, D. T. (1998a). *Serious mental illness and the family: The practitioner's guide*. New York: Wiley.
136. Marsh, N.F. (1998b). Does it Hurt to Care? Caregiving, Work and Family Conflict, and Midlife Well-Being. *Journal of Marriage and the Family* 60: 951-966.
137. Marsh, K., Darity, W.A., Cohen, P.N., Casper, L.M., & Salters, D. (2007). The Emerging Black Middle Class: Single and Living Alone. *Social Forces*, 86(2), 735-762.
138. Massakowski, K.N. (2008). Is the duration of poverty and unemployment a risk factor for heavy drinking? *Social Science & Medicine*, 67(6), 947-955.
139. Massakowski, K.N. (2009). The Influence of Past Unemployment Duration on Symptoms of Depression among Young Women and Men in the United States. *American Journal of Public Health*, 99(10), 1826-1832.

140. Mayberry R.M., Mili F., & Ofili E. (2000). Racial and Ethnic Differences in Access to Medical Care. *Medical Care Research and Review*, 57(1):108–45
141. McAdoo, H.P. (1998). African American Families: Strengths and Realities. In H. L. McCubbin, E. A. Thompson, A.I. Thompson, & J. A. Futrell (Eds.), *Resiliency in African-American Families* (pp. 17-30). Thousand Oaks, California: Sage Publications
142. McAdoo, H.P. & Younge, S.N. (2009). Black Families. In Handbook of African American Psychology, B.M. Tynes, H.A. Neville, & S.O. Utsey (Eds). Sage Publications: Thousand Oaks.
143. McCann, J. J., Hebert, L. E., Beckett, L. A., Morris, M. C., Scherr, P. A., Evans, D. A. (2000). Comparison of informal caregiving by black and white older adults in a community population. *Journal of the American Geriatrics Society*, 48,1612-1617
144. McCubbin, H. I., Futrell, J.A., Thompson, E.A., & Thompson, A. I. (1998). Resilient Families in an Ethnic and Cultural Context. In H.I. McCubbin, E.A. Thompson, A.I. Thompson, & J.A. Futrell (Eds.) *Resiliency in African-American Families*. Thousand Oaks: Sage Publications.
145. McCubbin, H.I. & McCubbin, H.A. (1988). Typologies of resilient families: Emerging roles of social class and ethnicity. *Family Relations*, 37, 245-254.
146. McCubbin, H. I., & McCubbin, M. A. (1991). Family stress theory and assessment. In H.I. McCubbin & A. I. Thompson (Eds.), *Family assessment inventories for*

research and practice (pp. 3-32). Madison, WI: University of Wisconsin-Madison.

147. McCubbin, H.I. & McCubbin, H.A. (1993). Coping with health crisis: Resiliency model of family stress, adjustment and adaptation. In C. Danielson, B. Hamel-Bissell, & P. Winstead-Fryze (Eds.), *Families, health and illness: Perspective on coping and intervention* (pp.21-53). New York: Mosby.
148. McCubbin, H., & McCubbin, M. (2001). Resiliency in Families: A Conceptual Model of Family Adjustment and Adaptation in Response to Stress and Crises. In H. McCubbin, A. Thompson & M. McCubbin (Eds.), *Family Measures: Stress, Coping and Resiliency- Inventories for Research and Practice*. Honolulu: Kamehameha Schools.
149. McCubbin, H.I. & Patterson, J.M. (1983). The family stress process: The Double ABCX model of adjustment and adaptation. *Marriage & Family Review*, 6, 7-37.
150. McCubbin, H.I., Thompson, A.I., & Thompson, E.A., Elver, K.M., & McCubbin, M.A. (1994). Ethnicity, schema, and coherence: Appraisal processes for families in crisis. In H.I. McCubbin, E.A. Thompson, A.I Thompson, & J.E. Fromer, (Eds.), *Sense of coherence and resiliency: Stress, coping, and health* (pp. 41-67). Madison, WI: University of Wisconsin System.
151. McDaniel, S.H. & Campbell, T.L. (1998). Family caregiving and coping with chronic illness. *Families, Systems, & Health*, 16 (3), 195-196.
152. McGoldrick, M. (1993). Ethnicity, Cultural Diveristy and Normality. In F. Walsh (Ed). *Normal Family Processes₂* (pp. 331-360). The Guildford Press, New York.

153. McKee-Ryan, F., Song, Z., Wanberg, C.R., Kinicki, A.J. (2005). Psychological and physical well-being during unemployment: a meta analytic study. *Journal of Applied Psychology, 90*(1), 53-76.
154. MetLife Mature Market Institute and National Alliance for Caregiving. (2006). *The MetLife caregiving cost study: Productivity losses to U.S. business*. Bethesda, MD: National Alliance for Caregiving.
155. Mirowsky, J., & Ross, C. E. (1989). *The social causes of psychological distress*. New York: Aldine de Gruyter.
156. Morano, C.L. (2003). Appraisal and Coping: *Moderators Mediators of Stress in Alzheimer's Disease Caregivers?* *Social Work Research, 27*, 116-124.
157. Mossakowski, K.N. (2009). The Influence of past unemployment duration on symptoms of depression among young women and men in the United States. *American Journal of Public Health, 99*(10), 1826-1832.
158. Muthén, L.T. & Muthén B.O. (2004) *Mplus User's Guide, 4.2 Edition*. Los Angeles: Muthén & Muthén.
159. National Alliance for Caregiving, & AARP. (2004). *Family caregiving in the U.S.: Findings from a national survey*, Bethesda, MD: National Alliance for Caregiving, and Washington D.C: AARP. Available at <http://www.caregiving.org/data/04finalreport.pdf>.
160. National Center for Health Statistics, 2005. *National Health Interview Survey (NHIS) Survey Description*. Hyattsville, MD: Division of Health Interview Statistics: March 2002

161. National Family Caregivers Association & Family Caregiver Alliance (2006). *Prevalence, Hours and Economic Value of Family Caregiving, Updated State-by-State Analysis of 2004 National Estimates* (by Peter S. Arno, PhD). Kensington, MD: NFCA & San Francisco, CA: FCA
162. Navaie-Waliser, M., Feldman, P. H., Gould, D.A., Levine, C., Kuerbis, A.N. & Donelan, K. (2002). When the caregiver needs care: the plight of vulnerable caregivers. *American Journal of Public Health, 92*(3), 409-413.
163. Newby, N.M. (1996) Chronic Illness and the Family Life Cycle. [*Journal of Advanced Nursing, 23* \(4\), 786 – 791.](#)
164. Nkongo, N., & Archbold, P. (1995). Reasons for caregiving in African American families. *Journal of Cultural Diversity, 2*(4), 116-123.
165. Nobles, W. W. (1988). African American Family Life – An instrument of culture. In H. P. McAdoo (Ed.), *Black Families* (pp. 44-53). Beverly Hills, CA: Sage
166. Odgen, C.L., Carroll, M.D., Curtin, L.R., McDowell, M.A., Tabak, C.J. & Flegal, K.M. (2006). Prevalence of Overweight and Obesity in the United States, 1999-2004. *Journal of the American Medical Association, 259*, 1579-1555.
167. Paez, C.A., Zhao, L., & Hwang, W. (2009). Rising Out-of-Pocket Spending for Chronic Conditions: A Ten-Year Trend," *Health Affairs, 28*(1):15–25.
168. Parham, W. J. (1990). Coping with perceived burden: ethnic and cultural issues in Alzheimer's family caregiving. *Journal of Applied Gerontology; 9*, 325-339.
169. Paul, K. I. & Moser, K. (2009). Unemployment impairs mental health: Meta-analyses. *Journal of Vocational Behavior, 74*(3), 264-282.

170. Pearlin, L.I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19*(1), 2-21.
171. Pearlin, L., Mullan, L., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583-594.
172. Perry, A. (2004). A model of stress in families of children with developmental disabilities: Clinical and research applications. *Journal on Developmental Disabilities, 11*(1), 1-16.
173. Picot, S. (1995). Rewards, costs, and coping of Black American caregivers. *Nursing Research, 44*, 147-152
174. Picot S. J., Debanne S. M., Namazi K. H., & Wykle M. L. (1997). Religiosity and perceived rewards of Black and White caregivers. *The Gerontologist 37*:89-101.
175. Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *.Psychology and Aging, 18*, 250–267.
176. Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45*, 90–106.
177. Pinquart, M. & Sörensen, S. (2007). Correlates of Physical Health of Informal Caregivers: A Meta-Analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 62*, P126-P137.

178. Pleis, J.R. & Lethbridge-Çejku, M. (2006). Summary of health statistics for U.A. adults: National health interview survey, 2005. *National Center for Health Statistics. Vital Health Statistics 10*(232).
179. Poole, T. G. (1990). Black families and the Black church: A sociohistorical perspective. In H. E. Cheatham & J. B. Stewart (Eds.), *Black families: Interdisciplinary perspective* (pp. 33-48). New Brunswick, NJ:
180. Pruchno, R. A. & Potashnik, S. L. (1989). Caregiving spouses. Physical and mental health in perspective. *Journal of the American Geriatric Society, 37*, 697-705.
181. Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.
182. Redinbaugh, E. M., MacCallum, R. C., & Kiecolt-Glaser, J. K. (1995). Recurrent syndromal depression in caregivers. *Psychology and Aging, 10*, 358-368.
183. Remington, P.L., Smith, M.Y., Williamson, D.F., Anda, R.F., Gentry, E.M. & Hogelin, G.C. (1988). Design, characteristics, and usefulness of state-based behavioral risk factor surveillance: 1981-1987. *Public Health Reports, 103*(4), 366-375.
184. Robert Wood Johnson Foundation and the Foundation for Accountability. (2001). *A portrait of the chronically ill in America 2001*. Princeton, NJ: Authors.
185. Robins, L. N. & Regier, D.A. (1991). *Psychiatric Disorders in America: The Epidemiologic Catchment Area Study*. New York: The Free Press
186. Rodriguez, E., Allen, J.A., Frongillo, E.A., & Chandra, P. (1999). Unemployment, depression, and Health: A Look at the African-American Community. *Journal of Epidemiology and Community Health, 53*, 335-342.

187. Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59B, P185–P190.
188. Rose, D., Mannino, D.M., & Leaderer, B.P. (2006). Asthma prevalence among US adults, 1998--2000: role of Puerto Rican ethnicity and behavioral and geographic factors. *American Journal of Public Health*, 96, 880-888.
189. Roth, D.L., Burgio, L.D., Gitlin, L.N., Gallagher-Thomas, D., Coon, D.W., Belle, S.H. et al. (2003). Psychometric analysis of the Revised Memory and Behavior Problem Checklist: Factor structure of occurrence and reaction ratings. *Psychology & Aging*, 18, 906-915.
190. Roth, D.L., Haley, W.E., Owen, J.E., Clay, O.J., & Goode, K.T. (2001). Latent Growth Models of the Longitudinal Effects of Dementia Caregiving: A Comparison of African American and White Family Caregivers. *Psychology and Aging*, 16(3), 427-436.
191. Rozario, P. A., Chadiha, L.A., Proctor, E.K., & Morrow-Howell, N. (2008). Predicting the influence of social resources on African American with and daughter caregivers' depressive symptoms. *Journal of Family Issues*, 29, 317-333.
192. Rozario, P.A. & DeRienzi, D. (2008). Familism Beliefs and Psychological Distress Among African American Women Caregivers. *The Gerontologist*, 48(6), 772-780.

193. Rundall TG, Shortell SM, Wang MC, Casalino L, Bodenheimer T, Gillies R, Schmittiel J, Oswald N, Robinson JC. (2002). As good as it gets: Chronic care management in nine leading physician organizations. *British Medical Journal*, 325, 958-61.
194. Ryff, C.D. & Keyes, C.L..M. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology*, 69(4), 719-727.
195. Satcher D. Eliminating racial and ethnic disparities in health: the role of the ten leading health indicators. *Journal of the National Medical Association*; 92, 315–318.
196. Saunders, J.C. (2003). Families Living with Severe Mental Illness: A Literature Review. *Issues in Mental Health Nursing*, 24, 175-198.
197. Scharlach, A. (2001). *Family caregiving. SB-910 report*, Berkeley, CA: University of California, California Policy Research Center.
198. Scharlach, A., Sobel, E., & Roberts, E. (1991). Employment and caregiver strain: An integrative model. *The Gerontologist*, 31, 778-787.
199. Scharlach, A.E., Giunta, N., Chow, J.C., & Lehning, A. (2008). Racial and Ethnic Variations in Caregiver Service Use. *Journal of Aging and Health*, 20(3), 326-346.
200. Schoenbom, C.A. (2004). Marital Status and Health: United States, 1999-2002. *Advance Data*, no. 351

201. Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association*, 282, 2215-2219.
202. Schulz, R. & Sherwood (2008). Physical and Mental Health Effects of Family Caregiving. *American Journal of Nursing*, 108 (9), 23-27.
203. Shaw, M C., & Halliday, P H. (1992). The family, crisis and chronically illness: an evolutionary model. *Journal of Advanced Nursing*, 17, 537-543.
204. Shurgot, G.R. & Knight, B.G. (2005). Influence of neuroticism, ethnicity, familialism, and social support on perceived burden in dementia caregivers: Pilot test of the Transactional Stress and Social Support Model. *Journal of Gerontology:Psychological Sciences*, 60B, 331-334.
205. Simon, R.W. (2002). Revisiting the relationships among gender, marital status, and mental health. *American Journal of Sociology*, 4, 1065-1096.
206. Smedley, B.D., Stith, A.Y., & Nelson, A.R. (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care. Institute of Medicine Report.* Washington, D.C.: National Academy Press.
207. Snowden, L. (2001). Barriers to Effective Mental Health Services for African Americans. *Mental Health Services Research*, 3(4), 181-187.
208. Snowden L.R. & Pingitore D. (2002). Frequency and scope of mental health service delivery to African Americans in primary care. *Mental Health Services Research*, 4, 123-30.

209. Son, J., Erno, A., Shea, D., Femia, E., Zarit, S.H., Stephens, M.P. (2007). The Caregiver Stress Process and Health Outcomes. *Journal of Aging Health, 19*(6), 871-887.
210. Sprecher, S., Felmlee, D., Schmeeckle, M., Shu, X., Fine, M.A. & Harvey, J.H. (2006). No breakup occurs on an island: Social networks and relationship dissolution. In M.A. Fine & J.H. Harvey (eds) *Handbook of divorce and relationship dissolution*. Mahwah, NJ: Erlbaum, pp. 457-478.
211. Sridhar, G.R. & Madhu, K. (2001). Stress in the Cause and Course of Diabetes. *International Journal of Diabetes in Developing Countries, 21*, 112-120.
212. Steelfisher, G.K. (2004). Addressing unequal treatment: disparities in health care. Issue Brief, *Commonwealth Fund, (709)*, 1-9.
213. Substance Abuse and Mental Health Services Administration. (SAMHSA) (2002). Results from the 2001 national household survey on drug abuse: Summary of national findings. *DHHS Publication No. (SMA) 02-3758*. Rockville, MD
214. Sue, S. & Chu, J.Y. (2003). The mental health of ethnic minority groups: Challenges posed by the supplement to the Surgeon General's Report on Mental Health. *Culture, Medicine and Psychiatry 27, (4)*, 447-465.
215. Sun, F., Kosberg, J.I., Leeper, J., Kaufman, A.V., & Burgio, L. (2009). Racial Differences in Perceived Burden of Rural Dementia Caregivers: The Mediating Effect of Religiosity. *Journal of Applied Gerontology, 28*(2): 139 - 170
216. Sweet, J. A., & Bumpass, L. L. (1996). *The National Survey of Families and Households Waves 1 and 2: Data Description and Documentation*. Center for

Demography and Ecology, University of Wisconsin-Madison

(<http://www.ssc.wisc.edu/nsfh/home.htm>).

217. Sweet, J.A., Bumpass, L.L., & Call, V. (1988). The design and content of the National Survey of Families and Household. *NSFH Working Paper #1*. Madison, WI: Center for Demography and Ecology, University of Wisconsin.
218. Talley R. C. & Crews, J.E (2007). Framing the public health of caregiving. *American Journal of Public Health*, 97(2), 224-228.
219. Tang, M. X., Cross, P., Andrews, H., Jacobs, D. M., Small, S., & Bell, K., (2001). Incidence of Alzheimer's disease in African Americans, Caribbean Hispanics, and Caucasians in northern Manhattan. *Neurology*, 56, 49-56
220. Taylor, R. & Chatters, L. (1991). Extended family networks of older black adults. *Journal of Gerontology*, 46,210-217.
221. Taylor, R. J., Chatters, L. M., Hardison, C. B., & Riley, A. (2001). Informal Social Support Networks and Subjective Well-Being among African Americans. *Journal of Black Psychology*, 27, 439-463
222. Taylor, R.J., Chatters, L., & Jackson, J.S. (2007). Religious and Spiritual Involvement among older African American, Caribbean Blacks, and Non-Hispanic Whites: Finding from the National Survey of American Life. *Journal of Gerontology*, 62B(4), S238-S250.
223. Taylor, R.J., Chatters, L. M., & Levin J. (Editors) (2004). *Religion in the lives of African Americans: Social, psychological, and health perspectives*, Thousand Oaks, CA : Sage Publications

224. Tennstedt, S., & Chang, B.H. (1998). The relative contribution of ethnicity versus socioeconomic status in explaining differences in disability and receipt of informal care. *Journal of Gerontology: Social Sciences*, 53B(2), S61-S70.
225. Thomas, C., Benzeval, M., Stansfeld, S. (2007). Psychological distress after employment transitions: the role of subjective financial position as a mediator. *Journal of Epidemiology and Community Health*, 61, 48-52.
226. US Department of Health and Human Services. Healthy people 2010 (conference ed, in 2 vols). Washington, DC: US Department of Health and Human Services; 2000. Available at <http://www.health.gov/healthypeople>.
227. U.S. Department of Health and Human Services (1998). *Informal caregiving: Compassion in action*. Retrieved November 15, 2008, from <http://aspe.hhs.gov/daltcp/reports/Carebro2.pdf>.
228. U.S. Department of Health and Human Services (2001). *Mental Health: Culture, Race, and Ethnicity - A Supplement to Mental Health: A Report of the Surgeon General – Executive Summary*. Rockville, MD: Department of Health and Human Services, Public Health Service, Office of the Surgeon General.
229. Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946–972.
230. Wanberg, C. R., Kammeyer-Mueller, J. D., & Shi, K. (2001). Job loss and the experience of unemployment: International research and perspectives. In N. Anderson, D. S. Ones, H. K. Sinangil, & C. Viswesvaran (Eds.), *Handbook of Industrial, Work and Organizational Psychology* (pp. 253-269). London: Sage

231. Wang P.S., Berglund P, Kessler R.C. Recent care of common mental disorders in the United States. (2001). *Journal of General Internal Medicine*, 15, 284–292.
232. Wang, P.S., Berglund, P., Olfson, M. et al. (2005) Failure and delay in initial treatment contact after first onset of mental disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62, 603-613.
233. Wang, P.S., Lane, M., Olfson, M. et al. (2005). Twelve-month use of mental health services in the United States: results from the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62, 629-640.
234. Walsh, F. (1996). The concept of family resilience: Crisis & Challenge. *Family Process*, 35, 261-281. .
235. White, T.M., Townsend, A.L., & Stephens, M.A.P. (2000). Comparisons of African American and White women in the present carer role. *The Gerontologist*, 40, 718-728.
236. Williams, I.C. (2005). Emotional Health of Black and White Dementia Caregivers: A Contextual Examination. *Journal of Gerontology: Psychological Sciences*, 60B(6), P287-P295.
237. Williams, E. & Barton, P. (2003). Successful support groups for African American caregivers. *Generations*, 27(4), 81-83.
238. Williams D.R. & Collins C.A. (2001). Racial residential segregation: a fundamental cause of racial disparities in health. *Public Health Reports*, 116, 404–416.

239. Wilcox, S., Bopp, M., Wilson, D.K., Fulk, L.J., Hand, G.A., 2005. Race differences in cardiovascular and cortisol responses to an interpersonal challenge in women who are family caregivers. *Ethnicity & Disease, 15*, 17–24.
240. Wilkinson, D. (1993). Family Ethnicity in America. In H.P. McAdoo (Ed.) *Family Ethnicity: Strength in Diversity* (pp. 15-59). Sage Publications, Inc.
241. Wilkinson, A. & Lynn, J. (2005). Caregiving for Advanced Chronic Illness Patients. *Techniques in Regional Anesthesia and Pain Management, 9*(3), 122-132.
242. Wood, R.G., Goesling, B., & Avellar, S. (2007). The Effects of Marriage on Health: A Synthesis of Recent Research Evidence. *U.S. Department of Health and Human Services, Mathematica Policy Research Inc.* , Washington D.C.
243. Wykke, M. & Segal, M. (1991). A comparison of black and white family caregivers experience with dementia. *Journal of the National Black Nurses Association; 5* (1)29-41.
244. Yeo, G., & Gallagher-Thompson, D. (1996). *Ethnicity and the dementias*. Washington, DC: Taylor & Francis.
245. Young, C.J. & Gaston, R.S. (2000). Renal transplantation in black Americans. *New England Journal of Medicine, 343*, 1545–1552.