2010

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Recommended Citation

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EFFECTS OF CAREGIVING STRAIN ON ALL-CAUSE MORTALITY

by

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A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

BIRMINGHAM, ALABAMA

2010

EFFECTS OF CAREGIVING STRAIN ON ALL-CAUSE MORTALITY

MARTINIQUE PERKINS

LIFESPAN DEVELOPMENTAL PSYCHOLOGY

ABSTRACT

Purpose. This study examined how perceived caregiving strain is related to quality of life, mental and emotional health, and mortality in a large, national sample.

Methods. We used 3,714 caregivers from the REasons for Geographic and Racial Differences in Stroke (REGARDS) study. Participants had to complete baseline, in-home visit, and follow-up interviews to be included.

Results. Approximately 12% of the REGARDS sample reported that they provided on-going care to a family member with chronic illness or a disability. Highly strained caregivers had the worst mental, physical, and emotional health but there was evidence of increased social support lessening the relationships between high caregiving strain and adverse dependent variables. Caregivers who reported a lot of strain from caregiving were at an increased risk for mortality. Mediation analyses were conducted to estimate the amount that self-rated health or caregiving strain differences between racial groups extend to differences in all-cause mortality rates. We found that 17.6% of the race effect on mortality was accounted for by self-rated health.

Conclusions. Caregivers reporting higher levels of mental and emotional strain from caregiving have a greater chance of experiencing adverse health outcomes. African American caregivers are also at an increased risk for mortality, yet this effect is partially accounted for by worse reports of self-rated health. Through a combination of diverse samples and longitudinal studies, interventions can be developed to counteract the adverse health effects of caregiving.

DEDICATION

Above all I would like to thank God, because it was through his blessings that I was able to complete my dissertation project. Words cannot describe the depth of my gratitude to my committee chair, Dr. David Roth. For the past four years, he pushed me to continue my research, provided me with immeasurable advice, and expanded my research knowledge in the fields of Psychology, Gerontology, and Biostatistics. My wonderful committee, Dr. Michael Crowe, Dr. Virginia Howard, Dr. Monika Safford, and Dr. Virginia Wadley, offered me substantial support not only on this dissertation, but in preparation for a future career in academia. There are countless others who enhanced my graduate studies at UAB, including my fellow Psychology graduate students, my program directors, the faculty and staff in the Departments of Psychology and Biostatistics, the CARES team, the Center for Aging, and the UAB Graduate School. They all assisted in training me as a social scientist, and for that, I am extremely thankful. I want to thank my loved ones: parents (especially my mom Deirdre Harris Stepter), grandparents, siblings, godparents, extended family and friends for offering constant encouragement and enthusiasm when I felt I was ready to give everything up. Among them are those few who had to endure emotional conversations, endless hours of work, and a considerable amount of discussion during this degree pursuit. They endured without a complaint.

ACKNOWLEDGEMENTS

Funding for this dissertation project is provided by a Ruth Kirschstein NRSA Predoctoral Fellowship to Promote Diversity (1F31AG032215-01A1) by the National Institute on Aging. REGARDS is supported by a cooperative agreement (U01 NS041588) from the National Institute of Neurological Disorders and Stroke, National Institutes of Health, Department of Health and Human Service. The authors thank the other investigators, the staff, and the participants of the REGARDS study for their valuable contributions.

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INTRODUCTION

Providing care to a family member with a chronic disability is a common experience for many older adults. The family member and caregiver create a unique dyad where the caregiver often has a direct impact on the treatment, recovery, and ensuing lifestyle of the family member. Therefore research must consider resources available to both the family member and caregiver when examining factors associated with illness and recovery.

Caregiving is often reported to be stressful and associated with many problems in physical health and emotional well-being. Caregivers may be hindered by health issues prior to caregiving responsibilities and these issues may be exacerbated with additional stress. At the same time, reasonably healthy caregivers may develop increasing physical and mental health problems after the start of caregiving.

Caregiving and the health behaviors related to providing care for elderly individuals have been studied in many domains, nationally and internationally, including: dementia (Almberg, Jansson, Grafstrom, & Winblad, 1998; Anthony-Bergstone, Zarit, & Gatz, 1988; Betrand, Fredman, & Saczynski, 2006; Chou, LaMontagne, & Hepworth, 1999; Coen, O'Boyle, Swanwick, & Coakley, 1999; Collins & Jones, 1997; Gallagher-Thompson & Powers, 1997; Gold et al., 1995; Gonzalez-Salvador, Arango, Lyketsos, & Barba, 1999; Haley et al., 1995; Hooker et al., 2002; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Roth, Ackerman, Okonkwo, & Burgio, 2008; Roth, Mittelman, Clay, Madan, & Haley, 2005; Vitaliano, Russo, Young, Teri, & Maiuro, 1991), physical impairments (Arai, Zarit, Sugiura, & Washio, 2002; Roth, Haley, Owen, Clay, & Goode, 2001; Schulz & Beach, 1999), and stroke (Blake, Lincoln, & Clarke, 2003; Bugge, Alexander, & Hagen, 1999; Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998; Smith et al. 2004; Thommessen, Wyller, Bautz-Holter, & Laake, 2001; Thommessen et al., 2002; Thompson, Bundek, & Sobolew-Shubin, 1990; van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2000; van Exel, Koopmanschap, van den Berg, Brouwer, & van den Bos, 2005; Visser-Meily, Post, Schepers, & Lindeman, 2005). Within these studies, particular types of caregivers are often examined to identify the impact caregiving has on their finances, physical health, and emotional well-being, just to name a few. Specific types of caregivers that have been studied include: spouses (Aschbacher et al, 2008; Baker, 1997; Bauer et al., 2000; Blake & Lincoln, 2000; Caswell et al., 2003; Dorfman, Holmes, & Berlin, 1996; Hadjiconstantinou et al., 2001; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Kiecolt-Glaser et al., 2003; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Mastrian, Ritter, & Deimling, 1996; Mittelman, Haley, Clay, & Roth, 2006; Pruchno, Kleban, Michaels, & Dempsey, 1990; Russo & Vitaliano, 1995; Soskolne, Halevy-Levin, Cohen, & Friedman, 2006), daughters (Cattanach & Tebes, 1991; Franks & Stephens, 1996; Pruchno, Peter, & Burant, 1995), and men (Keith & Wacker, 1999; Kramer, 1997). Of this caregiving research, much has been based on convenience samples recruited in association with specific disorders or in connection with specific clinics, where the illnesses may be more severe. Relatively few studies have examined caregiving strain in the context of population-based epidemiologic investigations.

The REasons for Geographic and Racial Differences in Stroke (REGARDS) is an epidemiologic study examining racial and regional differences in stroke among adults age 45 years and older. A battery of questions assessing the participants' socioeconomic status, physical and mental health, and social contacts was administered by trained telephone interviewers at baseline. Questions assessing any caregiving responsibilities, strain associated with providing care, and mortality were the primary variables of interest for the current study.

Strain, due to caregiving, has been identified and defined in numerous ways across literature. Hunt (2003) combined several of these definitions and provided a comprehensive conceptual framework of caregiver strain. Caregiver strain is perceived as the tension individuals caring for the chronically ill experience due to the physical and mental demands of caregiving. Whereas much previous research has been targeted to caregivers of patients with specific illnesses, the size and diversity of the REGARDS sample could provide a more general and representative outlook on the prevalence and effects of caregiving strain across multiple conditions.

There are two constructs closely related to caregiving strain, caregiving stress and burden. Both have been measured at length in the caregiver literature. Research examined how caregiving stress is associated with physical health (Aschbacher et al., 2008; Bauer et al., 2000; Cacioppo et al. 1998; Goode, Haley, Roth, & Ford, 1998; Jones & Peters, 1992; Lawton et al., 1991; Son et al., 2007), social support (Baillie, Norbeck, & Barnes, 1988; Cox, 1995; Franks & Stephens, 1996), and mental health (Aschbacher et al., 2008; Hooker et al., 2002; Schwarz & Dunphy, 2003; Soskolne et al., 2006; Yates, Tennstedt, & Chang, 1999), which have all been shown to be associated with mortality in older adults. Goode and colleagues (1998) examined 122 patients and their caregivers from an Alabama memory disorders clinic on measures of caregiving stressors and the appraisals of these stressors, social support, coping strategies, and caregiver mental and physical health. The authors found that increases in stressfulness appraisals were related to worse changes in depression and physical health, while initial low stressfulness appraisals lessened the positive relationship between stressors and depression. Activity restriction and relationship strain were considered stress measures in Cox's (1995) study of 76 African American and 88 White caregivers of Alzheimer's disease patients. For White caregivers, increased activity restriction and relationship strain were associated with more patient disruptive behavior. In contrast, for African American caregivers, relationship strain was associated with feeling less competent as a caregiver. Informal support was not significantly associated with either stress measure for African American or White caregivers. In Jerusalem, Soskolne and colleagues (2006) examined 174 spouse caregivers and 145 adult child caregivers to test if psychosocial variables influence the relationship between type of caregiver and psychological distress. Care recipient activities of daily living (ADLs) and instrumental activities of daily living (IADLs) impairment, cognitive functioning, and problem behaviors and the frequency in which caregivers helped with ADLs and IADLs where considered stressors. For both spouse and adult child caregivers, more care recipient problem behaviors were associated with more psychological distress. For the adult child caregivers only, providing more help with ADL impairment was related to more distress. All of these studies provide evidence that increased stress, whether objectively or subjectively measured, results from a worse caregiving situation and affects the overall health of the caregiver.

Caregiving burden has also been associated with physical health (Draper et al., 1992; Gold et al., 1995; Lee, Yoon, & Kropf, 2007; Pruchno et al., 1995; Varona, Saito, Takahashi, & Kai, 2007), social support (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Coen, O'Boyle, Coakley & Lawlor, 2002; Martin, 2000; Tooth et al., 2008; Young & Kahana, 1995), and mental health (Anthony-Bergstone et al., 1988; Chou et al., 1999; Pruchno et al., 1990; Sherwood, Given, Given, & von Eye, 2005; Stommel, Given, & Given, 1990; Thompson et al., 1990). In Korea, the Family Strain scale was used to measure caregiving burden in 1,000 caregivers (Lee et al., 2007). Caregivers of care recipients with dementia and increased ADL and cognitive impairment reported more caregiving burden. Higher levels of caregiving burden were also associated with poorer caregiver health and less social support. Martin (2000) measured caregiving burden in 811 caregivers with troublesome ratings of different caregiving experiences. Overall, Martin (2000) found that White caregivers reported more burden than African American caregivers. In addition, increased burden was related to poorer health, less availability of back-up help, more hours providing care, and experiencing fewer positive caregiving benefits. Stommel and colleagues (1990) examined care recipient ADL and IADL impairment, support availability and utilization, finances, caregiver burden, and depression among 307 caregivers in the Midwest. Caregiver burden was measured on a five-point Likert Scale forming five distinct subscales (finances, health, schedule, abandonment, and entrapment). More involvement from the caregiver was associated with greater impact on the caregiver's schedule and health. Increased depression was related to higher levels of caregiver burden on all five caregiver burden subscales. It seems evident that having to provide more care, particularly if the care recipient is functionally impaired, increases the caregiver's burden and ultimately affects their physical and mental well-being.

Researchers have provided three constructs to represent the harmful aspect of caregivers' experience: caregiving stress, burden, and strain. Arguments can be made for caregiving stress, burden, and strain to be measured both objectively (i.e. tangible demands of caregiving) and subjectively (i.e. appraisal of the caregiving experience) (Hunt, 2003). For the current study, we examined risk factors for mortality using the number of caregiving hours per week as an objective measure while perceived stress and caregiving strain were the subjective measures. Caregiving strain was our main construct of interest and we investigated its association with various dependent variables. It should be noted that when examining the literature on factors related to caregiving strain, there is an overlap with the factors relating to caregiving stress and caregiving burden.

Factors related to caregiving strain

Health and social effects. Depression, health, availability of social support, quality of life, and the risk for mortality have been found to be associated with caregiving strain in previous research. There is extensive research that reports increased depression and depressive symptomology is related to increased caregiving strain (Dilworth-Anderson, Williams, & Cooper, 1999; Schwarz & Roberts, 2000; Sheehan & Nuttall, 1988; Visser-Meily et al., 2005; Wallace Williams, Dilworth-Anderson, & Goodwin, 2003). In a study that analyzed 1,500 caregivers from the 1996 National Caregiver Survey, caregivers of dementia patients were compared to caregivers of non-dementia patients to note their differences (Ory et al., 1999). Using a scale that rated emotional, physical, and financial strain due to caregiving, dementia caregivers reported more caregiving strain, greater suffering from mental health problems as a result of caregiving, greater time spent providing care, and less time for other family members than non-dementia caregivers. Beach, Schulz, Yee, and Jackson (2000) examined 391 caregivers and 299 matched noncaregivers on measures of stressful life events, perceived health, ADL and IADL impairment, depressive symptoms, anxiety, and health risk behaviors. To assess caregiver strain, the caregivers rated the amount of physical and emotional strain associated with each ADL or IADL with which the care recipient required assistance. Increased ADL and IADL impairment of both the care recipient and caregiver, higher levels of depressive symptomology and worse health were associated with more caregiver strain.

A sample of 80 wife caregivers of Department of Veteran Affairs patients were assessed using the Caregiver Strain Index (Dorfman et al, 1996). Shorter duration of caregiving, less social support, and support that is less dependable were all significant predictors of more strain. Caregivers who reported less life satisfaction also reported more caregiver strain. Almberg and colleagues (1998) compared 52 caregivers and 66 noncaregivers on strain experiences, which were based on items measuring health, family and friend relationships, informal social support, and the relationship with an elderly person. Caregivers reported more family conflict, a greater lack of positive outlook on being close to an elderly person, and less social support than noncaregivers. Overall, the research supports that increased caregiving strain is associated with worse mental and physical health, less social support, and less life satisfaction.

*Caregiving stress and burden***.** Research is also available that examines how caregiving strain is related to caregiving stress and burden. Blake and Lincoln (2000) measured caregiver strain and perceived stress among 222 co-resident spouse caregivers of stroke patients. Caregivers who reported more strain also reported more stress. In addition, increased caregiver strain was associated with higher levels of depressive symptoms and less emotional and practical support. Kim and Schulz (2008) used 606 caregivers of elders with cancer, dementia, diabetes, or who were frail from advanced age. Caregiver strain was measured as physical, emotional, and financial strain. Caregiver burden was measured by the number of care recipient ADL and IADL tasks that required assistance and the time spent caring for those tasks. More caregiver burden was related to greater physical and emotional strain. It is important to remember there is a close association between the adverse caregiving constructs and that more than one construct may be involved in caregivers' health and well-being.

Racial differences. As seen in the aforementioned research, Cox (1995) and Martin (2000) both found differences among African American and White caregivers. White caregivers' stress was largely affected by the care recipients' behavior while feeling less competent as a caregiver affected African American caregivers' experience of stress (Cox, 1995). After accounting for variables associated with the daily caregiving situation (i.e. hours spent caregiving, care recipient's functional level), White caregivers reported higher levels of caregiving burden than African American caregivers (Martin, 2000). Therefore it is possible that different mechanisms are responsible for the racial differences observed for adverse caregiving constructs. Previous research has also reported no racial differences in caregiving burden (Young & Kahana, 1995). REGARDS offers one of the largest samples of African Americans in a broad-based epidemiological study, and the current study tested whether these caregiving strain effects are explained by individual or racial differences.

Mortality

Health and social effects. Many risk factors for and associations with mortality in older adults have been identified including certain demographic factors (Ganguli, Dodge, & Mulsant, 2002), functional disability (Ganguli et al., 2002), and current self-rated health (Miller & Wolinsky, 2007). In addition to the relationship with caregiving strain, depression and social support have also been examined as risk factors for mortality in older adults. Schulz et al. (2000) used participants from the Cardiovascular Health Study to analyze the relative risk of mortality over a six year period as a function of depressive symptoms. When adjusting for sociodemographic factors, clinical and subclinical disease, and health risk factors separately, Schulz et al. found between 25% to 43% higher risk for mortality among those reporting higher levels of depressive symptoms. Fry and Debats (2006) examined various risk factors for mortality, including self-rated health, self reported physical function, and perceived control, and found dissatisfaction with social support to be associated with increased risk for mortality over a five year follow up period.

DeSalvo et al. (2005) examined a single item measure and a multiple item measure of self-rated health to see if the measures were comparable in predicting mortality. With a sample of approximately 20,000 participants, the SF-36 single-item measure of global self-rated health was compared to the SF-36 subscale physical and mental component summaries. DeSalvo et al. (2005) found the single-item measure to be comparable to the physical component summary measure in predicting mortality.

Individuals who reported “poor” health were at a significantly greater risk of mortality than those who reported health as “fair” or better. Idler and Benyamini (1997) reviewed 27 manuscripts that studied global self-ratings of health as predictors for mortality. The studies, based on community dwelling samples collected longitudinally, were consistent in the finding of self-rated health being a significant predictor of mortality, even when accounting for other factors relating to mortality. Therefore in the context of the current study, poor self-rated health was considered a marker and risk factor for all-cause mortality and was expected to show similar associations with caregiving strain.

Caregiving effects. Recognizing that providing care to a disabled spouse may result in heightened burden and health problems, Schulz and Beach (1999) utilized data from the Caregiver Health Effects Study and identified four subtypes of married participants: spouse not disabled, disabled spouse but not providing care, caring for disabled spouse but no reported strain, and caring for disabled spouse with reported strain. The sample consisted of 819 individuals, including 392 caregivers and 427 non-caregivers. The mean age of the caregivers was 79.6 years old. They were predominantly female (51.3%) and White (90%). Caregivers who reported strain were at a 63% higher risk for all-cause mortality over a 4-year period than participants without a disabled spouse.

Schulz and Beach (1999) claimed to be the first study to demonstrate caregiving as a risk factor for all-cause mortality and an examination of the research since this landmark study has found only a few manuscripts that investigate this relationship. Several manuscripts have cited Schulz and Beach (1999) as one of the indications of the harmful impact that caregiving can have on the caregiver. However, there is research to support the idea of caregiving actually reducing the risk of mortality. Brown and colleagues (2009) used 3,376 individuals from the Health and Retirement Study to examine if caregiving is associated with better or worse health for the caregiver. Caregiving behavior, as measured by the number of caregiving hours provided per week, was associated with a reduced risk for mortality. But spousal need for care, as measured by the number of spousal ADL and IADL impairments, was associated with an increased risk for mortality. Fredman and colleagues (2008) studied older adult caregivers and non-caregivers from the Health, Aging, and Body Composition Study on all-cause mortality and mobility limitation. Overall, fewer caregivers died compared to non-caregivers while caregivers who provided the most hours of care had the fewest deaths. Although not reaching significance, when accounting for physical activity, caregivers were actually at a 15% higher risk for mortality than non-caregivers. Therefore caregiving in itself may have beneficial qualities, possibly due to the protective nature of physical activity, but the level of disability of the care recipient may facilitate the harmful health effects.

Racial differences. Several reports have been issued over the years using data collected from the National Center for Health Statistics on mortality in the U.S. One of the more recent reports by Kung and colleagues (2008) presented data from 2005 on death, death rates, mortality, life expectancy, and various trends. Overall, adjusting for age, African Americans had an average 30% higher risk for mortality than Whites, even with death rates for both groups steadily declining since the late 1990s. Kung and colleagues (2008) also showed that in 2005, for individuals who have lived to at least 45 years old, African Americans had a life expectancy of 77 years old while Whites had a life expectancy of 80.6 years old.

Onawala and LaVeist (1998) researched self-rated health as a predictor of mortality among 1,209 African American participants in the Longitudinal Study on Aging. Participants who reported poor self-rated health were at a two times greater risk for mortality than participants who reported excellent health. This effect was attenuated, however, when more objective measures (i.e. annual number of bed days, annual number of physician visits, number of ADL problems) of self-rated health were included in the model. Yao and Robert (2008) examined the influence of race and socioeconomic variables on self-rated health and mortality. Over 1,600 older adult African Americans and Whites were analyzed to find African Americans declining in self-rated health at a faster rate than Whites but that effect dissipated when accounting for socioeconomic status (SES). While controlling for SES, African Americans were also at 71% greater odds for mortality than Whites by the fourth wave and SES explained some of the racial differences observed in self-rated health. Research supports the notion that African Americans have considerably higher risks for mortality than Whites and this risk may be heightened depending on health status.

HYPOTHESES

The current study examined the relationship of perceived caregiving strain with depressive symptoms, quality of life, social support, self-rated health, and risk for all-cause mortality. **The first research question investigated risk factors for all-cause mortality.** Demographics (age, race, gender, education, and income), self-rated health, depressive symptoms, perceived stress, and disease were expected to be significant risk factors for all-cause mortality (Fry & Debats, 2006; Ganguli et al., 2002; Miller & Wolinsky, 2007; Schulz & Beach, 1999; Schulz et al., 2000). Based on Brown's et al. (2009), finding of caregiving hours being associated with reduced risk of mortality, we hypothesized that the number of caregiving hours per week would be associated with mortality. Further, we hypothesized that caregiving strain would be associated with poorer self-rated health and, in turn, all-cause mortality, even after adjusting for demographics, depressive symptoms, perceived stress, and disease (Schulz & Beach, 1999). We hypothesized that the highest relative risk for all-cause mortality would be associated with the caregiving group that reported the most perceived strain while the lowest relative risk for all-cause mortality would be associated with the caregiving group that reported no perceived strain (Schulz & Beach, 1999).

The second research question investigated the difference among the three caregiving groups (caregivers reporting no strain, some strain, and a lot of strain) on the psychosocial and health measures and includes social support as a moderator. Previous research with REGARDS participants found that caregiving strain was positively related to adverse results, such that increased caregiving strain was associated with worse quality of life, mental health, and social support measures (Roth, Perkins, Wadley, Temple, & Haley, 2009). The current proposal used a smaller subset of participants than Roth and colleagues (2009) since only caregivers with baseline, in-home visits, and follow-up data were examined. Similar caregiving group comparisons were run with this sample to ensure that the previous results were retained. The study used health-related quality of life, depressive symptoms, and social contacts as primary dependent variables; self-rated health and perceived stress were additional dependent variables. It was expected that increased caregiving strain would also be associated with poor self-rated health and higher levels of perceived stress. Individual differences in social support were expected to moderate the relationships between caregiving strain and well-being and health measures, such that high levels of support decreased the strength of the relationship between increased caregiving strain and worse well-being and health.

The third research question examined whether caregiving strain and self-rated health mediate the risk for all-cause mortality. Since African American caregivers have been found to be less likely to report caregiving strain than White caregivers, African American caregivers may be less vulnerable to caregiving-related mortality risks (Martin, 2000). On the other hand, African Americans may report poor self-rated health (Yao & Robert, 2008). With these data, we were able to conduct an examination of how the relationship between race and all-cause mortality may be mediated by both self-rated health and caregiving strain mechanisms.

METHODS

Participants

REGARDS is a national, population-based, longitudinal study of African-American and White participants 45 years or older (Howard et al., 2005). The purpose of the study is to determine the reasons for increased stroke mortality for African Americans and a portion of the Southeastern region of the US referred to as the “Stroke Belt”. After randomly selecting potential participants and contacting them by mail and telephone, baseline data were collected on stroke risk, health, sociodemographic, and psychosocial measures. Every six months, brief phone follow-up interviews are conducted to identify potential outcomes.

Recruitment to the REGARDS study began in January of 2003 and was completed in October of 2007. Potential participants were selected from a commercially available nationwide list purchased through Genesys, Inc. and contacted by mail with a brief description of the project. Telephone contact was subsequently attempted, and respondents were invited to participate if they were determined to be eligible. The participant was informed of the in-home examination and if verbal informed consent was obtained, the interview was conducted using computer-assisted telephone interviewing (CATI) methods. CATI is a method that provides standardization and control over the data and allows for the comparison of the differences in participants completing and participants not completing the in-home exam. The in-home examination, administered by the Examination Management Services, Inc (EMSI), was scheduled at the convenience of the participant to collect physical measurements, blood, and urine samples. All interview procedures and informed consent procedures were reviewed and approved by the Institutional Review Boards of each REGARDS study site.

Potential participants were identified using a stratified random sampling design, which called for approximately one-half of the sample to be obtained from "stroke belt" region (the states of AL, AR, GA, LA, MS, NC, SC, and TN) and the remaining half resided in other areas throughout the 48 contiguous states. The total sample is 30,221 participants, 41.5% African American and 58.5% White, 55.1% female and 44.9% male. Exclusion criteria included age less than 45, race other than African American or White, previous diagnosis for cancer requiring chemotherapy, inability to communicate in English, or residence in or on a waiting list for a nursing home.

Procedures and Measures

Trained interviewers with the University of Alabama at Birmingham Survey Research Unit (SRU) made the telephone calls and first established eligibility for participation. Once eligibility was confirmed, the REGARDS study was further explained and verbal informed consent was obtained. CATI was then administered and obtained information on demographic variables, socioeconomic status, current living arrangement, medical history, health-related quality of life, number of social contacts, depressive symptoms, and caregiving questions. REGARDS participants who completed the baseline interview but later declined to participate in the home visit are not tracked longitudinally for outcome events including mortality. Consequently, these individuals were excluded from the current analyses.

The following baseline measures were used in the analyses. Race and gender were coded as dichotomous variables, age was included as a continuous variable, and education was coded as a 4 level ordinal variable (less than high school graduate, high school graduate, some college, college graduate or more). Income was coded as a 5 level ordinal variable (less than $20,000, $20,000 to $34,000, $35,000 to $74,000, $75,000 and above, those who were missing or refused to report). For analyses that require dichotomous independent variables, dummy variables were created for education and income variables (with college graduate or more and $75,000 and above as the referent groups, respectively).

Caregiving Status and Strain. Each participant was asked "Are you currently providing care on an on-going basis to a family member with a chronic illness or disability? This would include any kind of help such as watching your family member, dressing or bathing this person, arranging care, or providing transportation." For those who responded affirmatively to this question, they were then asked 1) whether they lived with this person, 2) how this person was related to them (i.e., spouse, parent, child, sibling, or other), 3) how many hours per week they spend providing care to this person (coded into four ordinal categories of < 10, 10-19, 20-29, and ≥ 30), and 4) how much of a mental or emotional strain was it on them to provide this care. Response options for the caregiving strain question were the same as those used by Schulz and Beach (1999) and included "no strain," "some strain," or "a lot of strain."

Depressive Symptoms. Participants were administered four items from the Center for Epidemiological Studies-Depression (CESD-4) Scale: 1) During the past week, would you say you felt depressed less than one day, one to two days, three to four days or five to seven days? 2) During the past week, would you say that you felt lonely less than one day, one to two days, three to four days, or five to seven days? 3) During the past week would you say that you had crying spells less than one day, one to two days, three to four days, or five to seven days? and 4) During the past week, would you say that you felt sad less than one day, one to two days, three to four days, or five to seven days? Responses ranged from 0 to 12 based on the number of days the participant indicated having those feelings in the previous week. Higher scores indicated more depressive symptoms. The CESD-4 is based on the 20 item CES-D (Radloff, 1977) and has been found to be highly correlated at 0.87 (Melchior, Huba, Brown, & Reback, 1993).

Health-Related Quality of Life. To measure quality of life, participants were asked with the Physical Component Summary (PCS) Scale and Mental Component Summary (MCS) Scale of the Medical Outcomes Study 12-item Short-Form (SF-12) Health Survey. Examples of questions from the two scales include "During the past 4 weeks, were you limited in the kind of work or other regular daily activities you do as a result of your physical health?" and "During the past 4 weeks, did you not do work or other regular daily activities as carefully as usual as a result of any emotional problems, such as feeling depressed or anxious?" Depending on the nature of the question, responses ranged from yes or no to all, most, a good bit, some, a little, or none of the time. SF-12 scores are standardized to

have population means of 50 and standard deviations of 10; higher scores on both scales suggest better physical and mental functioning. The SF-12 is based on the 36-Item Short-Form (SF-36) Health Survey and the PCS-12 and MCS-12 scales are highly correlated with the PCS-36 and MCS-36 scales (r = 0.95 and 0.97, respectively). The test-retest reliability of the PCS-12 was 0.89 and 0.76 for the MCS-12 over a two week period (Ware, Kosinski, & Weller, 1996).

Social Support. The number of social contacts was measured with three interview questions: 1) How many close friends do you have, that is, people who you feel at ease with, can talk to about private matters, and can call on for help? 2) How many relatives do you have that you feel close to? and 3) How many of these friends or relatives do you see at least once a month? Responses ranged from 0 to 50 for each question.

Self-rated Health. Each participant was asked "In general, would you say your health is excellent, very good, good, fair, or poor?," as a part of the SF-12. Self-rated health (SRH) scores range from 1 to 5, with higher scores indicating poorer health.

Perceived Stress. Participants were administered four items from Cohen's Perceived Stress Scale (PSS): 1) In the last month, how often have you felt that you were unable to control the important things in your life? 2) In the last month, how often have you felt confident about your ability to handle your personal problems? 3) In the last month, how often have you found that you could not cope with all the things that you had to do? and 4) In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? Response options included never, almost never, sometimes, fairly often or very often. Scores ranged from 0 to 16, with higher scores indicating more stress. The PSS has a Cronbach alpha of 0.72 and a test-retest reliability of 0.55 over two months (Cohen, Kamarck, & Mermelstein, 1983).

Disease/Co-Morbidity. Information was gathered based on direct questions about medical history including the history of stroke, cardiac disease, hypertension, and diabetes. Participants responded either “yes” or “no” to the presence or history of these diseases.

All-cause Mortality. Dates of death were initially obtained from family members or informants when follow-up interviews were attempted. Dates of death were verified with medical records, death certificates, and/or administrative databases. When a death was reported by a family member or another individual close to the family, permission was requested to obtain the deceased participants’ medical records to identify any hospitalization(s) during the months prior to death. Trained staff members asked additional open-ended questions to understand the participant’s illness and living situation at the time of death and scripts were used that ensure sensitivity and emotional support, which were validated based on other large national studies. In most circumstances, REGARDS was able to obtain the death certificate, generally from the next of kin. However if no next of kin was available or they refused to provide a copy of the death certificate, either a copy was requested from the State Department of Health or from the National Death Index. All-cause mortality was preferred over analyzing deaths in subgroups according to cause of death due to the already limited number of caregiver deaths.

Data Analyses

All analyses were conducted using SAS version 9.1. Descriptive statistics of the REGARDS sample were examined to obtain percentages of sociodemographic variables, the rates of caregiving, amount of caregiving hours, caregiver-care recipient relationships, the number of caregivers living with their care recipient, and the prevalence of disease by level of caregiving strain. SAS proc MEANS was used to analyze the continuous variables while SAS proc FREQ was used to analyze the categorical variables.

Analyses of variance and covariance were used to compare the three caregiving groups on psychosocial and health measures both before and after adjusting for demographic covariates. Demographic covariates included age, race, gender, education, and income, with comparisons made for depressive symptomology, health-related quality of life, self-rated health, perceived stress, and social support. SAS proc GLM was used to test for the presence of an omnibus main effect of a group difference. The Bonferroni multiple comparison technique was used for pairwise comparisons of group differences. With three groups of caregivers based on level of strain, two comparisons were made with a Bonferroni adjusted Type 1 error rate of 0.025 (0.05/2). To examine if social support modified the impact of caregiving strain on the well-being and health measures, an interaction term of caregiving strain and social support was included in regression analyses. The positive relationship between caregiving strain and adverse health and well-being measures was expected to be strengthened when there was less social support available. Caregiving strain was expected to be associated with more depressive symptoms, worse quality of life, poorer self-rated health, and more perceived stress and subsequently lead to an increased risk for all-cause mortality. The dependent variables were regressed on caregiving strain, social support variables, and interaction terms using SAS proc REG. Since regression analyses require continuous or dichotomous independent variables, caregiving strain was dummy coded into two vectors, with moderate strain from caregiving as the referent group. Social support as a moderator was tested with interaction terms of each caregiving strain vector and the three social support measures.

Proportional hazards modeling was used to examine the effect of caregiving strain on all-cause mortality both before and after adjusting for the covariates. The target event was all-cause mortality; the first time point was initial enrollment. Censoring was assumed to be non-informative because those not experiencing the event as of April 1, 2010 or who were lost to follow-up may have experienced the event had the participant still been enrolled (Singer & Willet, 2003). Individuals for whom death was not known to have occurred were right-censored at the last known data collection point, which are conducted in 6-month intervals. In Cox regression modeling, right-censoring events such as dropout are considered non-informative with regard to the target event of all-cause mortality, and this assumption was made for our analyses.

Covariates were examined individually and in combinations to determine their predictive effects on all-cause mortality and their associations with caregiving strain. This guided the final selection of covariates for the multivariable proportional hazards model of all-cause mortality. The possible covariates included age, race, gender, education, income, self-rated health, depressive symptoms, perceived stress, disease, and number of caregiving hours per week. A life table was created with SAS proc LIFETEST to illustrate the sample distribution of event occurrence with the main focus on the risk set. The risk set is the number of participants who survive the previous time interval, placing them at risk of experiencing the event (known as hazard) in the current time period (Singer & Willet, 2003). Hazard is based on the probability that a participant will experience the event in a particular time period and is algebraically represented by the hazard function, h(t). Cox regression models assume parallel hazard functions, therefore we tested this assumption by stratifying the caregiving strain variable using SAS proc LIFETEST and plots option. The log-log survival plots for each caregiving strain group did not cross indicating that the assumption was met. SAS proc PHREG (Allison, 1995) was used to estimate the effects in all proportional hazards models.

Proportional hazards modeling was used to examine the racial difference in self-rated health and caregiving strain and their mediating effect on all-cause mortality after adjusting for covariates. Race was expected to be associated with self-rated health and caregiving strain, and mediation analyses were conducted to estimate the amount that self-rated health or caregiving strain differences between racial groups extend to differences in all-cause mortality rates. Baron and Kenny (1986) established the causal steps approach to test mediation and these methods were used in the current study (MacKinnon, Lockwood, Hoffman, West, & Sheets, 2002). Based on the Baron and Kenny criteria, we tested that: 1) the independent variable (race) was related to the dependent variable (mortality), 2) the independent variable was related to the mediators (self-rated health and caregiving strain), 3) the mediators were related to the dependent variables and 4) the relationship between the independent variable and the dependent variable was reduced when the mediators when controlling for the mediators. The joint significance method was used to identify significant mediation effects (MacKinnon, Lockwood, Hoffman, West, & Sheets, 2002). The Sobel test was not used to test mediation in these analyses because we used logistic regression and proportional hazards modeling which do not depend on the assumptions used in multiple regression analyses. Using Ordinary Least Squares regression analyses, African American caregivers were expected to report worse self-rated health than White caregivers. African American caregivers were expected to report less caregiving strain than White caregivers and we tested this with logistic regression using SAS proc LOGISTIC. In addition, increased caregiving strain and worse self-rated health was expected to be related to increased risk for all-cause mortality. In the mediation model, the percentage of any race differences on all-cause mortality due to self-rated health or caregiving strain differences were calculated using methods described by Hosmer and Lemeshow (2008) and implemented by Mittelman et al. (2006). The equations below illustrate the logical steps of mediation modeling using a proportional hazards approach. Equation A specifies the log of the hazard function (h(t)) for mortality as a function of the baseline hazard function (log h0(t)), the effect of race (B1) and the effect of other demographic covariates (e.g., gender, age). Equation B accounts for the effect of race on mortality after adjusting for the effect of self-rated health (B2) and level of reported caregiving strain (B3). The percent mediated was calculated by taking the difference between the effect of race from Equation A and B and dividing this difference by the effect of race from Equation A [(B1A – B1B)/B1A].

A) log h(t) = log h0(t) + B1 (race) + (other covariates)

B) log h(t) = log h0(t) + B1 (race) + B2 (self-rated health) + B3 (caregiving group) + (other covariates)

Power analysis. REGARDS has approximately 30,000 participants with completed baseline, in-home visit, and follow-up data. Roth and colleagues (2009) reported that 12% of REGARDS participants were currently providing care to a family member, therefore we expected approximately 3,600 caregivers. We based the following power calculations on half of that approximation due to the fact that high strain and no strain caregivers each comprised about one fourth of the total number of caregivers (Roth et al., 2009). With conservative estimates of a 5% annual attrition rate and 1.4% annual mortality rate (Kung, Hoyert, Xu, & Murphy, 2008), 80% power is available to detect a hazard ratio for high strain caregivers compared to no strain caregivers of 1.58. Schulz and Beach (1999) reported hazard ratio of 1.63 for strained older spouse caregivers compared to noncaregivers. Therefore, we expected to have excellent power to detect relatively modest differences in mortality rates among REGARDS caregivers and to examine racial differences on mortality risk factors.

RESULTS

Descriptive Information

A total of 3,714 family caregivers were identified from the REGARDS participants who completed baseline and in-home data, making them eligible for follow-up interviews. The sample consisted of 1,134 African American women, 503 African American men, 1,193 White women, and 884 White men. Table 1 provides background descriptive information based on the amount of mental or emotional strain reported by the caregiver (none, some, or a lot of strain).

Chi-square tests indicated that caregivers with some strain and a lot of strain were more likely to be White (58.2% and 57.7%, $p = 0.001$, respectively) and female (65.9% and 78.2%, $p < 0.0001$, respectively), while there were no race and gender differences for caregivers reporting no strain. Highly strained caregivers were also younger, on average, than caregivers reporting no strain and some strain ($p < 0.0001$). Most caregivers had an income level between \$35,000 and \$74,000 ($p = 0.03$) and had at least a college degree ($p < 0.0001$). Within each caregiving strain group, providing care to a parent had the largest percentage among the caregiver-care recipient relationships ($p < 0.0001$). Highly strained caregivers were more likely to reside with their care recipient ($p < 0.0001$). Unsurprisingly, no strain caregivers spent the least amount of time caregiving, and caregivers spent more than 30 hours caregiving ($p < 0.0001$). When considering racial differences, African American caregivers were more likely to be living with their care recipients and providing greater than 30 hours of care per week than White caregivers ($p < 0.0001$).

Table 2 displays the caregivers' chronic illnesses that impede their own health while caring for their loved ones. There were significant differences between the three caregiving groups on hypertension ($p = 0.049$), stroke ($p = 0.005$), and myocardial infarction ($p = 0.006$). When we considered reported conditions across the caregiving strain levels, highly strained caregivers were the least likely to have had hypertension (18.1%), stroke (17.9%), or myocardial infarction (17.5%). Overall, 35.7% of our caregivers had no reported disease, 41.8% had one disease, and 22.4% had two or more diseases.

Table 1. Descriptive statistics of caregivers by reported level of caregiving strain

Caregivers (N = 3714)	No strain	Some strain	A lot of strain
Caregivers n (%)	1240 (33.5)	1836 (49.6)	624 (16.9)
Age M (SD)	63.79 (8.95)	62.98 (9.07)	62.11 (8.76)
Race n (%)			
White	640 (51.6)	1068 (58.2)	360 (57.7)
African American	600 (48.4)	768 (41.8)	264 (42.3)
Gender n (%)			
Male	619 (49.9)	626 (34.1)	136 (21.8)
Female	621 (50.1)	1210 (65.9)	488 (78.2)
Education n (%)			
Less than HS	173 (14.0)	166 (9.0)	66 (10.6)
HS graduate	333 (26.9)	411 (22.4)	162 (26.0)
Some college	335 (27.0)	544 (29.7)	189 (30.3)
College grad & above	398 (32.1)	714 (38.9)	207 (33.1)
Income n (%)			
Less than $20,000	213 (17.2)	285 (15.5)	136 (21.8)
$20,000-$34,000	315 (25.4)	470 (25.6)	154 (24.7)
$35,000-$74,000	371 (29.9)	600 (32.7)	176 (28.2)
$75,000 and above	181 (14.6)	279 (15.2)	89 (14.3)
Refused	160 (12.9)	202 (11.0)	69 (11.0)
Live w/ CR n (%)			
Yes	602 (48.6)	975 (53.2)	376 (60.3)
No	637 (51.4)	859 (46.8)	248 (39.7)
Relationship of CR to CG n (%)			
Spouse	276 (25.0)	436 (25.9)	168 (29.1)
Parent	350 (31.7)	671 (39.8)	226 (39.2)
Child	161 (14.6)	219 (13.0)	85 (14.7)
Other	318 (28.7)	360 (21.3)	98 (17.0)
Hours of Care a week n (%)			
<10	582 (54.4)	575 (34.8)	109 (20.0)
10-19	175 (16.4)	315 (19.1)	90 (16.5)
20-29	101 (9.4)	226 (13.7)	88 (16.1)
≥30	212 (19.8)	534 (32.4)	259 (47.4)
Deceased n (%) As of Apr. 1, 2010			
No	1143 (93.8)	1742 (96.4)	572 (93.9)
Yes	75 (6.2)	65 (3.6)	34 (6.1)

HS = High School. CR = Care recipient. CG = Caregiver.

Table 2. Disease status by reported level of caregiving strain

Caregivers	**No strain**	**Some strain**	**A lot of strain**
Diabetes n (%)			
Yes	284 (23.1)	365 (20.0)	146 (23.4)
No	948 (76.9)	1465 (80.0)	477 (76.6)
Stroke n (%)			
Yes	74 (6.0)	64 (3.5)	30 (4.8)
No	1160 (94.0)	1766 (96.5)	592 (95.2)
Myocardial Infarction n (%)			
Yes	105 (8.5)	102 (5.6)	44 (7.1)
No	1129 (91.5)	1730 (94.4)	574 (92.9)
Hypertension n (%)			
Yes	717 (58.0)	1028 (56.4)	385 (62.0)
No	519 (42.0)	796 (43.6)	236 (38.0)

Relationships among the physical, mental, and social support measures are displayed in Table 3 using Pearson's correlation coefficients. The strongest relationships occurred between the measures assessing the same constructs: MCS and CESD-4, PCS and SRH, and measures of social support network size and frequency of contact. More depressive symptoms were associated with worse mental health functioning ($r = -0.69$, $p < .0001$), worse self-rated health was related to less physical functioning ($r = -0.64$, $p < .0001$), and having more friends and relatives was highly correlated with the number of friends or relatives seen at least once a month ($r = 0.61$, $p < .0001$ and $r = 0.64$, $p < .0001$, respectively).

Table 3. Correlations among mental, physical, and social support variables

	CESD-4	MCS	PCS	SRH	PSS	Friends	Relatives	Timespent
CESD-4	1.00	--	--	--	--	--	--	--
MCS	-0.69**	1.00	--	--	--	--	--	--
PCS	-0.22**	0.05*	1.00	--	--	--	--	--
SRH	0.30**	-0.29**	-0.64**	1.00	--	--	--	--
PSS	0.52**	-0.56**	-0.26**	0.31**	1.00	--	--	--
Friends	-0.12**	0.15**	0.06*	-0.12**	-.0.11**	1.00	--	--
Relatives	-0.11**	0.14**	0.02	-0.05*	-0.13**	0.41**	1.00	--
Timespent	-0.13**	0.16**	0.04*	-0.09**	-0.15**	0.61**	0.64**	1.00

PCS = Physical Component Summary score of the SF-12. MCS = Mental Component Summary score of the SF-12. CESD-4 = 4-item Center for Epidemiological Studies-Depression scale. SRH = Self-Rated Health. PSS = Perceived Stress Scale. Friends = Number of close friends. Relatives = Number of close relatives. Timespent = Number of friends or relatives seen at least once a month.
* significantly different from 0, $p < .05$
** significantly different from 0, $p < .0001$

Caregiving Strain

Analyses of variance and covariance found that highly strained caregivers had the worst relationships with mental, physical, and social support measures. The results provided in this section are based on similar analyses used in Roth's and colleagues' (2009) manuscript comparing REGARDS noncaregivers and the caregiving strain groups. With the exception of the number of friends, all omnibus main effects were significant when caregiving strain was included as an explanatory variable of PCS, MCS, CESD-4, SRH, PSS, and social support, with and without demographic covariate adjustment ($ps < 0.0001$). Caregiving strain also significantly explained number of the friends, with and without demographic covariate adjustment ($p < 0.05$). As shown in Table 4, we found that caregivers who reported high levels of caregiving strain also reported, on average, lower physical and mental health functioning scores, more depressive symptoms, worse self-rated health, higher perceived stress scores, fewer close relatives, fewer close friends, and fewer relatives or friends seen at least once a month compared to caregivers reporting none or moderate levels of strain. However, to determine the significant differences among the caregiving strain levels for each health measure, we conducted further pairwise comparisons (social support measures were not analyzed for pairwise comparisons, but continue below with the moderation results).

Table 4. Psychosocial measures by reported level of caregiving strain

	No strain	**Some strain**	**A lot of strain**
SF-12 PCS			
n	1188	1765	583
M (SD)	47.04 (10.16)	46.81 (10.23)	44.19 (12.47)
SF-12 MCS			
n	1188	1765	583
M (SD)	55.60 (7.20)	52.99 (8.53)	45.93 (11.41)
CESD-4			
n	1228	1827	623
M (SD)	0.92 (1.91)	1.23 (2.05)	2.92 (3.17)
SRH			
n	1237	1835	622
M (SD)	2.54 (1.01)	2.58 (1.00)	2.87 (1.08)
PSS			
n	1240	1836	624
M (SD)	2.57 (2.67)	3.74 (2.92)	5.55 (3.48)
# of friends			
n	1217	1814	618
M (SD)	5.96 (7.07)	5.62 (6.49)	4.87 (5.83)
# of relatives			
n	1225	1816	618
M (SD)	8.01 (8.95)	6.78 (7.35)	5.36 (5.81)
# of social contacts seen per month			
n	1210	1814	605
M (SD)	8.68 (9.06)	7.36 (7.20)	5.93 (6.15)

PCS = Physical Component Summary score of the SF-12. MCS = Mental Component Summary score of the SF-12. CESD-4 = 4-item Center for Epidemiological Studies-Depression scale. SRH = Self-Rated Health. PSS = Perceived Stress Scale. Friends = Number of close friends. Relatives = Number of close relatives. Timespent = Number of friends or relatives seen at least once a month.

The Bonferroni multiple comparison technique was used for pairwise comparisons of group differences. With three groups of caregivers based on level of strain, two comparisons were made with a Bonferroni-adjusted Type I error rate of 0.025 (0.05/2). Table 5 illustrates the adjusted mean differences and standardized effects when caregivers who reported no strain and high strain are compared to caregivers who reported some strain on the various health measures. The mean differences were adjusted for age, race, gender, education, and income and are presented in the metric of the dependent variable. The adjusted mean differences were then divided by the total sample standard deviation for that specific dependent variable to provide a standardized effect in standard deviation units (SDUs). Standardized effects allow for comparison on varying measures by interpreting the effect size. With the exception of the difference between caregivers reporting no strain and some strain on PCS, almost all adjusted mean differences were significant at least at the Bonferroni-adjusted Type I error rate. Caregivers who reported no strain had significantly better means than caregivers with moderate strain on the MCS, CESD-4, SRH, and PSS, with relatively small effect sizes. However, the difference between highly strained caregivers and those who reported some strain produced moderate standardized effect sizes for MCS, CESD-4, and PSS. Highly strained caregivers were found to have significantly worse functioning than caregivers with some strain on all five dependent measures for the adjusted mean values.

Table 5. Pair-wise comparison of no and high strain caregivers to some strain caregivers

Variable	No Strain Caregivers	High Strain Caregivers
PCS		
Adjusted Mean Difference	0.22	-2.63**
Standardized Effect	0.02	-0.25
MCS		
Adjusted Mean Difference	2.60**	-7.07**
Standardized Effect	0.28	-0.76
CESD-4		
Adjusted Mean Difference	-0.31**	1.70**
Standardized Effect	-0.13	0.73
SRH		
Adjusted Mean Difference	-0.04*	0.29**
Standardized Effect	-0.04	0.28
PSS		
Adjusted Mean Difference	-1.17**	1.81**
Standardized Effect	-0.38	0.58

PCS = Physical Component Summary score of the SF-12. MCS = Mental Component Summary score of the SF-12. CESD-4 = 4-item Center for Epidemiological Studies-Depression scale. SRH = Self-Rated Health. PSS = Perceived Stress Scale.
Note: All effects adjusted for race, gender, age, education, and income.
* significantly different from 0, $p < 0.025$
** significantly different from 0, $p < 0.0001$

Moderating Effects of Social Support

To examine social support as a moderator of the relationship between caregiving strain and PCS, MCS, CESD-4, SRH and PSS, we tested several models with regression analyses. Figure 1 shows the pathways that were tested and the hypothesized results. As reported above, caregiving strain was found to be associated with social support. To test the remaining pathways, caregivers with some strain were used as the referent group and the results are provided in Table 6. Similar to the pairwise comparisons in Table 5, reporting caregiving strain was related to worse well-being and health measures. Caregivers who reported more friends and more friends or relatives seen at least once a month also reported better health-related quality of life, fewer depressive symptoms, better self-rated health, and less perceived stress. Having more relatives was associated with better mental health functioning, fewer depressive symptoms, better self-rated health, and less perceived stress. For the moderation effect, there was evidence of increased social support lessening the relationships between high caregiving strain and MCS, CESD-4, and PSS. For highly strained caregivers compared to moderately strain caregivers, being one standard deviation above the mean for both number of friends and relatives was associated with an increase of the MCS effect by 0.05 SDUs. We also found that highly strained caregivers who were one standard deviation above the mean for both number of relatives and those seen at least once a month was associated with a decrease of PSS by 0.06 SDUs. One standard deviation above the mean for number of friends or relatives seen at least once a month was associated with a decrease of CESD-4 by 0.09 SDUs among caregivers with high strain. To further illustrate the effect modification, the caregivers who reported a lot of strain had worse mental health functioning than moderately strained caregivers (-0.28) yet having more close friends reduced this effect to -0.23.

Figure 1. Moderating effects of social support

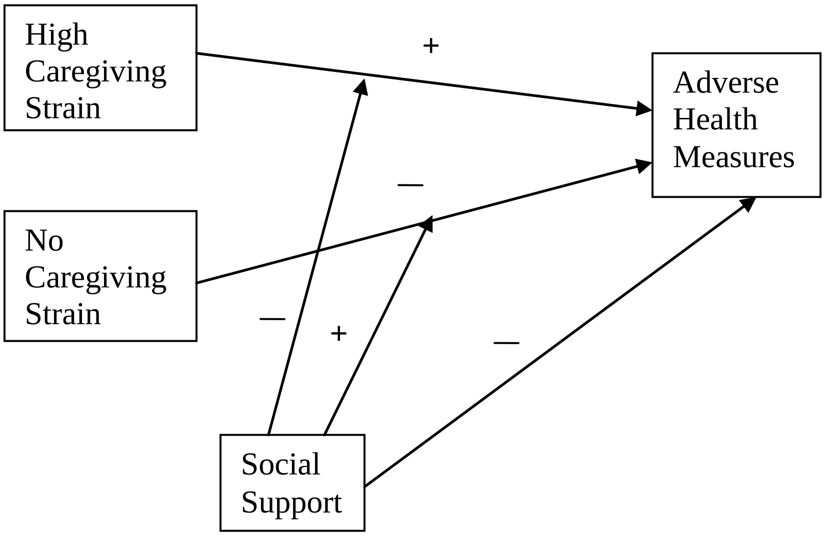


Table 6. Standardized estimates of caregiving strain and social support associations with well-being and health measures

	Dependent Variables				
Independent Variables	PCS	MCS	CESD-4	SRH	PSS
No strain[a]	NS	0.13**	-0.06*	NS	-0.17**
A lot of strain[a]	-0.09**	-0.28**	0.27**	0.11**	0.22**
Friends	0.06*	0.15**	-0.12**	-0.12**	-0.11**
Relatives	NS	0.14**	-0.11**	-0.05*	-0.13**
Timespent	0.05*	0.16**	-0.12**	-0.09**	-0.14**
No strain/Friends	NS	NS	NS	NS	NS
A lot of strain/Friends	NS	0.05*	-0.06*	NS	-0.05*
No strain/Relatives	NS	-0.06*	NS	NS	NS
A lot of strain/Relatives	NS	0.05*	-0.08*	NS	-0.06*
No strain/Timespent	NS	NS	NS	NS	NS
A lot of strain/Timespent	NS	0.06*	-0.09*	NS	-0.06*

PCS = Physical Component Summary score of the SF-12. MCS = Mental Component Summary score of the SF-12. CESD-4 = 4-item Center for Epidemiological Studies-Depression scale. SRH = Self-Rated Health. PSS = Perceived Stress Scale. Friends = Number of close friends. Relatives = Number of close relatives. Timespent = Number of friends or relatives seen at least once a month.

[a] Some strain caregivers are used as the referent group.

NS=not significant

*<.05

**<.0001

Proportional Hazards Modeling and Mortality

A total of 178 caregivers (4.8% of REGARDS caregivers) had died as of April 1, 2010. An average of 4.36 years passed between the baseline interview and either death or last follow-up interview for those still living. Descriptive analyses found that caregivers who died (M = 69.81) were older than survivors (M = 62.82, p < 0.0001) and more likely to be male (61.80%, p < 0.0001) than female. Table 7 provides additional descriptive information about the surviving versus the deceased caregivers.

Table 7. Descriptive statistics of caregivers by mortality

	Living (n = 3470)	**Deceased (n = 178)**	**p value**
Education n (%)			0.0008
Less than HS	365 (10.5)	35 (19.7)	
HS graduate	844 (24.3)	41 (23.0)	
Some college	998 (28.8)	53 (29.8)	
College grad & above	1261 (36.4)	49 (27.5)	
Income n (%)			< 0.0001
Less than $20,000	582 (16.8)	40 (22.5)	
$20,000-$34,000	851 (24.5)	69 (38.8)	
$35,000-$74,000	1099 (31.7)	33(18.5)	
$75,000 and above	530 (15.2)	15 (8.4)	
Refused	408 (11.8)	21 (11.8)	
Live w/ CR n (%)			0.0008
Yes	1812 (52.2)	116 (65.2)	
No	1656 (47.8)	62 (34.8)	
Relationship of CR to CG n (%)	811 (25.6)	57 (36.1)	< 0.0001
Spouse	1201 (38.0)	28 (17.7)	
Parent	416 (13.1)	41 (26.0)	
Child	736 (23.3)	32 (20.2)	
Other			

HS = High School. CR = Care recipient. CG = Caregiver

To determine their predictive effects on all-cause mortality, caregiving strain, age race, gender, education, income, self-rated health, depressive symptomology, perceived stress, disease, and number of caregiving hours per week were examined in separate Cox regression models. Since we were interested in the risk for caregivers reporting none or a lot of strain, caregivers reporting some strain were used as the referent group. As seen in Table 8, depressive symptoms and perceived stress are the only measures not independently associated with mortality. Surprisingly, caregivers reporting no strain (HR = 1.65) as well as a lot of strain (HR = 1.73) were at increased risk for mortality when compared to caregivers reporting some strain (ps < 0.05). African American caregivers had a 60% increased risk for mortality compared to White caregivers (p = 0.002). Caregivers with a history of stroke or cardiac disease were 3 times more likely to die than caregivers with no history (ps < 0.0001).

Table 8. Unadjusted effects-Cox proportional hazards model of time to caregiver death

	Hazard Ratio	**p value**	**95% Confidence Interval**
No strain vs. Some strain	1.65	0.04	(1.18, 2.30)
A lot of strain vs. Some strain	1.73	0.008	(1.15, 2.60)
African American (1) vs. White (0)	1.60	0.002	(1.19, 2.16)
Gender: Male (1) vs. Female (0)	2.46	<0.0001	(1.81, 3.34)
Age (years)	1.08	<0.0001	(1.06, 1.10)
Education			
Less than HS vs. College +	2.53	<0.0001	(1.64, 3.90)
HS graduate vs. College +	1.25	0.30	(0.82, 1.90)
Some College vs. College +	1.41	0.09	(0.95, 2.08)
Income			
Refused vs. $75,000 +	1.87	0.06	(0.97, 3.63)
Less than $20,000 vs. $75,000 +	2.31	0.006	(1.28, 4.20)
$20,000-$34,000 vs. $75,000 +	2.61	0.0008	(1.49, 4.57)
$35,000-$74,000 vs. $75,000 +	1.04	0.90	(0.57, 1.92)
Hypertension (Y/N)	1.66	0.002	(1.21, 2.29)
Myocardial Infarction (Y/N)	3.17	<0.0001	(2.16, 4.65)
Diabetes (Y/N)	1.92	<0.0001	(1.40, 2.63)
Stroke (Y/N)	3.45	<0.0001	(2.26, 5.28)
Depressive Symptoms	1.01	0.89	(0.94, 1.07)
Caregiving Hours	1.004	0.01	(1.00, 1.01)
Perceived Stress Scale	1.00	0.97	(0.95, 1.05)
Self-Rated Health	1.46	<0.0001	(1.27, 1.69)

HS = High School.

All significant unadjusted effects were then tested in sequential multivariable proportional hazards models of all-cause mortality and reported in Table 9. Since previous research found caregiving strain was a risk factor for mortality adjusting for sociodemographic factors and physical health status, we conducted the analyses in blocks adding demographic covariates, health and caregiving covariates, and interaction effects. Three predictor blocks were run with the two caregiving strain coding vectors (some strain as the referent group): demographic covariates only (race, gender, age, education, income), demographic and health covariates (cardiac disease, hypertension, diabetes, stroke, self-rated health, caregiving hours), and demographic and health covariates with selected, targeted, exploratory two-way interaction effects (the two caregiving strain vectors by race, gender, and three social support measures). Since we found evidence of social support as a moderator, we included the social support interaction to test the same effect with mortality.

Table 9. Sequential Multivariate Cox proportional hazards models of time to caregiver death

(Covariate adjusted)	Hazard Ratio	p value	95% Confidence Interval
Block 1			
No strain vs. Some strain	1.33	0.10	(0.94, 1.87)
A lot of strain vs. Some strain	2.00	0.001	(1.32, 3.02)
African American (1) vs. White (0)	1.64	0.002	(1.20, 2.24)
Gender: Male (1) vs. Female (0)	2.55	<0.0001	(1.85, 3.53)
Age (years)	1.07	<0.0001	(1.05, 1.09)
Education			
Less than HS vs. College +	1.30	0.29	(0.80, 2.12)
HS graduate vs. College +	0.96	0.87	(0.61, 1.52)
Some College vs. College +	1.29	0.23	(0.86, 1.93)
Income			
Refused vs. $75,000 +	1.30	0.46	(0.65, 2.61)
Less than $20,000 vs. $75,000 +	1.51	0.23	(0.77, 2.95)
$20,000-$34,000 vs. $75,000 +	1.76	0.06	(0.97, 3.21)
$35,000-$74,000 vs. $75,000 +	0.80	0.47	(0.43, 1.49)
Block 2			
No strain vs. Some strain	1.30	0.18	(0.89, 1.90)
A lot of strain vs. Some strain	1.64	0.05	(1.01, 2.66)
African American (1) vs. White (0)	1.49	0.03	(1.04, 2.14)
Gender: Male (1) vs. Female (0)	2.15	<0.0001	(1.47, 3.14)
Age (years)	1.07	<0.0001	(1.05, 1.09)
Education			
Less than HS vs. College +	1.01	0.97	(0.59, 1.74)
HS graduate vs. College +	0.69	0.16	(0.41, 1.15)
Some College vs. College +	1.03	0.91	(0.66, 1.59)
Income			
Refused vs. $75,000 +	0.89	0.78	(0.37, 2.11)
Less than $20,000 vs. $75,000 +	1.39	0.40	(0.65, 2.98)
$20,000-$34,000 vs. $75,000 +	1.76	0.10	(0.90, 3.46)
$35,000-$74,000 vs. $75,000 +	0.82	0.56	(0.41, 1.62)
Hypertension (Y/N)	1.00	0.99	(0.68, 1.48)
Myocardial Infarction (Y/N)	1.74	0.02	(1.11, 2.73)
Diabetes (Y/N)	1.25	0.25	(0.86, 1.82)
Stroke (Y/N)	1.76	0.03	(1.04, 2.95)
Self-Rated Health	1.28	0.009	(1.06, 1.54)
Caregiving Hours	1.00	0.71	(1.00, 1.00)

Note: Steps 3-7 were not reported because there were no significant interaction effects. HS = High School.

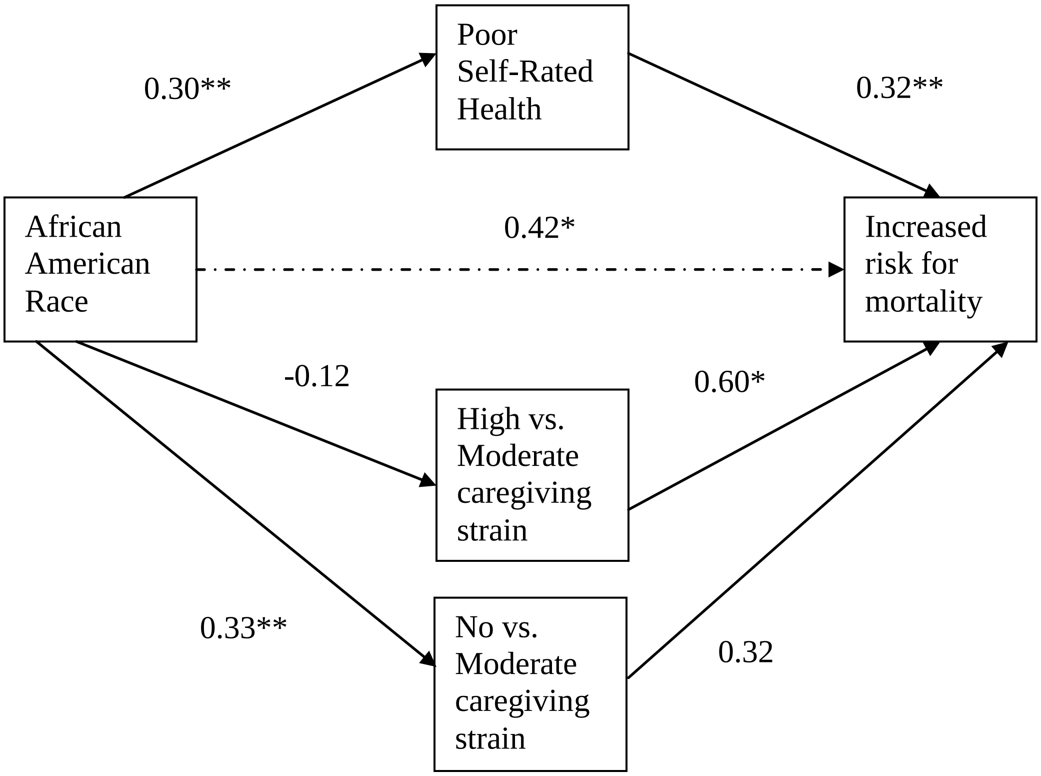
Highly strained caregivers had an increased risk for mortality over moderately strained caregivers in the demographic covariates model (HR = 2.00, p = 0.001). Being African American, male, older, and reporting worse self-rated health was associated with increased risk for mortality in almost all models ($p < 0.05$). With the exception of the model including the caregiving strain by race interaction, African American caregivers were at a 47% to 64% increased risk for mortality. The interaction effects were not found to be significant risk factors for mortality.

Mediation Effects of Self-Rated Health and Caregiving Strain

To test if self-rated health or caregiving strain differences between racial groups extend to differences in all-cause mortality rates, we used Ordinary Least Squares regression, logistic regression, and proportional hazards modeling to examine the pathways illustrated in Figure 2. This figure identifies the pathways of the overall mediation model, with unstandardized weights provided for the regression and proportional hazards analyses. These analyses were based on the 3,629 caregivers who had complete data for the variables of interest (race, self-rated health, caregiving strain, and mortality). First we regressed self-rated health and caregiving strain on race while accounting for gender, age, income, and education. Self-rated health was treated as a continuous variable and caregiving strain was treated as two dummy variables with some strain as the referent group. African American caregivers demonstrated risks for worse self-rated health (b = 0.30, $p < 0.0001$) and less caregiving strain (b = 0.33, $p < 0.0001$) compared with White caregivers. There were no differential risks for high versus moderate caregiving strain by race.

Next, we established the total effect of race on mortality, and the relationships of self-rated health and caregiving strain with mortality. African American caregivers were at a 66% increased risk for mortality compared with White caregivers ($b = 0.51$, $p = 0.002$). Worse self-rated health was associated with a 43% increased risk for mortality ($b = 0.36$, $p < 0.0001$). The no caregiving strain effect was not significant but highly strained caregivers were 2 times more likely to die than caregivers reporting moderate strain ($b = 0.69$, $p = 0.001$). These results were used only to establish the significant relationships between race, self-rated health, caregiving strain, and mortality and were not reported in the Figure 2. We then included race, self-rated health, caregiving strain, and the demographic covariates in the final model to test the direct effect on mortality and found that the race effect was still significant, but reduced with African American caregivers at a 52% increased risk for mortality compared with White caregivers ($b = 0.42$, $p = 0.009$). The self-rated health ($b = 0.32$, $p < 0.0001$) and high caregiving strain ($b = 0.60$, $p = 0.005$) effects remained significant. The no caregiving strain effect, again, was not significant. The percent mediated was calculated by subtracting the direct race effect (0.42) from the total effect (0.51) and dividing the difference by the total effect. Therefore self-rated health accounted for 17.6% of the association between race and mortality.

Figure 2. Conceptual overview of mediation analysis



**< 0.0001
*0.05

DISCUSSION

Our study provides the opportunity to examine a large sample of caregivers obtained through epidemiological methods rather than clinical or convenience sampling. REGARDS has 30,221 participants who completed baseline, in-home, and follow-up interviews and 3,714 (12.3%) of those individuals indicated caregiving responsibilities during their baseline interview. The baseline interview specifically asks if they are providing care on an on-going basis to a family member with a chronic illness or disability. Those who answered affirmatively to this question were then asked how much of a mental or emotional strain it is to provide this care. We examined how perceived caregiving strain is related to depressive symptoms, social support, health-related quality of life, self-rated health, perceived stress, and all-cause mortality.

Schulz and Beach (1999) observed that strained caregivers of a disabled spouse were at a 63% higher risk for all-cause mortality over a 4-year period than those without a disabled spouse after adjusting for age, sex, race, education, and stressful life events. We found that in REGARDS, highly strained caregivers were 2 times more likely to die than caregivers reporting some strain over an average of 4.36 years after demographic covariate adjustment. At the same time, we did not find support for the caregiving group reporting no strain as the lowest risk for all-cause mortality. Although not reported, we examined caregivers who reported both moderate and high strain to caregivers who reported no strain, with only White spousal caregivers who lived with their care recipient, as a more direct comparison with Schulz and Beach (1999). After demographic covariate adjustment, we did not find evidence of a caregiving strain effect. The current study was not a direct replication of Schulz and Beach (1999); their study involved older, predominantly White and female, spousal caregivers while REGARDS caregivers where almost equally divided on race and gender and allowed for all types of caregiver/care-recipient relationships. Therefore, our sample of caregivers may provide results that are a greater reflection of what actually occurs in the community caregiving population.

We also established that demographic variables, self-rated health, disease, and caregiving hours may be associated with all-cause mortality, at least in the unadjusted models (Ganguli, Dodge, & Mulsant, 2002; Miller & Wolinsky, 2007; Schulz & Beach, 1999). We did not find support for Schulz and colleagues' (2000) finding of a higher risk for mortality for those reporting higher levels of depressive symptoms, nor for Brown and colleagues' (2009) finding that caregiving hours were associated with a decreased risk for mortality. Our sample of caregivers did report levels of depressive symptoms that were, on average, lower than the cut off score for clinically significant psychological distress, which could account for the lack of association with mortality. Across most sequential models, race, gender, age, and self-rated health were significant risk factors for mortality. The consistent findings of African American, male, and older caregivers at higher mortality risks were consistent with prior research (Schulz & Beach, 1999); poor self-rated health as a risk factor among older adults was found in the Cardiovascular Health Study, the parent to the Caregiver Health Effects study used by Schulz and Beach (Fried et al., 1998). African American caregivers were consistently at a higher risk for mortality compared with White caregivers with covariate adjustment and to our knowledge, this current study is the first to specifically examine racial differences in mortality among caregivers. African American caregivers were at a 64% increased risk for all-cause mortality over White caregivers whereas for the entire REGARDS sample, African Americans were only at a 20% increased risk for all-cause mortality over White caregivers. Therefore, REGARDS African American caregivers are displaying worse health risks than REGARDS African American participants overall. More importantly, the evidence of caregiving related mortality risks extending to increased racial differences in mortality risk supports the necessity of continuing caregiving research.

Analyses of the three caregiving strain groups on the various psychosocial and health measures resulted in findings consistent with our previous research (Roth, Perkins, Wadley, Temple, & Haley, 2009). Increased caregiving strain was associated with worse quality of life, poor self-rated health, more depressive symptoms, higher levels of perceived stress, and less social support. Highly strained and caregivers who reported no strain were compared to moderately strained caregivers on the measures of physical, mental, and emotional well-being. Standardized effect sizes for the comparison with no strain caregivers were relatively small, yet all in the direction of better functioning compared to some strain caregivers. There were greater differences between the highly and moderately strained caregivers, evidenced by the effect sizes for the SF-12 mental health composite score, the 4-item CES-D, and Cohen's perceived stress scale. Self-rated health and the SF-12 physical health composite score had smaller, yet significant, effect sizes. The largest difference between the caregiving strain groups tended to be mental and emotional rather than physical health, evidenced by the smaller PCS and SRH effect sizes. These results are supported by Neugaard and colleagues (2008), who reported that poor mental health functioning had a stronger association with caregiving than physical health functioning. At the same time, caregiving strain is geared to assess the psychological stress of providing care, therefore the group differences are considerable for the psychological measures.

Caregivers who indicated higher levels of strain had fewer close relatives, friends, and number of friends or relatives seen at least once a month. Partnered with worse health and well-being, these associations with high caregiving strain are unfavorable. Yet, larger numbers of friends, relatives, and those seen at least once a month were related to better health-related quality of life, fewer depressive symptoms, better self-rated health, and less perceived stress. Caregivers with greater social support also showed reductions in the relationship between increased caregiving strain and worse well-being and health. The reductions were observed for measures of mental health and stress functioning rather than the physical health measures. The increased amount of family and friend support is influential on the psychological health of the caregiver, and previous research has supported this (Majerovitz, 2001), but this is not necessarily translating to improvement in the caregivers' self-reported physical health.

African American caregivers in REGARDS provided more than 30 hours a week of care and were more likely to be residing with their care recipient than White caregivers. Similar to previous findings (Martin, 2000; Roth, Perkins, Wadley, Temple, & Haley, 2009), African American caregivers reported less caregiving strain despite reporting greater amounts of time spent on caregiving. African American caregivers showed the adverse health correlates with self-rated health and the present results are consistent with Yao and Robert's (2008) findings of African Americans declining self-rated health at a faster rate. The self-rated health effect was no longer significant when accounting for gender, education, age, family income, marital status, and neighborhood socioeconomic disadvantage index (Yao & Roberts, 2008). Although the current paper did not look at rate of decline, the self-rated health effect remained even accounting for comparable variables. African American caregivers present a unique situation of extensive caregiving responsibility, feel minimal psychological strain about providing care, yet demonstrate worse physical health outcomes. We examined if the variability in the relationship between African American caregivers and all-cause mortality could be accounted for by self-rated health and caregiving strain. As hypothesized, African American caregivers were at an increased risk for mortality and this relationship was partially accounted for by worse self-rated health. African American caregivers were also found to be more likely to report no caregiving strain than White caregivers. Therefore self-rated health differences between racial groups extend to differences in all-cause mortality rates. For African American caregivers, their assessment of their health is directly related to an adverse health outcome.

Limitations of the current study relate to the design and sampling methods of REGARDS. The main purpose of REGARDS is to discover why stroke incidence and mortality are more prevalent in the southeast region of the US and among African Americans (Howard et al., 2005). Therefore, recruitment methods enrolled more African Americans and participants from the Stroke Belt. We mentioned how previous caregiving research has been based on convenience samples associated with specific disorders or clinics and REGARDS allows for a more population-based caregiving sample (Roth, Ackerman, Okonkwo, & Burgio, 2008). Therefore our results may include biases toward African Americans and residents of the stroke belt as caregivers greater than what is present in the population, but studying a large sample of caregivers allows for modeling techniques not feasible with single site convenience samples. Additionally, African American adult caregivers are not adequately studied in the literature and the relatively large sample of this study provides a notable contribution.

Another limitation relates to the availability of caregiving information, in particular, how long the caregiver had been in the role and the level of assistance required by the care recipient. The benefits of having a large epidemiological sample are offset by the limited amount of specific information that can be gained with a large battery of survey questions. Participants who had been caregivers for 10 years versus 1 month may have considerably different reports of strain, associations with psychosocial and health measures, social support and risk for mortality. Access to the date of caregiving onset would also allow comparisons of caregivers with chronic illness onset before and after caregiving responsibilities begin. Haley and colleagues (2009) found that depending on the care recipient's impairments and problems, there were varying levels of stressfulness associated with the type of issue. Spousal need for care has been associated with an increased risk for mortality whereas the number of caregiving hours provided per week was protective against mortality (Brown et al., 2009). Therefore, if we were able to know the disease, disorder, level of disability, or amount of impairment of the care recipients, we could better differentiate the differences among caregivers reporting different levels of strain.

Our findings confirm previous research suggesting that highly strained caregivers have a greater chance of experiencing adverse health outcomes related to the increased strain from providing care. The number of caregivers is globally on the rise and caregiving research needs to continue expanding to include more nationally representative samples and cross-cultural studies. This study supports the need for effective interventions targeted at caregivers to counteract the increased prevalence of poor mental, physical, and emotional functioning of caregivers. We have provided evidence that studying risk factors for mortality within caregivers in not only valid but necessary. We have taken groundbreaking research that began with Schulz and Beach and expanded to include a larger and more diverse sample through race and caregiver/care-recipient relationship. Future research should focus on discovering more mechanisms that can explain the pathways resulting in health risks for caregivers, in particular the transition into and out of the caregiving role, and adverse health outcomes. Through a combination of diverse samples and advance modeling techniques, interventions can be developed with effective strategies to assist caregivers depending on their health and resource need levels. It is imperative that we continue work to enhance the health, quality of life, and well-being of our caregivers as they are crucial to the health, quality of life, and well-being of our growing disabled, chronically ill, and elderly populations.

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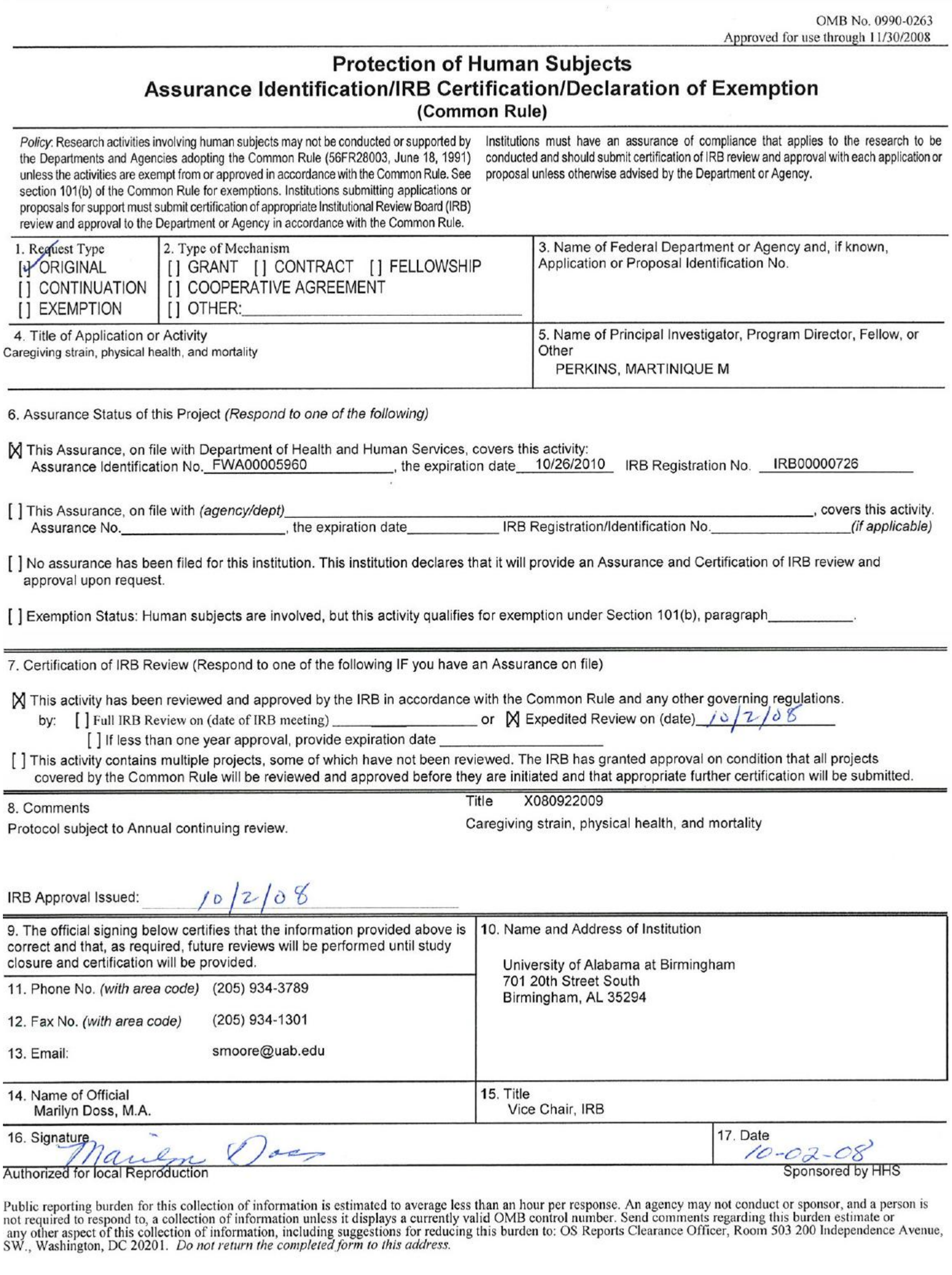
APPENDIX

UAB IRB APPROVAL FORM



OMB No. 0990-0263
Approved for use through 11/30/2008

Protection of Human Subjects
Assurance Identification/IRB Certification/Declaration of Exemption
(Common Rule)

Policy: Research activities involving human subjects may not be conducted or supported by the Departments and Agencies adopting the Common Rule (56FR28003, June 18, 1991) unless the activities are exempt from or approved in accordance with the Common Rule. See section 101(b) of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate Institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the Common Rule.

Institutions must have an assurance of compliance that applies to the research to be conducted and should submit certification of IRB review and approval with each application or proposal unless otherwise advised by the Department or Agency.

1. Request Type [✓] ORIGINAL [ ] CONTINUATION [ ] EXEMPTION	2. Type of Mechanism [ ] GRANT [ ] CONTRACT [ ] FELLOWSHIP [ ] COOPERATIVE AGREEMENT [ ] OTHER:________	3. Name of Federal Department or Agency and, if known, Application or Proposal Identification No.
4. Title of Application or Activity Caregiving strain, physical health, and mortality		5. Name of Principal Investigator, Program Director, Fellow, or Other PERKINS, MARTINIQUE M

6. Assurance Status of this Project *(Respond to one of the following)*

☒ This Assurance, on file with Department of Health and Human Services, covers this activity:
Assurance Identification No. FWA00005960, the expiration date 10/26/2010 IRB Registration No. IRB00000726

[ ] This Assurance, on file with *(agency/dept)*________, covers this activity.
Assurance No.________, the expiration date________ IRB Registration/Identification No.________ *(if applicable)*

[ ] No assurance has been filed for this institution. This institution declares that it will provide an Assurance and Certification of IRB review and approval upon request.

[ ] Exemption Status: Human subjects are involved, but this activity qualifies for exemption under Section 101(b), paragraph________.

7. Certification of IRB Review (Respond to one of the following IF you have an Assurance on file)

☒ This activity has been reviewed and approved by the IRB in accordance with the Common Rule and any other governing regulations.
by: [ ] Full IRB Review on (date of IRB meeting)________ or ☒ Expedited Review on (date) 10/2/08
[ ] If less than one year approval, provide expiration date________

[ ] This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the Common Rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments
Protocol subject to Annual continuing review.

Title X080922009
Caregiving strain, physical health, and mortality

IRB Approval Issued: 10/2/08

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed until study closure and certification will be provided.	10. Name and Address of Institution University of Alabama at Birmingham 701 20th Street South Birmingham, AL 35294
11. Phone No. *(with area code)* (205) 934-3789 12. Fax No. *(with area code)* (205) 934-1301 13. Email: smoore@uab.edu	
14. Name of Official Marilyn Doss, M.A.	15. Title Vice Chair, IRB
16. Signature Marilyn Doss	17. Date 10-02-08

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