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Authors

Cothran, Fawn A
Chang, Emily
Beckett, Laurel
[et al.](#)

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A Landscape of Subjective and Objective Stress in African American Dementia Family Caregivers

Fawn A. Cothran, PhD, RN, GCNS-BC, FGSA¹, Emily Chang, MS², Laurel Beckett, PhD³, Julie T. Bidwell, PhD, RN¹, Candice A. Price, PhD⁴, Dolores Gallagher-Thompson, PhD, ABPP¹

¹Family Caregiving Institute at the Betty Irene Moore School of Nursing; University of California, Davis;

²Department of Statistics; Department of Public Health Sciences, University of California, Davis;

³Division of Biostatistics, Department of Public Health Sciences, University of California, Davis;

⁴Department of Molecular Biosciences, School of Veterinary Medicine, University of California, Davis

Abstract

Stress is a significant part of daily life, and systemic social inequities, such as racism and discrimination, are well-established contributors of chronic stress for African Americans. Added exposure to the stress of caregiving may exacerbate adverse health outcomes. This secondary analysis describes subjective and objective stress in African American family caregivers, and relationships of subjective and objective stress to health outcomes. Baseline data from 142 African American dementia family caregivers from the “Great Village” study were described using means and frequencies; regression models and Pearson’s correlation were used to examine associations between demographics, social determinants of health, and health outcomes. Mixed models were used to examine change and change variation in cortisol. Most caregivers had moderate degrees of stress. Stress was associated with sleep disruption and depressive symptoms, and discrimination appeared to be an independent contributor to depressive symptoms. This work provides a foundation for interpreting subjective and objective indicators of stress to tailor existing multi-component interventions.

Keywords

African American; caregivers; dementia; cortisol; allostatic load

Over 11 million family caregivers provide 18 billion hours of care for persons with Alzheimer’s disease (AD) in the United States, and 5.6 million of these caregivers are African American (Alzheimer’s Association, 2021). The stress effects of caregiving on mental and physical health outcomes have been well documented, and the effects include higher rates of depression, sleep disturbance, impaired cognitive function, and greater

mortality risk (Fonareva & Oken, 2014). However, the majority of caregiving research has focused primarily on white caregivers, despite evidence suggesting African American caregivers have higher caregiving demands due to increased incidence, prevalence, and survival (Mehta & Yeo, 2017). For example, African American caregivers spend more time in the caregiving role, manage greater dementia related behaviors of care recipients, and are less likely to place family members in long term care residences (Alzheimer's Association, 2021; Dilworth-Anderson et al., 2002).

Stress, African American Caregivers, and Health Outcomes

Stress broadly depicts a process where the perceived demands or threats of an individual's experience exceed available resources (American Psychological Association [APA], 2017). Given that African American caregivers experience a range of increased demands from the caregiving context, additional challenges to understanding stress and its effects on African American caregivers remain. One challenge to understanding stress surrounds differing subjective responses. For example, in important intervention research African American caregivers' have reported low stress or low burden, and/or no change in stress or burden in response to the study intervention (Belle et al., 2006; Elliott et al., 2010; Gitlin et al., 2003). In a recent meta-analysis of racial and ethnic dementia family caregiver interventions, African American dementia family caregivers possessed better psychological well-being on average in comparison to White caregivers (Liu et al., 2020). Further, subjective stress perceptions derived from African American caregivers' qualitative interviews describe varied forms of caregiving hardship or negative aspects, juxtaposed with seemingly discordant quantitative survey responses indicating low burden or higher quality of life (Brewster, Bonds, et al., 2020; Cothran et al., 2020). These important differences in subjective responses further demonstrate misalignment and a need for further investigation in research.

Another challenge is objective stress measurement. In examining objective stress, salivary cortisol is the most widely used measure of acute stress in dementia caregiver research (Allen, Curran, et al., 2017; Fonareva & Oken, 2014; Potier et al., 2018). In general, cortisol increases dramatically upon awakening, gradually declining throughout the day (Adam et al., 2017). Dysregulation is represented by blunted or flattened response instead of a decline between awakening and evening (Adam et al., 2017), with caregivers demonstrating dysregulation compared to non-caregivers (Fonareva & Oken, 2014; Merritt & McCallum, 2013). African American dementia family caregivers have been underrepresented and underexamined in studies examining objective stress, limiting our understanding (Allen, Curran, et al., 2017; Fonareva & Oken, 2014; Potier et al., 2018). However, scarce research has demonstrated higher levels of stress in African American dementia caregivers (McCallum et al., 2006; Merritt et al., 2011; Merritt & McCallum, 2013).

For many African Americans, stress is a significant part of daily life, where systemic social inequities, such as racism and discrimination, are well-established contributors of chronic stress (APA, 2016; APA, 2017). Research highlights the impact of racism and discrimination as important social determinants of health that, exacerbate existing health disparities for African Americans (Berger & Sarnyai, 2015; Paradies et al., 2015). For example,

discriminatory stress has been associated with worse outcomes in African Americans for depression, sleep, cortisol response, cognitive decline, inflammation (C-reactive protein), cardiovascular risk, and mortality (APA, 2016; Berger & Sarnyai, 2015; Forrester et al., 2019; Korous et al., 2017; Paradies et al., 2015). Furthermore, African Americans as a whole develop age-related diseases at earlier ages than whites, and experience health disparities including worse physical health and mortality, especially in cardiovascular health and among women (Centers for Disease Control [CDC], 2017; National Center for Health Statistics [NCHS], 2021). These significant health disparities may be due to higher levels of allostatic load observed in African Americans (Geronimus et al., 2006). Allostatic load, also known as ‘weathering,’ refers to the prolonged activation of the hypothalamic-pituitary-adrenocortical (HPA) axis (Geronimus et al., 2006; Juster et al., 2010). The long-term impact on organ systems, including metabolic (e.g., triglycerides), neuroendocrine (e.g., cortisol), immune (e.g., C-reactive protein), and cardiovascular (e.g., blood pressure), results in significant long-term consequences to health (Borrell et al., 2020; Forde et al., 2019; Juster et al., 2010; Samuel et al., 2018).

Overall, African Americans experience daily stressors that are known to adversely affect health. The added exposure to the stresses of dementia family caregiving may exacerbate adverse health outcomes. Characterizing subjective and objective stress with social determinants of health is one approach to help broaden our understanding in African American caregivers.

Purpose

The primary goal of this secondary analysis was to describe subjective stress (e.g., perceived stress) and objective stress (cortisol, allostatic load) in African American family caregivers. The secondary goal was to explore relationships between caregiver demographics, subjective stress, objective stress, social determinants of health (e.g., discrimination) and health outcomes (e.g., sleep). The Environmental Affordance Model (Mezuk et al., 2013) and the NIA Health Disparities Framework (Hill et al., 2015) guided this study. The Environmental Affordance Model links stress, social determinants of health, health behaviors, and health outcomes using psychological, environmental, and sociobiological lenses to understand health inequities in racial and ethnic groups (Mezuk et al., 2013). The NIA Health Disparities Framework (Hill et al., 2015) helps further contextualize fundamental characteristics and social determinants of health for analysis. Examining both subjective and objective stress, health outcomes, as well as combining social determinants of health can help answer the questions: a) What does stress look like for African American dementia family caregivers, and b) What relationships exist between stress and health outcomes?

Methods

Overall Study Design

This was a secondary analysis of baseline data from the “Great Village” study (N = 142), a randomized-controlled trial of psychoeducational and exercise interventions to improve caregiver physical function and reduce caregiving-related strain. The design of the “Great

Village” study and its main results have been published previously (Brewster, Epps, et al., 2020). In brief, the study was conducted between 2010 and 2014; caregivers were randomized into three intervention groups: (1) attention control, (2) psychoeducation or (3) psychoeducation + aerobic exercise. Data were collected prior to randomization (baseline) and at six months. This secondary analysis includes data collected at the baseline time point only.

Participants

African American caregivers were recruited in the Southern United States and were eligible if they were 21 years of age or over, caring for a family member with AD, providing at least four hours of daily care in a home setting, and not moderately exercising three or more days per week. Because the original study was a randomized intervention with exercise, prior exercise was an exclusion criterion (Brewster, Epps, et al., 2020). Institutional review board approval was obtained, and all participants provided written informed consent.

Procedures

Procedures from the original study for data collection included screening and consent, baseline demographics, and interview data and schedule of the first study visit. During the first study visit, participants answered questionnaires, and participated in a history and physical exam, which included anthropometric data and fasting blood collection for serum biomarkers. Salivary cortisol samples were performed at home by participants two days before coming for their scheduled study visit. Following procedures modeled by Matthews and colleagues (2006), participants were provided detailed instructions for home collection, including not to consume food or beverage prior to sample collection. Samples were collected via study-provided salivettes with labels (for recording of collection time). Participants stored the samples in a study provided sealed container in their home freezer and delivered to study team staff in a provided portable cooler on ice to the study laboratory the day of their baseline study visit. Samples were stored at -80°C until assay. Randomization into study groups and subsequent intervention occurred after completion of baseline data collection. For secondary analysis of data for this study, we used baseline assessments prior to intervention for all 142 participants for demographics, subjective and objective stress, social determinants of health, physical health, and mental health.

Demographics

Sociodemographic data included age, gender, marital status, education level, caregiving duration (reported in months and converted to years), living with care recipient (y/n), caring for others (y/n), and relationship to care recipient.

Care Recipient Function

Instrumental activities of daily living (IADL) is an 8-item scale that elicits caregiver assessment of care recipient level of independence/function (Lawton & Brody, 1969). There are eight domains, including ability to use telephone, shopping, food preparation, housekeeping, laundry, transportation, responsibility for medications, and finances. Summary scores range between 0 (low function, dependent) and 8 (high function,

independent). Evidence of good reliability and validity have been established in African American dementia caregiving samples (Desin et al., 2016; McCallum et al., 2006).

Subjective Stress

Caregiver Burden—The caregiver’s perception of burden was assessed with the Zarit Burden Interview (ZBI), a 22-question instrument asking caregivers to evaluate the impact of caregiving (Zarit et al., 1985). Individuals rate each item on a scale from 0 to 4 (never, rarely, sometimes, quite frequently, nearly always.) Subscales reflect the personal strain and role strain. Total scores range from 0 to 88, with higher scores indicating greater burden. A score of 17 or above would indicate high burden. Cronbach’s alpha for the ZBI in the parent study was excellent: 0.92 (Brewster, Epps, et al., 2020); acceptable reliability has also been demonstrated in other studies with African American dementia caregivers (Belle et al., 2006; Griffiths et al., 2018).

Perceived Stress—The caregiver’s perceived stress was measured by the Perceived Stress Scale (PSS-10), a 10-item Likert scale where participants indicate the frequency of thoughts or feelings in the last month (e.g., “how often have you felt difficulties were piling up so high that you could not overcome them?”). Response items are on 5-point Likert scale ranging between 0 (never) to 4 (very often), with total possible score ranging from 0 to 40. Higher scores reflect greater perceived stress. This scale is more global than the caregiver burden, with sensitivity to chronic stress as well as to specific events deriving from caregiving (Cohen et al., 1983). Cronbach’s alpha for the PSS in the parent study was excellent: 0.88 (Brewster, Epps, et al., 2020) and high reliability has been demonstrated in caregiving studies with African American dementia caregivers (McCallum et al., 2006; Merritt et al., 2011).

Objective Stress

Acute—Cortisol level was assessed by saliva samples upon awakening, 30 minutes after awakening, and at bedtime. Samples were taken on two successive days, and the average of the two days was used for each of the three time points (Kraemer et al., 2006).

Chronic—Allostatic load, a cumulative measure of long-term stress, was calculated from multiple systems, specifically, immune, cardiovascular, and metabolic biomarkers (Juster et al., 2010). We identified available biomarkers from each system, using clinical guidelines from the National Heart, Lung, and Blood Institute to guide cut points. Adapting similar procedures summarized by Juster and colleagues (2010), we dichotomized each biomarker (0 - normal, 1 - abnormal) and then summed to create a cumulative score with a potential range between 0 to 12. Higher cumulative scores represented high allostatic load. Immune system biomarkers included interleukin-6 (IL-6) greater than or equal to 1.8 pg/mL and C-reactive protein (CRP) greater than or equal to 1 mg/dL. Cardiovascular system biomarkers included the following: 1) systolic blood pressure greater than or equal to 120 mmHg; 2) diastolic blood pressure greater than or equal to 80mmHg; 3) body mass index (BMI) less than or equal to 18.5 kg/m², or greater than or equal to 24.9 kg/m²; and 4) waist-to-hip ratio for women greater than 0.80, and for men greater than 0.90. Metabolic biomarkers included: 1) triglycerides greater than or equal to 150 mg/dL; 2) cholesterol greater than

or equal to 200 mg/dL; 3) high density lipids (HDL) less than or equal to 60 mg/dL; 4) low density lipids (LDL) greater than or equal to 100 mg/dL; 5) glucose greater than 130 mg/dL; and 6) insulin greater than 24.9 mcIU/mL. We omitted cortisol from this summary, even though it represents the neuroendocrine system, because it was analyzed separately as a measure of short-term objective stress rather than a long-term indicator.

Social Determinants of Health

Discrimination—Participants' experience of discrimination was measured by the Everyday Discrimination Scale (Williams et al., 1997). This 9-item scale asks participants to rate such events as being treated with less courtesy than others, people acting as if you are not as smart, or being called names or insulted on a scale from one (never) to six (almost every day). The total possible score ranges from 9 to 54. Higher scores represent greater experiences of discrimination. Cronbach's alpha for the Everyday Discrimination Scale in the parent study was excellent: 0.89 (Brewster, Epps, et al., 2020). This scale has been used in community-based samples of African Americans in varied contexts with good reliability and validity (Krieger et al., 2005; Taylor et al., 2004).

Physical Health

Sleep—Pittsburgh Sleep Quality Index (PSQI; Buysse et al., 1989). A 19-item self-report measure covering seven domains of sleep quality and disturbance over a one-month period with established test-retest reliability and validity. A global score of five or higher distinguishes poor sleepers. Cronbach's alpha for the PSQI in the parent study was good: 0.71 (Brewster, Epps, et al., 2020).

Mental Health

Depressive Symptoms—The presence and strength of depressive symptoms were measured using the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) version with 20 Likert-style items, each with a range of 0 to 3, so the scale ranges from 0 to 60. The CES-D is a screening instrument where higher scores on the CES-D indicate greater depressive symptoms and a score of 16 or higher suggests individual risk for depression. Cronbach's alpha for the CES-D in the parent study was excellent: 0.87 (Brewster, Epps, et al., 2020) with evidence of good reliability established in prior dementia caregiving studies with African American samples (Belle et al., 2006; McCallum et al., 2006; Merritt et al., 2011; Griffiths et al., 2018).

Analyses

Demographic characteristics, measures of subjective and objective stress, and health outcomes were summarized using means and frequencies. Graphical summaries (histogram, box plots) identified potential outlying measurements and to assess whether log transformation or non-parametric summaries might be required. Models for individual trajectories of cortisol change (acute stress) at awakening, 30 minutes later, and at bedtime were fitted with a repeated measures longitudinal analysis approach. The model included person-level terms for effects of caregiver age and sex and treated other between-caregiver differences as a random effect. The predicted means at each of the three time points were

parameterized in this model as baseline level (at awakening), the difference between baseline and 30 minutes after awakening, and the difference between 30 minutes after awakening and bedtime, allowing direct formal tests in the model of how the cortisol level changed during the day. Spaghetti plots were used to illustrate the variation in patterns of change over the day.

The relationships proposed in the Environmental Affordance Model (Mezuk et al., 2013) were assessed by a systematic series of linear regression models and quantified with Pearson correlation coefficients. The first set of regression models examined potential predictors of objective stress (cortisol) and subjective (perceived) stress, following the structure laid out in the Environmental Affordance Model. First, the association of stress with demographic variables (age, sex, education, marital status, relationship, length of caregiving, residence with care recipient) was assessed (Arrow A, Figure 1). Then we examined the potential added impact of social determinants of health (discrimination) proposed by the NIA Health Disparities Framework (Hill et al., 2015; Arrow B plus A, Figure 1). Next, we examined the possible additional effects of care recipient function on stress (IADL; Arrow C plus A and B, Figure 1). The second set of models then examined the association of stress with mental and physical health (depressive symptoms and sleep, respectively) via a series of regression models, which further built on results from the first set of models. First, the association with stress was measured (Arrow D, Figure 1), then models included demographics and caregiving setting (Arrows A and D, Figure 1). Finally, discrimination was included (Arrows A, D, and E, Figure 1). All models were examined via residual diagnostics for possible violations of assumptions (linearity, normality, homoscedasticity). Variables not meeting criteria for statistical significance or adding to explanatory power (Akaike Information Criterion) were omitted from final models. All analyses were carried out in R 3.6.1 (R Core Team, 2019) and 95% confidence limits provided for point estimates.

Results

Participant Characteristics

Participants were predominantly women (86%), with an average age of 55 years, ranging between 27–78 years ($SD = 9.7$). The group was well educated, with less than one fifth having no college and a quarter having some post-graduate education. The majority were unmarried (62%) and they had typically been caregiving for four years, but with a wide range (one month to 21 years). More than half were caregiving for their mother (54%), followed by a spouse (14%), or father (11%); 41% were caring for others, and 71% lived with the care recipient. Perceptions of everyday discrimination varied widely among caregivers, with a mean of 16 and a standard deviation of six (range 9 to 38).

Sleep disruption, as measured by the PSQI, was common among caregivers, with 112 of 135 caregivers (83%) scoring five or more, the level that distinguishes poor sleepers. The mean score was 8.5, standard deviation four, with range of 1 to 19, the full possible range of scores. Depressive symptoms, as measured by the CES-D, were a common finding for this cohort, with a mean score of 13.3, standard deviation 9.1, and a range of 0 to 43 (with 44 missing). Among those with CES-D data, 39% (38/98) met the criterion of at least 16 points, suggesting individual risk for depression.

What Does Stress Look Like for African American Dementia Family Caregivers?

Despite individual variation, both subjective and objective stress appeared closely linked to the burden of caregiving (data not shown). The mean score for burden of caregiving measured by the ZBI was 39, or an average of almost 2 points (“sometimes”) across the items, with a standard deviation of 16 points, reflecting the wide range from 4 to 74 points. A more global assessment of stress, the PSS, showed a similar wide range from 0 to 33 of a possible 40 points, with a mean of 17 and standard deviation of 6 points. Perceived stress was strongly associated with assessment of burden from caregiving ($r=0.68$, $p<0.0001$). Perceived stress was not associated with the age of the caregiver ($p=0.38$), age of the care recipient ($p=0.92$), or with length of caregiving ($p=0.53$), but was higher when the care recipient was the mother than for other family members, or non-family ($p=0.02$). As measured by IADLs, with an average function level of 2.2 ($SD=2$), which is considerably low, and a range between 0–8, care recipients were functionally dependent on caregivers.

Salivary cortisol was available for 94 of the 142 participants, all but one with complete data at all three times. The 48 with missing cortisol data were similar to those with data in age (mean 54.4 vs. 55.5), education (mean 16.6 vs. 15.9), and gender (87% vs. 85% female). Measurements showed a highly skewed distribution at all three time points. Mean levels at awakening, 30 minutes after awakening, and bedtime were 0.57, 0.69, and 0.98 respectively, with medians of 0.30, 0.45, and 0.08. Natural log transformations were used in subsequent longitudinal and regression model analyses to address this problem ($\log(\text{cortisol} + 1)$ to allow for values reported as 0). Daily patterns of cortisol: A mixed-effects model was run, allowing for random individual effects, and controlling for age and gender. As shown in Figure 2, almost all caregivers experienced little change in cortisol level during the day, with the exception of two people; the prediction interval based on the mixed-effects model (shown as a shaded region) shows a narrow band with little within-person variation in the individual trajectories within it. The cortisol awakening response was a modest 0.084 unit increase in log cortisol, corresponding to an 8.7% increase in cortisol in the first half hour (95% CI 0.011–0.156, Table 1). For the daytime cortisol slope there was a 0.20 unit decrease in log cortisol, corresponding to an 18% drop from 30 minutes after awakening (95% CI $-0.273 - -0.127$, Table 1). There was no trend in cortisol behavior with age, nor were men significantly different from women. Change in cortisol from awakening to 30 minutes later was not significantly associated with either ZBI total burden score ($p=0.71$), or the PSS stress score ($p=0.78$).

The mean allostatic load score was 5.7, with a standard deviation of 1.9 and range of 1 to 10. Indicators of cardiovascular risk most commonly fell outside analysis guidelines. Specifically, frequencies were higher among more than half of the sample for systolic blood pressure (61%), LDL (61%), BMI (84%), waist-to-hip ratio (82%), and CRP (70%). Despite the wide range of allostatic load in this sample, there was little evidence of association with other stress measures or with potential predictors. Allostatic load was not associated with age and sex of caregiver, or with relationship to patient ($p>0.4$, all regressions). Allostatic load was uncorrelated with the ZBI score ($p=0.99$) and with the PSS score ($p=0.86$), and adjustment for demographics did not modify this.

What Relationships Exist Between Stress and Health Outcomes?

Regression models (Table 2) found perceived stress associated with an increase in sleep problems, with a one-point increase in stress associated with a 0.23-point increase in the sleep scale (95% CI 0.13–0.33). No other variables, including demographics, cortisol, care setting, and everyday discrimination, were associated with the magnitude of sleep problems.

In regression models (Table 2), higher levels of perceived stress were associated with greater depressive symptoms; for every 1-point increase in stress, the CES-D rose almost a full point (95% CI 0.67 – 1.06). Everyday discrimination was associated with greater depressive symptoms, with a one-point increase in the discrimination index associated with an 0.86-point increase on average in CES-D (95% CI 0.40 – 1.33). Neither age nor sex was associated with CES-D score, and other factors considered (cortisol, relationship to care recipient, whether the caregiver lived with the care recipient – data not shown) were not associated with depressive symptoms. Very similar results were found in models with the ZBI score instead of the PSS; a one-point increase in burden was associated with a 0.30-point increase in CES-D (95% CI 0.19–0.41 with other findings unchanged, results not shown). Allostatic load showed only a slight, non-significant association with increased CES-D depressive symptoms ($r=0.16$, $p=0.11$), and a similar slight association with increased sleep problems ($r=0.13$, $p=0.14$).

Discussion

The purpose of this study was to characterize the landscape of stress (subjective and objective) in African American caregivers, and secondarily to explore relationships between individual caregiver characteristics, stress, social determinants of health, and health outcomes. First, overall, most caregivers in this sample reported some degree of subjective stress and exhibited indicators of objective stress. For subjective stress, most caregivers had been caregiving less than five years, although there was wide variation demonstrating the long-term process of AD caregiving (Alzheimer's Association, 2021). In addition, although less than half of caregivers were providing care for others in addition to the care recipient, this is not an uncommon experience for African American caregivers contributing to the complexity and stress of the role (Cothran et al., 2020; AARP & National Alliance on Caregiving, 2020). Functional decline often trails with disease progression, where increased dependence on caregivers contributes to a wide range of recipient care provision (Alzheimer's Association, 2021). In our sample, care recipient functional status was considerably low, and caregivers appeared to report a high level of burden while perceiving their level of stress to be elevated as well. This experience may represent different levels of adaptation. Specifically, as new challenges emerge, or continue, including changes in support or resources, various strategies are required such that caregiver perceptions of stress, and burden of caregiving, may increase with disease progression (Gallagher-Thompson et al., 2020).

In general, objective acute stress, as measured by cortisol, indicated a disrupted pattern where caregivers had high cortisol awakening responses and remained high, with some outliers who were extremely high. In general, African Americans have high cortisol levels, lower cortisol awakening response, and slower decline, but various psychosocial aspects

such as education, SES, age, and discrimination add complexity to cortisol patterns (Berger & Sarnyai, 2015; Forrester et al., 2019; Samuel et al., 2018). For dementia family caregivers in general, blunted cortisol patterns are not uncommon, where caregivers tend to have higher baseline cortisol levels that gradually decrease over time (Allen, Curran, et al., 2017).

However, the drastically blunted cortisol awakening response in this sample of African American caregivers, is consistent with the limited work available (Allen, Curran et al., 2017; McCallum et al., 2006; Merritt et al., 2011), but also concerning. In relation to health implications of ongoing or chronic stress, consequences of dysregulated cortisol include decreased immune function, increased risk for diabetes and hypertension, and cognition changes (Korous et al., 2017). In addition, the adoption of coping behaviors by African Americans in the presence of stress may offer temporary relief, but adversely influence chronic health conditions, or worsen mental health outcomes long-term, particularly when exchanged for health promoting behaviors (Jackson et al., 2010). Specifically, while subjective stress drives modifiable behaviors such as intake of high sugar or high fat foods/beverages (Lattimore & Maxwell, 2004), physical inactivity (Stults-Kolehmainen & Sinha, 2014), and alcohol intake (Becker, 2017), sugar also has a calming effect on cortisol reactivity to stress (Tryon et al., 2015). The relationship of coping behaviors (e.g., overeating, alcohol consumption, and physical inactivity) to obesity and diabetes (Adam & Epel, 2007; Tomiyama et al., 2011) may place African American dementia caregivers at further risk (Dallman et al., 2003).

Objective chronic stress, as measured by allostatic load, was moderately high, demonstrating a similar trend from previous work (Geronimus, Hicken et al., 2006). In particular, because a large majority of this sample were middle-aged, well-educated African American women, existing literature has demonstrated that allostatic load in this population is higher, and allostatic load scores of >3 are associated with increased mortality (Borrell et al., 2020; Geronimus, Hicken et al., 2006). In addition, ongoing literature has consistently demonstrated that for African American women, education and economic status are not protective from stress outcomes, including allostatic load (Allen, Thomas, et al., 2019; Borrell et al., 2020; Geronimus, Hicken et al., 2006). Further, it is worth noting that cardiovascular risk factors contributing to higher allostatic load scores are of particular concern, considering African American women are more likely to have heart disease and are at increased risk of cardiovascular events, including myocardial infarction and stroke (CDC, 2017; NCHS, 2021). Although this disparity in presentation is well known, the effects of caregiving-related stress on cardiovascular disease risk in African American women requires attention.

Our sample of caregivers also reflect trends in African American caregivers who are predominantly women, unmarried, adult children, and live with the care recipient (Alzheimer's Association, 2021). In our study, adult children were not only caring for a parent, but more commonly caring for a mother, underscoring the disproportionate impact of AD in women both as caregivers and as persons living with AD (Alzheimer's Association, 2021). Further, perceived stress scores were significantly higher when the care recipient was the mother, which may underscore complex relationships between mothers and their caregiving daughters (Cothran et al., 2020). In addition, caregiving remains a socialized

gender role, particularly in the African American/Black community. Coping strategies such as the ‘Superwoman Schema’ archetype, which demonstrate the demand of role expectations at the intersection of race and gender, may influence unacknowledged stress and long-term health effects, necessitating further examination (Borrell et al., 2020; Versey, 2017; Woods-Giscombe, 2010).

Second, stress was associated with depressive symptoms, sleep problems and perceived burden when controlling for age, sex, and relationship of the caregiver. Whether caregivers were younger or older, and regardless of gender and relationship status, caregivers experienced stress, depressive symptoms, sleep problems and perceived burden. Because caregiving is a long-term endeavor, the impact on mood and sleep, depending on the stage of the care recipient, as well as the responsibility of associated tasks, including maintaining safety, navigating day-to-day demands, and even managing medical and nursing tasks, all contribute to a strenuous experience (Alzheimer’s Association, 2021; Reinhard et al., 2020). Disrupted sleep patterns, whether living with a care recipient or not, were common in caregivers. This is not a surprising finding, as varied dementia related behaviors, such as wandering, heightened vigilance on the part of caregivers for other concerns during the night, or general alterations in care recipient sleep patterns all impact caregiver sleep (Fonareva & Oken, 2014; Mehta & Yeo, 2017; Peng & Chang, 2013). Further, with one-third of caregivers in this analysis meeting criteria suggesting risk for depression, disrupted sleep may also reflect depressive symptoms (Peng & Chang, 2013). Although literature specifically examining African American caregivers and sleep outcomes is limited, given the known associations with cognition and depression, further examination is warranted (Allen, Curran, et al., 2017; Fonareva & Oken, 2014; Peng & Chang, 2013).

Discrimination was associated with depressive symptoms. Our findings are consistent with ongoing literature highlighting associations between discrimination and mental health outcomes for African Americans (APA 2016; Berger & Sarnyai, 2015; Forrester et al., 2019; Forde et al., 2019). Discrimination scores had wide variation in general, and while we do not know the reasons, this could be attributed, in part, to hesitancy to report (“name”) the experience of discrimination or racism, or to the geographic location of the parent study being in a predominantly African American region in the United States. It is worth noting, however, that despite varied individual experiences, systemic discrimination and racism enacted through policies may be operating in the background, reinforcing well-established health inequities.

This study extends current knowledge as it focused on an exclusively African American sample. Previous studies, which have compared African Americans with other racial/ethnic groups, may be overlooking nuanced within-group differences important to better understand the stress process in African American caregivers. Additional strengths include the variety of measures uniformly assessed (i.e., care recipient function, mental and physical health outcomes), offering a foundation to capture heterogeneity within this group. In addition, this is one of the few studies to examine both objective and subjective stress and discrimination in African American caregivers. This allows incorporation of the Environmental Affordance Model and NIA Health Disparities Framework to help organize and contextualize the unique experience of stress of African American caregivers on health

outcomes, as well as extend current models in caregiving research. Specifically, this work provides important insight into the impact of caregiving on African American physical health and mental health symptoms.

Despite these important strengths there are some limitations worth acknowledging. First, potentially relevant demographic variables, such as hours of caregiving, and employment, were not available, which represent additional factors known to compound caregiver stress, and limit the full picture of caregiving. Second, as participants recruited for a clinical intervention trial based on specific eligibility criteria and with proximity to an Alzheimer's Disease Research Center, participant characteristics represent some levels of homogeneity on key demographic factors, such as education, that differ from the general population and may limit robust within-group analyses/interpretation. Third, cortisol measures may not contain enough density to capture the variation needed to fully examine differences across age and socioeconomic status. Specifically, we only analyzed three daily time points at baseline of available data, and it is unclear what changes persisted over time. Fourth, this analysis focused on baseline data from a clinical trial, thus limiting the ability to establish temporal sequence between concurrently measured predictors (e.g., caregiver-care recipient context), stress measures, and health outcomes. The associations observed in this study are informative about the association between stress and health burdens in African American caregivers but cannot establish causality. Finally, the PSQI is a subjective sleep measurement tool, where interpretation is based on individual recall and accompanying objective measures would strengthen data on sleep patterns. However, given the limited data on African American dementia family caregivers and sleep outcomes, this work contributes to the existing body of literature with room for further study.

Although the stress of dementia caregiving is well known, a limited understanding of stress for African American caregivers remains. This work helps extend what is currently known by providing a foundation of understanding subjective and objective indicators of stress, including care recipient factors, and potential associations with mental and physical health outcomes in African American dementia family caregivers. The ongoing impact of racism, discrimination, and social injustice in African American communities is a tangible everyday reality, which has important health implications. It is important to understand factors or characteristics that contribute to stress susceptibility as well as the role of protective factors to help explain inconclusive findings in current caregiver intervention research with African American family caregivers of persons living with dementia. We need additional data to examine caregiver stress over time using mixed method approaches to better understand the trajectory of caregiving in relation to care recipient disease progression, social determinants of health within cultural contexts, as well as of coping and resilience behaviors. Intervention studies that include both objective and culturally relevant subjective measures of stress, plus an organizing framework that incorporates psychosocial and environmental factors known to affect stress in African Americans, are needed. Interventions with a longitudinal design, and a comparable sample of African American non-caregivers are also needed. Without a better understanding of stress in African American caregivers, health inequities will persist, and intervention development will be limited or even ineffective for this population. The more we can understand the impact of stress and protective behaviors in a broader context to improve the physical and mental health outcomes of African American caregivers, the better

able we will be to tailor existing multi-component interventions, especially for those at risk for poor cardiovascular outcomes.

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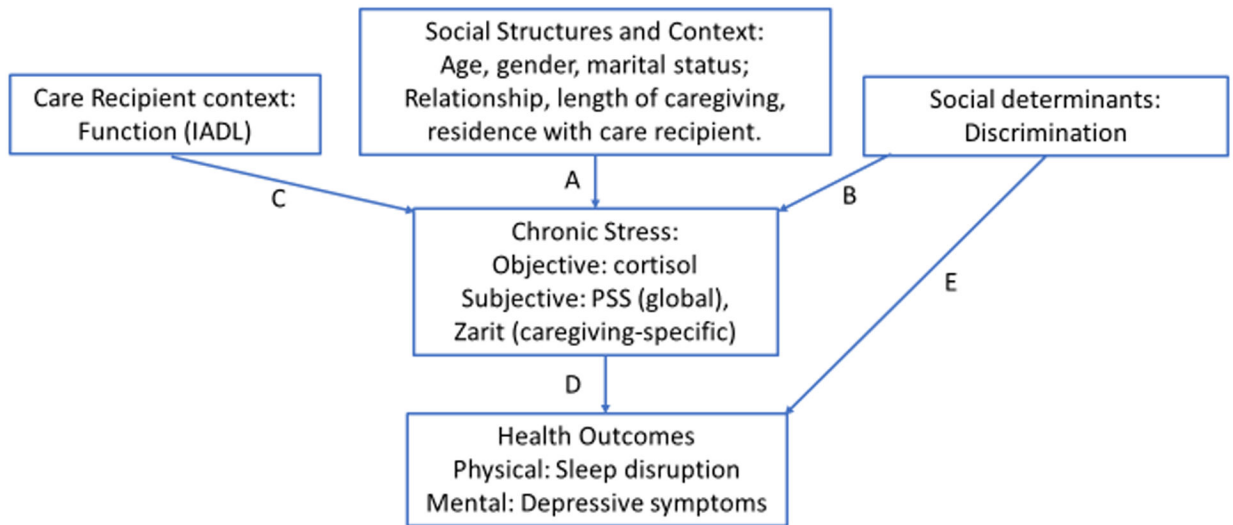


Figure 1. Regression Model Sequence

Note. Model sequence based on Environmental Affordance Model (Mezuk et al., 2013). Arrows represent components of successive regression models as described in text: A alone, A+B, A+B+C for stress measures as outcome; D alone, A+D, A+D+E for health measures as outcome.

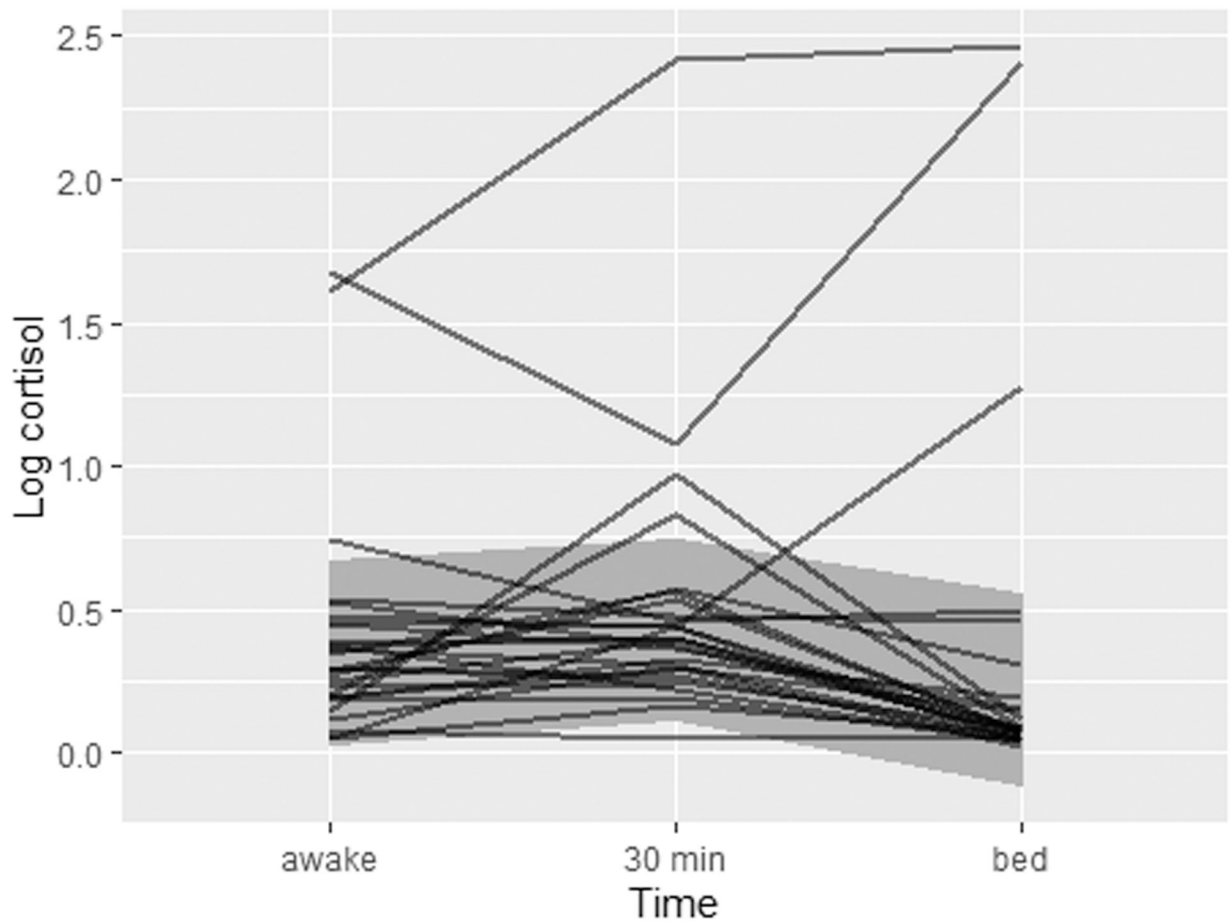


Figure 2. Cortisol Distribution

Note. Trajectories of cortisol (two-day averages) for a random subset of 30 subjects, with 95% prediction interval from mixed longitudinal model fitted to $\log(\text{cortisol} + 1)$. Prediction interval based on 55-year old female; model showed no significant differences by age or sex of caregiver. Mean cortisol increased 8.7% from awakening to 30 minutes later (95% CI 0.1% – 17%, $p = 0.024$) and decreased 18.1% from then to bedtime (95% CI 17% – 19%, $p < 0.00001$).

Table 1

Estimated Changes in Log (Salivary Cortisol; n=94)

Variable	Estimate	Std Error	95% CI
Log (cortisol at awakening)	0.456	0.246	(-0.023, 0.936)
Change: awakening to 30 min later	0.084	0.037	(0.011, 0.156)
Change: 30 min after to bedtime.	-0.200	0.037	(-0.273, -0.127)
Age in years	-0.001	0.004	(-0.009, 0.007)
Male (Ref: female)	0.054	0.111	(-0.271, 0.162)

Note. 93 participants had all three measurements and one lacked bedtime cortisol, with age and sex as predictors.

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Table 2

Associations Between Depression and Sleep Outcomes, Versus Predictors Including Perceived Stress, Age, Sex, and Everyday Discrimination Score

Variable	CES-D (n=97)				PSQI (n=132)			
	Estimate	Std. Error	95% CI	p-value	Estimate	Std. Error	95% CI	p-value
(Intercept)	-4.164	2.005	(-8.15, -0.18)	0.041	4.169	1.001	(2.19, 6.15)	<0.001
PSS10 total	0.865	0.097	(0.67, 1.06)	<0.001	0.232	0.050	(0.13, 0.33)	<0.001
Age	-0.047	0.074	(-0.19, 0.10)	0.532	0.026	0.034	(-0.04, 0.09)	0.445
Male sex	3.266	1.673	(-0.06, 6.59)	0.054	0.521	0.953	(-1.37, 2.41)	0.586
Everyday discrimination	0.864	0.232	(0.40, 1.33)	<0.001	0.034	0.117	(-0.20, 0.27)	0.772