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Examining Elevated Stress Levels Among African American Caregivers of Relatives with Dementia

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Abstract

Examining Elevated Stress Levels Among African American Caregivers of Relatives with Dementia

By Lindsey N. Blevins

Background: Alzheimer's disease is an incurable condition characterized by irreversible biological and cognitive changes. African Americans are at higher risk for Alzheimer's disease compared to non-Hispanic whites as multiple research studies have identified an incidence rate among African Americans to be 2 to 2.5 times that of whites (Demirovic et al., 2003; Froehlich, Bogardus, & Inouye, 2001; Gurland et al., 1999; Husaini et al., 2003; Krishnan et al., 2005; Tang et al., 2001). Research on dementia caregiving has consistently portrayed that the caregiving role entails sustained levels of stress, higher rates and levels of depression, burden, and mood disorders (Pinquart & Sorensen, 2003; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz & Sherwood, 2008), and higher risk for mortality (Schulz & Beach, 1999).

Objective: The objectives of this study were to 1) identify predisposing factors among caregivers that were associated with higher levels of stress and 2) analyze self-efficacy, knowledge, and coping in the stress process, in relation to perceived stress and IL-6.

Methods: This study was a secondary, cross-sectional analysis of the baseline data from a randomized-control trial testing interventions to improve well-being among 142 African American caregivers in Atlanta, Georgia. The following statistically analyses were conducted to test for associations with perceived stress and IL-6: Pearson and Spearman's Rho correlation tests, One-Way ANOVAs, and Multiple Linear Regressions.

Results: The study found a statistically positive significant association between gender, family help, co-residence, family cohesion (communication, problem solving, global family functioning), coping, anxiety, burden, depression and perceived stress. A statistically negative association was found between the caregiver/care-recipient relationship, self-efficacy, and perceived stress. The multiple linear regressions indicated that there was a statistically significant association between gender, a little family help, self-efficacy, ways of coping, and perceived stress.

Conclusions: African American dementia caregivers experience many disparities that are compounded by the additive effects of chronic daily stressors and pre-existing health conditions. These findings illustrate the need for targeted interventions focusing on increasing caregivers' self-efficacy and positive coping. These findings can also inform healthcare professionals of the increased health risks caregivers face in comparison to the general population.

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Chapter One

Introduction

Introduction

Alzheimer’s disease is an incurable condition characterized by irreversible biological and cognitive changes. Currently, it is the 6th leading cause of death in Caucasians and the 4th leading cause of death among African Americans ("Alzheimer's disease facts and figures," 2015). Alzheimer’s disease currently affects over five million people in the United States, with projections expected to exceed 14 million by 2050 ("2009 Alzheimer's disease facts and figures," 2009). “Based on the 2010 Census data, 20% of the 65-year and older population is comprised of racial minorities” (Barnes & Bennett, 2014). The older African American population is projected to triple by 2050 and reach 10.5 million ("2009 Alzheimer's disease facts and figures," 2009). Barnes and Bennett predict that by 2050, minorities will represent 42% of the 65-year and older population (Barnes & Bennett, 2014), meaning that African Americans will increase as a proportion of the overall population affected with Alzheimer’s disease and other dementia-related disorders.

African Americans are at higher risk for Alzheimer’s disease compared to non-Hispanic whites as multiple research studies have identified an incidence rate among African Americans to be 2 to 2.5 times that of whites (Demirovic et al., 2003; Froehlich et al., 2001; Gurland et al., 1999; Husaini et al., 2003; Krishnan et al., 2005; Tang et al., 2001). Individuals who have a first degree relative with Alzheimer’s disease are also at higher risk for the disease. Specifically, African Americans with this relationship to the care-recipient are at a higher risk of the disease, compared to whites with the same relationship (Green et al., 2002). Although some research suggests that African Americans have lower rates of cognitive decline (Helzner et al., 2008; Wilson et al., 2006) and lower hazard for mortality (Mehta et al., 2008); other research studies do not accept these findings on the basis of racial differences (Fillenbaum et al., 1998; Fitzpatrick et al., 2004).

Traditionally, studies have examined health and disease based on race and ethnicity. Many researchers discourage this aggregation and recommend using other measures such as educational history, social class history, or others to elicit finer distinctions among people (Dilworth-Anderson, Hendrie, Manly, Khachaturian, & Fazio, 2008; Manly et al., 2008). Nevertheless, the findings of racial and ethnic differences regarding incidence and prevalence rates, extended survival, familial transmission, and projected growth of the African American Alzheimer’s disease population draw attention to this group as one whose needs must become a public health priority.

Eighty-one percent of care for Alzheimer’s disease patients living in the community is family care (Zhu et al., 2008). Of these caregivers, there are 2 to 2.5 times more women than men providing care for someone with dementia ("Alzheimer's disease facts and figures," 2014). Additionally, African Americans spend more time caregiving than whites; they are also “more likely to experience high caregiver burden” ("Alzheimer's disease facts and figures," 2014). A report released in February 2015, assessed the cost of Alzheimer’s disease in the United States to be 217.7 billion dollars, over half of which is concentrated in the South ("Alzheimer's disease facts and figures," 2015). Many of these dollars represent unpaid caregiver hours, characterized by spouses and adult children of individuals with Alzheimer’s disease. One-third of the overall cost of dementia care is accounted for through family caregiving (Wimo, Jonsson, & Winblad, 2006). In addition to the previous statistic, 70% of caregivers have no outside help; 40% provide 20 hours or more of care each week, and 80% spend at least one-year caregiving (Navaie-Waliser et al., 2001). More specifically, analyses of data conclude that African American patients admitted into nursing homes have higher rates of dementia, longer survival, and increased severity of dementia upon admission compared to whites (Helzner et al., 2008; Weintraub et al., 2000; Yaffe et al., 2002). These findings suggest that African American dementia patients stay in the community longer and require longer periods of community caregiving.

Disease progression and severity, in addition to other social factors, influence the level of burden that caregivers experience. Research findings conclude that as disease symptoms worsen (e.g. as patient functionality decreases), caregiver burden tends to increase ("Alzheimer's disease facts and figures," 2014; Dauphinot et al., 2015; Iavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014; Kang et al., 2014; Reed et al., 2014). This burden and distress is primarily a result of patient behaviors (Deimling & Bass, 1986; Molloy, Bédard, Pedlar, & Lever, 1999; Pruchno & Resch, 1989a; Teri, Logsdon, Uomoto, & McCurry, 1997) and care recipient's incontinence (Noelker, 1987), rather than the severity of cognitive impairment. Patient behavior and incontinence were also strong predictors of patient institutionalization (Noelker, 1987). Family support is linked to delayed institutionalization for the Alzheimer's disease patient (Gaugler, Zarit, & Pearlin, 1999). In contrast, dysfunction among family members is linked to greater caregiver burden (Tremont, Davis, & Bishop, 2006). Premorbid relationships between caregiver and Alzheimer's disease patient are associated with caregiver burden (Noelker

& Wallace, 1985), where good premorbid relations predict low burden (Steadman, Tremont, & Davis, 2007) and vice versa.

Research on dementia caregiving has consistently portrayed that the caregiving role entails sustained levels of stress, higher rates and levels of depression, burden, and mood disorders (Pinquart & Sorensen, 2003; Schulz et al., 1995; Schulz & Sherwood, 2008), and higher risk for mortality (Schulz & Beach, 1999). As caregiver burden increases, adverse outcomes such as, “emotional stress, depression, impaired immune system response, health impairments, lost wages due to disruptions in employment, depleted income and finances” ("Alzheimer's disease facts and figures," 2014), and diminished quality of life (Elizabeth W Gonzalez, Polansky, Lippa, Gitlin, & Zauszniewski, 2014) begin to emerge. According to the "Alzheimer's disease facts and figures" 2014), 38% of caregivers reported high physical distress. Even though dementia caregivers have higher rates of disease, depression, and anxiety, they have lower rates of healthcare use (Pruchno & Resch, 1989b) and are less likely to engage in self-care activities (Pinquart & Sorensen, 2006; Schulz & Martire, 2004). In particular, African American caregivers seem to engage in fewer self-care activities, do not take anti-depressant medications, are less likely to use formal services (Scharlach et al., 2006) and reduce social activities outside of the home when compared to whites. Despite this, African American caregivers experience increased visits to the home from family and friends (Haley et al., 1995), were more resourceful and resilient (Clay, Roth, Wadley, & Haley, 2008; E. W. Gonzalez, 1997), and had better scores on measures of positive coping (Roff et al., 2004) and life satisfaction (Roth, Haley, Owen, Clay, & Goode, 2001).

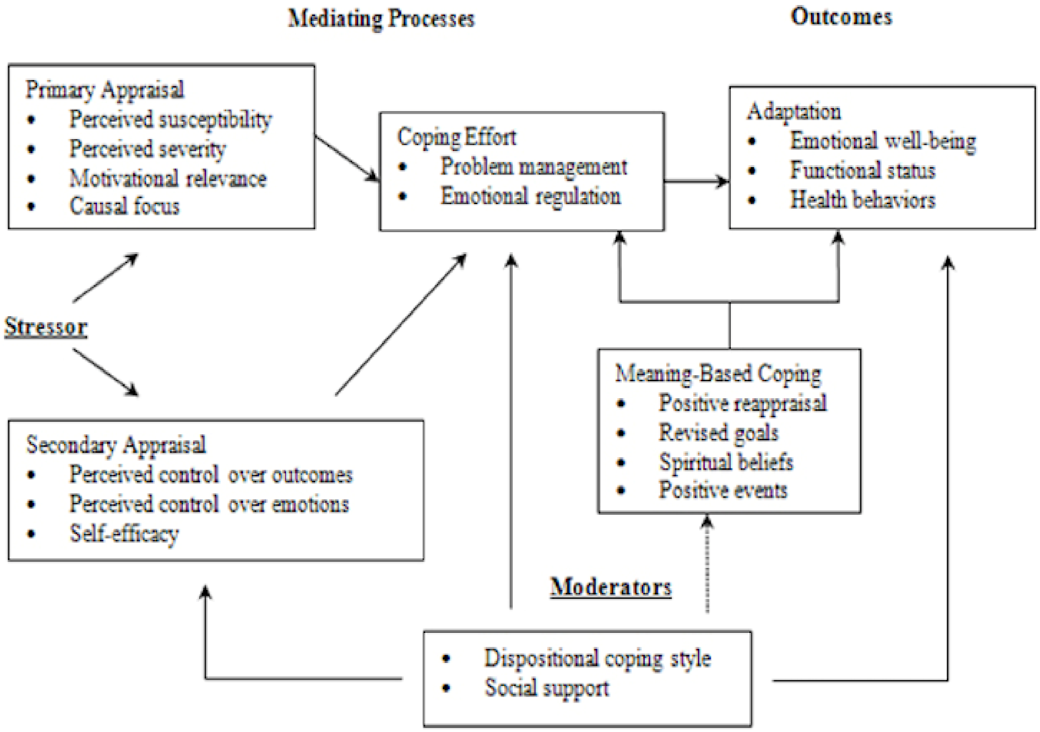
The additive effect of consistent and chronic stressors lead to constant activation of the hypothalamic-pituitary-adrenal (HPA) axis, which is critical in stress-response, and results in negative outcomes related to health (Gouin, Glaser, Malarkey, Beversdorf, & Kiecolt-Glaser, 2012)). Caregivers are at high risk for poor physical, psychological, immunological, and cardiovascular health outcome, which often lead to mortality (Aneshensel, Pearlin, & Schuler, 1993; Fredman et al., 2008; Janevic & Connell, 2004; Lee, Colditz, Berkman, & Kawachi, 2003; Schulz & Beach, 1999; von Kanel et al., 2006). Many research studies have consistently found various stress-related insults to the nervous and immune systems (Gouin, Hantsoo, & Kiecolt-Glaser, 2008; Stowell, Kiecolt-Glaser, & Glaser, 2001), including slower wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995), higher IL-6 markers (von Kanel et al., 2006), increased telomere erosion (Damjanovic et al., 2007), reduced β2-adrenergic receptor sensitivity (Mausbach et al., 2008), and reduced sympathetic arousal (Roepke et al., 2008) among the caregiving population.

Theoretical Framework

The Transactional Model of Stress and Coping

In response to the amount of stress caregivers face on a daily basis, researchers have developed interventions and analyzed coping strategies utilized by caregivers. Theories, such as the Transactional Model of Stress and Coping (TMSC), have served as guiding tools when creating, redirecting, and understanding coping behavior that occur as a result of an intervention. This theory serves as a tool to evaluate the coping process in relation to stressful situations and/or events that threaten the physical, mental, and social well-being of an individual (Glanz, 2008). This model acknowledges that stressors from the internal and external environments affect the physical and psychological well-being of the individual (Glanz, 2008). A disturbance of homeostasis, caused by the stressor, can result in physiological effects, such as increased inflammation or maladaptive health behaviors (Glanz, 2008). However, stress does not affect every individual equivalently. Glanz (2008) states, "Perceived stressors, rather than objective stressors, are the main determinants of effects on behaviors and on health status." The idea of perceived stressors versus objective stressors leads to the comprehensive analysis of moderating factors within the stress and coping framework (Glanz, 2008).

Figure 1. Diagram of Transactional Model of Stress and Coping.



The TMSC uses primary appraisal, secondary appraisal, coping efforts, and coping outcomes (adaptation) to analyze the coping process as a response to a given stressor (Figure 1) (Glanz, 2008). Coping styles, social support, information seeking, optimism, positive psychology, and stress management interventions are considered potential moderators and acknowledged as extensions in the stress and coping framework (Glanz, 2008). For example, Sun and Hodge (2014) and Heo and Koeske (2013) examined the effects of spirituality and religion on depression and found that religion may lower caregiver burden, furthermore, decreasing depression. Garcia-Alberca et al. (2012) found that high caregiver burden in combination with disengagement coping strategies can be used to predict anxiety and depression among caregivers. All of these examples illustrate how specific coping efforts affect the biological and/or psychological well being of caregivers.

Additionally, this model has been useful in analyzing and understanding the effects of race on health disparities, particularly among African Americans (Glanz, 2008). Previous research conducted by D. R. Williams (1999) indicated the racism could directly and indirectly affect health by acting as an acute or chronic stressor (Glanz, 2008). Supplementary research verified this conclusion by providing evidence that racism and cardiovascular reactivity are positively associated (Glanz, 2008). However, perception and coping styles can moderate the effect of these stressors on the physical and psychological well being of the afflicted individual.

Self-Efficacy

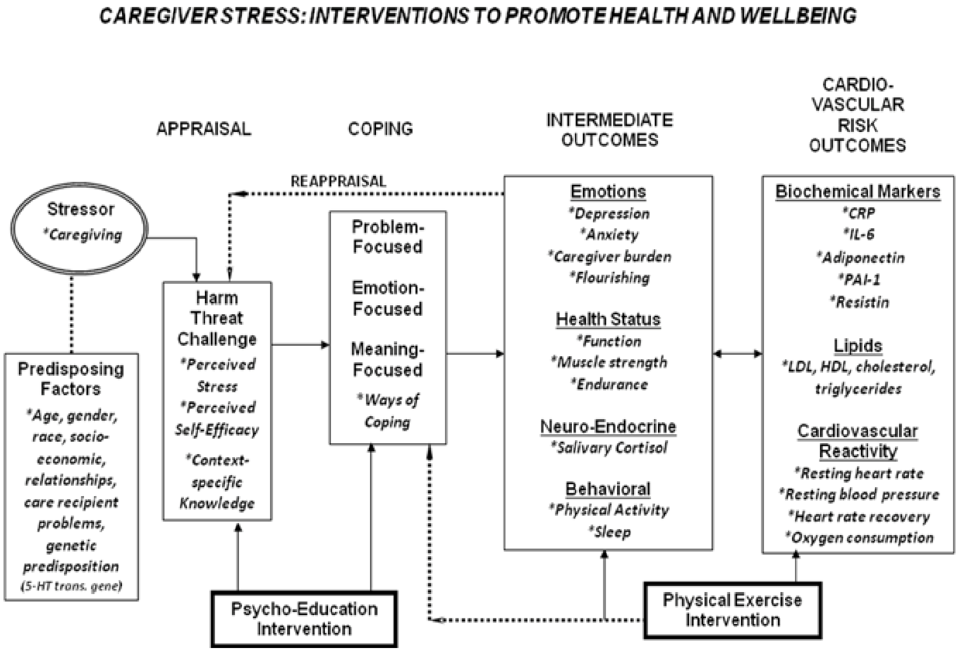
A great deal of research has also been conducted on coping self-efficacy and its influence on caregiver health. Self-efficacy is defined as, “beliefs about personal ability to perform behaviors that bring desired outcomes” (Glanz, 2008). Mausbach et al. (2011) study specifically analyzed the effects of coping self-efficacy on IL-6, a protein that plays a role in inflammation. Results showed that “low coping self-efficacy was significantly related to higher levels of IL-6” (Mausbach et al., 2011). This suggests that high levels of self-efficacy reduce the presence of biomarkers associated with stress; further decreasing stress levels among caregivers. Nogales-Gonzalez, Romero-Moreno, Losada, Marquez-Gonzalez, and Zarit (2015) also found that in relation to managing behavioral and psychological symptoms, caregiver distress decreased as self-efficacy increased. Additionally, Romero-Moreno et al. (2011) suggested that using self-efficacy to control thoughts might also ease caregiver distress.

Study Purpose

The purpose of the Caregiving Opportunities for Optimizing Lifestyles-Alzheimer’s Disease (COOL-AD) study was to develop and test a combined psycho-education and exercise program. The aim of this program was to promote health and well being through 1) positively affecting primary and secondary appraisal and 2) enhancing caregiving self-efficacy among African Americans caring for a relative with a dementia-related disorder. Even though the caregiving situations across both Caucasian and African American races have many similarities, African American caregiving lasts longer than Caucasian caregiving. Additionally, there are no evidence-based programs to date that solely focus on African American dementia family caregiving. In the first stage of the COOL-AD study, an evidence-based psycho-education program was adapted into a culturally sensitive program for African American caregivers. This program was proven to enhance caregiver self-efficacy and lower distress among caregivers. During the second stage, African American caregivers were recruited, enrolled, and randomized into two intervention arms, psychoeducation alone or psychoeducation and exercise, or into a usual care-attention control group. The psychoeducation and exercise intervention arm was a combination of the psychoeducation program in addition to an individualized aerobic and resistance exercise regimen. This arm was expected to work on both the psychological and physiological level, aiming to reduce the impact of stress holistically. The psychoeducation portion of the program was intended to focus on self-care.

The study analyzed the effects of each intervention on caregiving appraisal and coping efforts, the intermediate effects at all levels, and the effects on cardiovascular risk or health. The intermediate outcomes included psychosocial factors such as emotions, health status, neuro-endocrine, and behavioral outcomes (Figure 2) (Hepburn). The cardiovascular risk factors that were assessed included biochemical markers (CRP, IL-6, Adiponectin, PAI-1, and Resistin), lipids (LDL, HDL, cholesterol, and triglycerides), and cardiovascular reactivity (resting heart rate, resting blood pressure, heart rate recovery, and oxygen consumption).

Figure 2. Caregiver Stress: Interventions to Promote Health and Wellbeing.



Research Question

In the context of African American caregivers in the COOL-AD study, the TMSC provided a framework to 1) identify predisposing factors among caregivers that are associated with higher levels of stress and 2) analyze self-efficacy, knowledge, and coping in the stress process, in relation to perceived stress and IL-6.

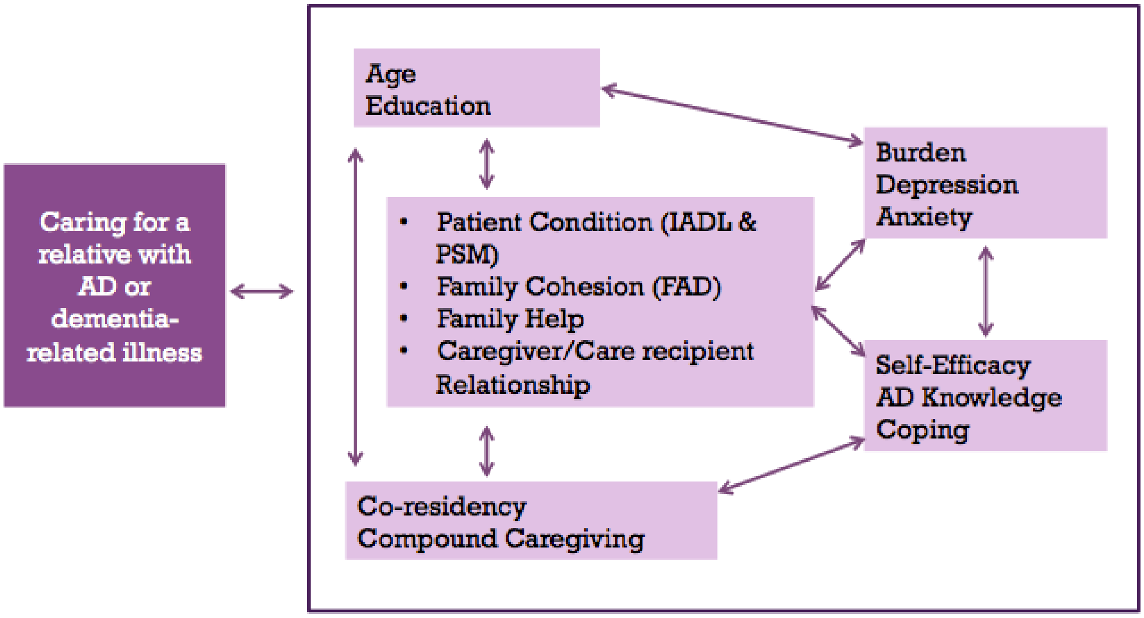
The study hypotheses include the following:

1) Live-in caregivers, compound caregiving, lack of family cohesion, duration of caregiving, patient condition, education, low self-efficacy, low Alzheimer's disease knowledge, and poor coping efforts will be identified as factors that are associated with elevated IL-6 levels and perceived stress scores in caregivers at baseline.
2) Self-efficacy will have a more profound impact on IL-6 and perceived stress levels, compared to Alzheimer's disease knowledge and coping efforts. High self-efficacy scores will be associated with lower IL-6 levels and perceived stress scores among caregivers at baseline.

Theoretical Application

The original COOL-AD study used a combination of theory and physiology to analyze the effects of caregiving on cardiovascular risk factors. This study utilized the TMSC to gain a more in-depth understanding of the immediate situation of caregiving, particularly caregiving risk factors that are associated with elevated stress levels among African Americans. At the time when caregivers are presented with a stressor, in this case the situation of caregiving for a family member with dementia, a host of factors and potentially additive stressors are already existent within that caregiver's life. How the caregiver perceives and reacts to these stressors are critical in the physiological stress response that occurs. If the caregiver appraises the situation as being threatening, his or her body will initiate a stress response. Additionally, if the caregiver fails to cope with this threat, their HPA axis may remain activated over a sustained period of time, which can result in negative health outcomes. By using the TMSC to further analyze the associations between caregiving risk factors and stress, researchers can classify caregivers as being at high-risk, moderate-risk, or low-risk for elevated stress and develop strategic interventions that can be utilized accordingly based on risk status.

Figure 3. Examining Elevated Stress Levels Among African American Caregivers of a Relative with Dementia Concept Map.



Significance of the Study

Health disparities spearhead much of the increased mortality risks among the African American community. According to Truman et al. (2011), “Health disparities are differences in health outcomes and their determinants between segments of the population, as defined by social, demographic, environmental, and geographic attributes.

Health inequalities, refers to summary measures of population health associated with individual- or group-specific attributes (e.g., income, education, or race/ethnicity)." Research studies have shown that African Americans are undertreated and underserved within the healthcare setting and tend to be under-users of the healthcare system as well. Perceived and experienced discrimination by healthcare providers is higher among African Americans, (Barnes, Mendes de Leon, Bienias, & Evans, 2004; Hausmann, Jeong, Bost, & Ibrahim, 2008) which affects the population's willingness to utilize services (Musa, Schulz, Harris, Silverman, & Thomas, 2009). Discrimination and disrespect directed towards African American patients from physicians are higher than towards other racial groups (Barnes et al., 2004) and may serve as the principal influential factor in the utilization of healthcare services among this population. Specific to Alzheimer's disease, African Americans are under-diagnosed (Wilkins et al., 2007), receive fewer gold standard dementia medications (Poon, Lal, Ford, & Braun, 2009; Zuckerman et al., 2008), and are underrepresented in Alzheimer's disease drug trials (Faison et al., 2007). African American dementia patients and caregivers experience many disparities that are compounded by the additive effects of chronic daily stressors and pre-existing health conditions. This research study aimed at narrowing the gap on African American health disparities research and expanding current knowledge regarding Alzheimer's disease and caregiving. The findings from this study can inform healthcare professionals of the increased health risks African American caregivers face in comparison to the general population and can be used to guide the development of interventions aimed to alleviate caregiver stress levels and burden.

Chapter Two

Literature Review

Introduction

The purpose of this study was to 1) identify predisposing factors among African American caregivers that are associated with higher levels of stress and 2) analyze self-efficacy, knowledge, and coping in the stress process, in relation to perceived stress and IL-6. Previous literature has determined that Alzheimer's disease incidence rate among African Americans is 2 to 2.5 times that of whites (Demirovic et al., 2003; Froehlich et al., 2001; Gurland et al., 1999; Husaini et al., 2003; Krishnan et al., 2005; Tang et al., 2001). The African American dementia family caregiving experience is comparable with white caregivers' experience. In the context of health disparities, this experience does not promote caregiver health or well-being and has a profound impact on the African American population. Furthermore, caregivers are exposed and affected by multiple chronic stressors.

The application of the TMSC utilizes primary appraisal, secondary appraisal, coping efforts, and coping outcomes (adaptation) to describe the coping process as a response to a given stressor (Figure 1) (Glanz, 2008). Coping styles, social support, information seeking, optimism, positive psychology, and stress management interventions are considered potential moderators and are acknowledged as extensions in the model (Glanz, 2008). This chapter will discuss the literature that is relevant to this issue and is organized into the following sections: Dementia versus Alzheimer's Disease; Dementia Etiology; Dementia Diagnosis and Treatment; African Americans and Dementia; Caregiving Role and Responsibilities; Health Effects of Caregiving on

Caregivers; Stress; Biomarkers of Stress; Theoretical Framework; Self-efficacy; Context Specific Knowledge; Coping Styles; Summary.

Dementia versus Alzheimer's disease

Dementia "is not a specific disease, but a group of symptoms affecting memory, thinking and social abilities severely enough to interfere with daily functioning," (Mayo Clinic, 2014) Dementia is an umbrella term that encompasses a variety cognitive losses that are caused by a multitude of different factors or conditions ranging from the environment to genetic mutations. Symptoms of dementia vary across individuals. However, at least two of the following core mental functions must be impaired for a dementia diagnosis: memory, communication and language, ability to focus and pay attention, reasoning and judgment, and visual perception ("Alzheimer's disease facts and figures," 2015). Dementia is a progressive disorder, which means that symptoms gradually appear and worsen over time. The known causes of dementia are: Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal lobar degeneration, mixed dementia, Parkinson's disease dementia, Creutzfeldt-Jakob disease, and normal pressure hydrocephalus ("Alzheimer's disease facts and figures," 2015). The two most common causes are Alzheimer's disease and vascular dementia ("Alzheimer's disease facts and figures," 2015).

"The hallmark pathologies of Alzheimer's are the progressive accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are eventually accompanied by the damage and death of neurons" ("Alzheimer's disease facts and figures," 2015). Alzheimer's disease is the most common type of dementia accounting for 60-80% of all dementia cases. Alzheimer’s disease currently affects over five million people in the US, with projections expected to exceed 14 million by 2050 ("2009 Alzheimer's disease facts and figures," 2009) “One in nine people age 65-years and older have Alzheimer’s disease. Every 67 seconds, someone in the United States develops this disease” ("Alzheimer's disease facts and figures," 2015).

Dementia Etiology

Dementia causes a steady decline in cognitive and physical function. This decline results in difficulty remembering recent conversations, behavior fluctuations, issues with critical motor functions (e.g. swallowing and walking), and many other deficits regarding the patient’s functionality ("Alzheimer's disease facts and figures," 2015). The Alzheimer’s Association lists several factors that may increase an individual’s risk for dementia and Alzheimer’s disease. Age is the paramount risk factor in regards to dementia onset ("Alzheimer's disease facts and figures," 2015). Additional risk factors include familial history, genetics, traumatic brain injury, mild cognitive impairment, decreased social engagement, contributors of cardiovascular disease (smoking, obesity, diabetes, hypertension, and high cholesterol), and educational attainment ("Alzheimer's disease facts and figures," 2015). Sandu, Buga, Uzoni, Petcu, and Popa-Wagner (2015) explain that age and cardiovascular risks factors stimulate a chronic proinflammatory state, which is linked to multiple neurodegenerative pathways. Particularly, pro-inflammatory cytokines assist in establishing the sustained inflammatory state, which activates the neurodegenerative mechanism (Sandu et al., 2015). Zuliani et al. (2007) conducted a cross-sectional study analyzing the effects of systemic inflammation and functional status among individuals with Alzheimer’s disease and vascular dementia and found that IL-6 was negatively associated with the functional status of patient with vascular dementia. This suggests that as IL-6 increase, the patient with vascular dementia’s functional status decreases.

Dementia Diagnosis and Treatment

In order to receive a dementia diagnosis, the individual must undergo a comprehensive evaluation from a primary care physician and neurologist. These evaluations include some or all of the following: an extensive review of family history, self and family reporting of symptoms, cognitive tests, neurological examinations, brain imaging, and/or biomarker testing ("Alzheimer's disease facts and figures," 2015). Existing pharmacological and non-pharmacological therapies can be used to help manage and mitigate the severity of the symptoms ("Alzheimer's disease facts and figures," 2015). The duration of the disease from diagnosis to death varies for every person. Typically this condition lasts from 4 to 20 years, with the majority of years spent in the most severe stage ("Alzheimer's disease facts and figures," 2015).

African Americans and Dementia

Incidence, prevalence, and disease course of Alzheimer’s disease may be greater in African Americans than among whites. Based on the current literature, African Americans are at higher risk of developing Alzheimer’s disease, and have an incidence rate that is 2 to 2.5 times that of whites (Demirovic et al., 2003; Froehlich et al., 2001; Gurland et al., 1999; Husaini et al., 2003; Krishnan et al., 2005; Tang et al., 2001). African Americans with a first degree relative with Alzheimer’s disease have a higher risk of developing the disease than whites with the same familial relationship (Green et al., 2002). Additionally, research suggests that African Americans have lower rates of cognitive decline (Helzner et al., 2008; Wilson et al., 2006) and lower hazard for mortality (Mehta et al., 2008); other research studies do not accept these findings on the basis of race (Fillenbaum et al., 1998; Fitzpatrick et al., 2004). The "Alzheimer's disease facts and figures" 2015) states that the differences found among races are most likely explained through lifestyle, health, and socioeconomic differences. Despite these findings, other studies that have used rigorous analyses to account for these factors between races and ethnicities show no significant difference ("Alzheimer's disease facts and figures," 2015)

Caregiving Role and Responsibilities

The "Alzheimer's disease facts and figures" 2014) found that approximately 15 million caregivers are providing 17.7 billion hours of unpaid care for people with Alzheimer’s disease. Approximately one-third of the overall cost of dementia care is the ascribed value of assistance provided by family caregivers alone (Wimo et al., 2006). Studies analyzing the cost of informal care indicate that, as caregiving continues, it becomes more demanding financially (DeKosky, 2001; Zhu et al., 2006; Zhu et al., 2008). Of these caregivers, there are 2 to 2.5 times more women providing care for someone with Alzheimer’s disease or another type of dementia ("Alzheimer's disease facts and figures," 2014). Additionally, African Americans spend more time caregiving and are “more likely to experience high caregiver burden” than whites ("Alzheimer's disease facts and figures," 2014).

Alzheimer’s disease progression naturally causes an individual’s cognitive abilities and functional status to decline. The caregivers’ responsibilities depend on the care-recipients’ stage of dementia and demands of that stage. Huang et al. (2015)

analyzed and explained the caregiver role at all stages of the care continuum in addition to the responsibilities associated with each stage. During the early stages of the disease, caregivers assist the care-recipient with activities such as transportation and housekeeping. In the middle stage of the disease, the care recipient may require assistance walking, cooking, shopping, managing finances and medication, among others. In this stage, caregivers become more aware of the need to secure and implement protective measures around the living environment. In the last stage of the disease, the caregiver must assist with all of the aforementioned tasks in addition to personal care (Huang et al., 2015).

The 2011 National Caregiver Survey further indicated that 85% of caregivers of individuals with dementia provided assistance with personal care and mobility compared to 71% of caregivers of people without dementia ("Alzheimer's disease facts and figures," 2015). The survey also stated that 63% of dementia caregivers provided assistance with health or medical care compared to 52% of caregivers of individuals without dementia ("Alzheimer's disease facts and figures," 2015). Caregivers assume a role that has a wide range of responsibilities, ranging but not limited to: assisting the care recipient with: activities of daily living (bathing, dressing, grooming, etc.), instrumental activities of daily living (transportation, preparing meals, managing finances, etc.), medication management, behavioral management, medical care and health management, support and care service navigation and utilization, and long-term care plan development and implementation ("Alzheimer's disease facts and figures," 2015).

Health Effects of Caregiving on Caregivers

Alzheimer’s disease is characterized by irreversible biological and cognitive changes, and unfortunately there is no cure. As disease symptoms worsen and the care recipient’s functional status decreases, caregiver burden increases ("Alzheimer's disease facts and figures," 2014; Dauphinot et al., 2015; Iavarone et al., 2014; Kang et al., 2014; Reed et al., 2014). This burden and distress is primarily a result of patient behaviors (Deimling & Bass, 1986; Molloy et al., 1999; Pruchno & Resch, 1989a; Teri et al., 1997) and care recipient’s incontinence (Noelker, 1987), rather than the severity of cognitive impairment. Patient behavior and incontinence were also strong predictors of patient institutionalization (Noelker, 1987). Family support is linked to delayed institutionalization for the Alzheimer’s disease patient (Gaugler et al., 1999). In contrast, dysfunction among family members is linked to greater caregiver burden (Tremont et al., 2006). Premorbid relationships between caregiver and Alzheimer’s disease patient are also associated with caregiver burden (Noelker & Wallace, 1985), where good premorbid relations predict low burden (Steadman et al., 2007) and vice versa.

Roth et al. (2001) examined psychological and social indices of quality of life in the context of family caregiving. The Reasons for Geographic and Racial Differences in Stroke Study (REGARDS) study found that caregiving co-residency, premorbid relationships, hours of care, and mental and emotional strain contribute to poor functioning in caregivers (Roth et al., 2001). Additionally, co-residency was associated with poorer mental health outcomes and decreased social contacts among caregivers (Roth et al., 2001). Since the REGARDS study included a large African American sample, ethic and racial differences were analyzed. The study found that African

American adult-children were 2 times more likely to live with the parent for whom they are providing care, compared to whites (Roth et al., 2001).

The literature on Alzheimer’s disease and dementia caregiving has consistently linked the caregiving role to sustained and elevated stress levels. According to the "Alzheimer's disease facts and figures" 2014), 38% of caregivers reported high physical distress. In comparison to their non-caregiving peers, caregivers have substantially higher rates and levels of depression, burden, and mood disorders (Pinquart & Sorensen, 2003; Schulz et al., 1995; Schulz & Sherwood, 2008) and are at higher risk for mortality (Schulz & Beach, 1999). These impacts are more severe in women (Covinsky et al., 2003) – particularly on wives (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002). As caregiver burden increases, adverse outcomes such as, “emotional stress, depression, impaired immune system response, health impairments, lost wages due to disruptions in employment, depleted income and finances ("Alzheimer's disease facts and figures," 2014), diminished quality of life, and increased mortality (Elizabeth W Gonzalez et al., 2014) begin to emerge.

Even though Alzheimer’s disease caregivers have higher rates of disease, depression, and anxiety, they have lower rates of healthcare use (Pruchno & Resch, 1989b) and are less likely to engage in self-care activities (Pinquart & Sorensen, 2006; Schulz & Martire, 2004)). Some studies found that white caregivers experienced greater rates of depression (Janevic & Connell, 2004) and stress (Haley et al., 1995) and had more severe immune response effects (McCallum, Sorocco, & Fritsch, 2006). However, other studies found that African American caregivers experienced that same rate of depression and anxiety as white caregivers (Drentea & Goldner, 2006; Knight, Longmire, Dave, Kim, & David, 2007; Pinquart & Sorensen, 2005; I. C. Williams, 2005). Severe depression among caregivers was associated with higher prevalence of behavioral disturbances among the care-recipient (Chen, Borson, & Scanlan, 2000; Covinsky et al., 2003; Rozario & DeRienzis, 2008).

Furthermore, African American caregivers engage in fewer self-care activities, are less likely to take anti-depressant medications, and are less likely to use formal services (Scharlach et al., 2006). Socially, African Americans are less likely to participate in events and gatherings outside of the home compared to whites. Despite this, African American caregivers experience increased visits to the home from family and friends (Haley et al., 1995), are more resourceful and resilient (Clay et al., 2008; E. W. Gonzalez, 1997), and have better scores on measures of positive coping (Roff et al., 2004) and life satisfaction (Roth et al., 2001).

Stress

“Stress is commonly defined as a state of real or perceived threat to homeostasis,” (Smith & Vale, 2006). Stressors initiate activation of the HPA axis. Prolonged stimulation of the HPA axis results in negative outcomes related to health (Gouin et al., 2012). Caregivers are at high risk for poor physical, psychological, immunological, and cardiovascular health outcome, which often lead to mortality (Aneshensel et al., 1993; Fredman et al., 2008; Janevic & Connell, 2004; Lee et al., 2003; Schulz & Beach, 1999; von Kanel et al., 2006). Many research studies have consistently found various stress-related insults to the nervous and immune systems (Gouin et al., 2008; Stowell et al., 2001), including slower wound healing (Kiecolt-Glaser et al., 1995), higher IL-6 markers (von Kanel et al., 2006), increased telomere erosion (Damjanovic et al., 2007), reduced β2-adrenergic receptor sensitivity (Mausbach et al., 2008), and reduced sympathetic arousal (Roepke et al., 2008).

Biomarkers of Stress

"Interleukin-6 (IL-6) is a cytokine originally identified as a B-cell differentiation factor (BSF-2)," (Erta, Quintana, & Hidalgo, 2012). IL-6 has many trans-signaling roles within the central nervous, immune, skeletal, cardiovascular, and endocrine systems (Erta et al., 2012). IL-6 is commonly known as a proinflammatory cytokine that can lead to systemic inflammation (Rohleder, Aringer, & Boentert, 2012) and serves as an activator of the HPA axis (Willenberg, Path, Vogeli, Scherbaum, & Bornstein, 2002).

"Cortisol, which is a marker of the HPA axis, is an anti-inflammatory hormone which mobilizes energy, communicates with the immune system, and helps the body respond to stressful events" (Leggett, Zarit, Kim, Almeida, & Klein, 2015; Piazza, Almeida, Dmitrieva, & Klein, 2010). A majority of research studies utilize cortisol as a biomarker of the stress reaction in caregivers. However, cortisol is a fragile biomarker in determining accurate and reliable conclusions. Therefore, this study utilized IL-6 to examine the physiological effects of stress on caregivers.

Theoretical Framework

The TMSC has been useful in analyzing and understanding the effects of race on health disparities, particularly among African Americans (Glanz, 2008). Previous research conducted by D. R. Williams (1999) indicated that racism could directly and indirectly affect health by acting as an acute or chronic stressor (Glanz, 2008). Other research verified this conclusion by providing evidence that racism and cardiovascular reactivity are positively associated (Glanz, 2008). The model indicates that perception and coping styles can moderate the effect of these stressors on the physical and psychological well-being of the afflicted individual (Figure 1).

Many studies using the TMSC framework (Folkman, 1984, 1997; Folkman & Lazarus, 1988) have lead to an increased awareness and appreciation of how caregivers appraise the effects of both the care recipients' health status and the effects on them personally. Caregivers' ability to accurately appraise their caregiving situation may mediate the effects of stress on their own health (Pot, Deeg, Van Dyck, & Jonker, 1998).

Not only does accurate appraisal affect the caregivers' overall well being, but the caregivers' ability to cope with their situation also affects their overall health and well-being. Realistic coping strategies serve to mediate stress (C. Cooper, Balamurali, Selwood, & Livingston, 2007; Claudia Cooper, Katona, Orrell, & Livingston, 2008; Ulstein, Wyller, & Engedal, 2008). Emotion-focused strategies, which promote avoidance or denial, are associated with higher levels of caregiver distress (Knight, Silverstein, McCallum, & Fox, 2000). Religious beliefs and practices, that are often noted as sources of strength in African American caregivers, provide meaning to the situation and are identified as effective coping strategies (Hebert, Dang, & Schulz, 2007).

Self-efficacy

A great deal of research has also been conducted on coping self-efficacy and its influence on caregiver health. Self-efficacy is defined as, "beliefs about personal ability to perform behaviors that bring desired outcomes" (Glanz, 2008). Mausbach et al. (2011) study specifically analyzed the effects of coping self-efficacy on IL-6, a protein that plays a role in inflammation. Results showed that "low coping self-efficacy was significantly related to IL-6" (Mausbach et al., 2011). Nogales-Gonzalez et al. (2015) also found that as caregiver self-efficacy (in relation to managing behavioral and psychological symptoms) increased, distress decreased. Additionally, Romero-Moreno et al. (2011) suggested that using self-efficacy to control thoughts might also ease caregiver distress.

Context-Specific Knowledge

Knowledge affects how an individual decides to cope with a stressor. A lack of knowledge can make it difficult to accurately appraise the threat (Lazarus & Folkman, 1984). Information seeking is used as a coping response (Glanz, 2008) that has been proven to reduce distress and promote adaptive health behaviors (van Zuuren, Grypdonck, Crevits, Walle, & Defloor, 2006). “Monitors are individuals who seek information in response to a specific threat” (Miller & Mangan, 1983). “Monitors tend to have different characteristics in comparison to blunters, or individuals who do not seek information” (Miller & Mangan, 1983). Miller and Mangan (1983) state that the “monitoring” coping style could be attributed to an individual’s higher prevalence of threatening appraisals. A common example of this can be described by monitors’ increased physical distress during invasive medical procedures. By increasing an individual’s context-specific knowledge, he or she can accurately appraise the health threat, develop a coping style that best fits the situation at hand, and decrease the distress associated with the threat (Miller & Mangan, 1983).

Coping Styles

The Ways of Coping Inventory is a scale commonly used to assess problem- and emotion-focused coping (Glanz, 2008). Specifically, it uses several subscales to assess confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal. A high score on any subscale means that the individual uses that means of coping frequently in comparison to other means. Avoidance and denial (emotion-focused coping) have been deemed as maladaptive as coping strategies that can lead to “intrusive thoughts that can generate increased stress over time” (Carver et al., 1993; Schwartz, Lerman, Miller, Daly, & Masny, 1995). However, individual coping styles vary among every individual and stressful situation; therefore, coping styles may have different effects on physical, emotional, and functional outcomes (Glanz, 2008).

Summary

The prevalence of dementia is predicted to increase drastically by 2050, particularly among the African American population. As caregiving has proven to be a challenging task that has physical, mental, and social effects on the caregivers, continued research is needed to alleviate negative health outcomes. African American dementia patients and caregivers experience many disparities that are compounded by the additive effects of chronic daily stressors and pre-existing health conditions. Therefore, this research study aimed to identify factors that are associated with elevated caregiver stress levels and analyze the effects of self-efficacy, Alzheimer’s disease knowledge, and ways of coping on stress levels. By understanding this information, researchers and health educators can collaborate together to effectively inform and train caregivers and medical personnel in hopes of decreasing adverse health effects associated with the caregiving role.

Chapter Three

Methods

Introduction

This study was a secondary, cross-sectional analysis of the baseline data from a randomized-control trial testing interventions to improve well-being among African American caregivers in Atlanta, Georgia. The purpose of this study was to 1) identify predisposing factors among African American caregivers that are associated with higher levels of stress and 2) analyze self-efficacy, knowledge, and coping in the stress process, in relation to perceived stress and IL-6. Conversely, the purpose of the parallel, COOL-AD study was to focus on caregivers of persons with cardiovascular disease and analyze the effects of specific interventions.

All participants were screened for eligibility. After participant eligibility was determined, consenting participants completed multiple questionnaires assessing demographic, psychosocial, and physical health data. They were then scheduled for an evaluation at General Clinical Research Center (GCRC) at Emory Hospital. At this evaluation, participants underwent a variety of physical tests that examined identified biomarkers. Upon completion of the evaluation, the individuals were given scheduling information related to their group assignments. The data were collected and entered into Research Electronic Data Capture application (REDCap) to ensure confidentiality of personal health information. After the entire study was completed, the data were cleaned and prepared for analyses. Data analyses were then conducted using Statistical Package for the Social Sciences (SPSS) version 23.0 software.

Design

The COOL-AD study was designed to be a two-stage research study. In the first stage, an evidence-based psychoeducation program shown to enhance caregiver self-efficacy and reduce distress was adapted to be culturally appropriate for African Americans caring for a relative with Alzheimer's disease. This program incorporated the lessons of previous caregiver research indicating that effective programs should carefully target caregivers' needs (C. Cooper et al., 2007; S. H. Zarit & Femia, 2008), actively engage caregivers (Spijker et al., 2008), use psychoeducational approaches (Gallagher-Thompson & Coon, 2007), approach the issue from multiple perspectives (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007), and attend to the neuropsychoimmunological well-being of the caregiver (Broadbent & Gass, 2008; Haaland, Sabljic, Baribeau, Mukovozov, & Hart, 2008). During the second stage of the program, the psychoeducation and exercise program was tested in comparison to the psychoeducation alone program and usual care-attention control conditions in a randomized trial. This analysis was conducted in order to assess efficacy in reducing stress effects and cardiovascular risk. The psychoeducation arm consisted of delivering a theoretically based curriculum over the course of seven weeks, to affect caregivers' understanding and coping response. The pyschoeducation and exercise arm was comprised of the aforementioned curriculum, as well as an individualized exercise regimen created by a specialist to begin at 50% heart rate reserve and increase to 70% reserve over six weeks. The usual care control group received care as they normally would with their general practitioner and they also received standardized Alzheimer's disease informational materials.

Participants

The sample included adult (21 years and older), African American caregivers that met the following eligibility criteria: caregiver must have self-identified as African American, be 21 years of age or older, and was a family member of the care-recipient who had been diagnosed with Alzheimer's disease or dementia-related illness. If the caregiver was not co-residing with the care-recipient, he or she must have visited the care-recipient 4 out of 7 days of the week and provided at least 6 hours of care. The caregiver had to be cognitively intact (determined using the Blessed screening procedure), sedentary, and not under a physician's orders to exercise for any designated period of time. Additionally, the participant had to provide consent to participate in the study. Caregivers not meeting the aforementioned criteria or meeting the following criteria were excluded from the study: caregiver had a medical or physical condition that prevented their participation in the exercise component of the study, had sleep apnea, took steroids on a regular basis, had acute inflammation at baseline or follow-up testing, and/or if the care-recipient was likely to be institutionalized within the next 6 months. The eligibility criteria that were established were intended to eliminate persons with conditions that would confound the dependent variables or interfere with participation in the interventions.

Participant Recruitment

Due to the study's focus on African American caregivers, the research team used a targeted and well-developed approach for seeking involvement from minority communities (Gallagher-Thompson et al., 2004). The Registry for Remembrance (a community-academic partnership created to improve the participation of African

Americans in neurologic research at Emory University's Alzheimer's Disease Research Center (ADRC)) was the main platform used for recruitment, followed by the Emory University's ADRC. Additionally, the Georgia Chapter of the Alzheimer's Association also supported the project's recruitment. Recruitment activities included: presentations to community groups, media materials of cooperating entities (e.g. parish bulletins), regular ADRC and Alzheimer's Association newsletters, and sustained networking efforts of Registry board members and projected staff. The Atlanta Metro area is home to over 6 million residents, of which 30% are African American. The research team worked strategically with local churches and community groups to establish a trusting rapport, which ensured the success of a targeted sample size of 194 participants at enrollment. Of these participants, 142 completed the baseline assessment.

Measures

Demographic, psychosocial, and health data were collected using the following methods and instruments. Brief Patient Reported Outcomes Measurement Information System (PROMIS) scales for depression and anxiety were used in addition to those described below in order to collaborate with the NIH-supported efforts to create standard patient-reported measures (Reeve et al., 2007).

Demographic Information. Demographic information was collected using a general demographic information and health history sheet. This sheet gathered information about the caregiver's age, gender, marital status, education, relationship to care recipient, length of caregiving, and co-residence status with the care-recipient.

Care Recipient Problems. Care recipient problems were analyzed using the Lawton Physical Self-Maintenance and Instrumental Activities of Daily Living scales

(Lawton & Brody, 1969). This scale elicited the caregiver's assessment of the care recipient's activities of daily living (ADLs) and instrumental activities of daily living (IADLs) functioning. Overall, this scale is comprised of 13 items and is split into two subscales, physical self-maintenance scale (measures ADLs) and IADLs. If the answer corresponds with the number 1, the care-recipient is able to perform that task independently. However, if the answer corresponds with 0, then the care-recipient requires some level of assistance to complete that task. An example item for the personal self-maintenance scale includes the assessment of the care-recipient's ability to bathe oneself. Answer options include, "Bathes self (tub, shower, sponge bath) without help (1);" "Bathes self with help getting in and out of the tub (0);" "Washes face and hands only, but cannot bathe rest of body (0);" "Does not wash self, but is cooperative with those who bathe him or her (0);" "Does not try to wash self and resists efforts to keep him or her clean (0)." The ADL scale is comprised of 6 items. Adding all responses of the subscale and dividing by the number of items within each subscale computed a total ADL score. Scores for each subscale could range from (0) low functioning; needing assistance with ADLs to (6) high functioning; able to complete ADLs independently. The ADL mean score was 2.2 (SD=2.0).

An example item for the IADL subscale includes the assessment of the care-recipients ability to be responsible for his or her medications. The answer options are as follows, "Is responsible for taking medication in correct dosages at correct time (1);" "Takes responsibility if medication is prepared in advance in separate dosage (0);" "Is not capable of dispensing own medication (0)." The IADL scale is comprised of 8 items. Adding all responses of the subscale and dividing by the number of items within each subscale computed a total IADL score. Scores for each subscale could range from (0) low functioning; needing assistance with IADLs to (8) high functioning; able to complete IADLs independently. The IADL mean score was 2.2 (SD=2.0).

Family Functioning. Family functioning was analyzed using the McMaster Family Assessment Device (FAD) (Epstein, Baldwin, & Bishop, 1983). In total, the scale is comprised of 27 items that is split into three subscales, general family functioning, problem solving, and communication. Ten items needed to be recoded before computing each subscale score by adding all responses of each subscale and dividing by the number of items within each subscale. Scores for each subscale could range from (1) best functioning to (4) worst functioning. Lower scores are representative of better family functioning.

An example from the FAD problem solving subscale is “We usually act of our decisions regarding problems.” Answer options for this statement ranged from (1) “Strongly disagree” to (4) “Strongly agree.” The FAD problem solving subscale consisted of 6 items. The subscale had a Cronbach's alpha of 0.81 (Total Scale Mean= 2.20; SD= 0.60).

An example from the FAD communication subscale is “When someone is upset the others know why.” The subscale is comprised of 9 items. The scale had a Cronbach's alpha score of 0.78 (Total Scale Mean= 2.30; SD = 0.50).

An example from the FAD general family functioning subscale is “Planning family activities is difficult because we misunderstand each other.” The general family functioning scale is comprised of 12 items. The subscale had a Cronbach's alpha score of 0.89 (Total Scale Mean=2.20; SD= 0.60).

Dementia caregiver self-efficacy. Caregiver self-efficacy was assessed using the Pearlin Caregiver Stress Scale's subscale for Caregiving Competence (Pearlin, Mullan, Semple, & Skaff, 1990). This scale was 4-item scale with answer options ranging from (1) " Not at All," to (4) "Completely." An example item from the scale is, "Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving? How much do you: believe that you've learned how to deal with a very difficult situation." Summing all responses and dividing by the number of items in the scale computed a total self-efficacy score. Scores could range from (1) low self-efficacy to (4) high self-efficacy. The self-efficacy scale within the Pearlin Caregiver Stress Scale had a Cronbach's alpha reliability score of 0.794 (Total Scale Mean=3.50; SD=0.50).

Alzheimer's Disease Specific Knowledge. Alzheimer's knowledge is measured through the Alzheimer's Disease Knowledge Test (Dieckmann, Zarit, Zarit, & Gatz, 1988). This test is a 20 item multiple choice test of general knowledge of Alzheimer's disease. An example item from the test is, "AD is one type of dementia." The answer options that participants chose from are "True" and "False." True was coded as (1) in the data, whereas false was coded as (0). Summing all responses and dividing by the number of items in the scale computed a total Alzheimer's disease knowledge score. Scores could range from (0) no Alzheimer's disease knowledge to (20) high Alzheimer's disease knowledge. Missing answers were treated as incorrect, unless all or a majority of items were missing indicating that the participant did not take the test. The Kuder-Richardson-20 reliability for this scale was 0.692, which indicates adequate internal consistency of scale items (Total Scale Mean= 6.80; SD= 3.2).

Coping. Coping responses were measured through utilization of the Ways of Coping Scale, which is a 42-item scale that identifies emotion and problem-focused coping responses (Vitaliano, Russo, Carr, Maiuro, & Becker, 1985). “I turned to work or another activity to take my mind off things,” is an example of an item within the scale. Answer options for this particular scale range from (0) “Does not apply or not used” to (4) “Used a great deal.” A total ways of coping score was computed by summing all average scores from each subscale. Scores could range from (0) low coping to (32) high coping, with higher scores indicating better levels of coping. The Cronbach's alpha reliability for this scale was 0.916 suggesting excellent internal consistency (Total Scale Mean= 9.30; SD= 3.20).

Depression. Depression was measured using the Center for Epidemiologic Studies Depression Scale, which is a 20-item scale with subscales analyzing somatic and psychological effects (Radloff, 1977). An example item from the scale included, “During the past week…I was bothered by things that usually didn’t bother me.” The responses for each question used Likert scale responses ranging from (0) “Rarely of none of the time (less than one day)” to (3) “Most or all of the time (5-7 days)”. A total depression score was computed by summing all responses. The scores could range from 0- 60, with higher scores indicating higher levels of depression. The Cronbach's alpha reliability for this scale was 0.866 suggesting good internal consistency of scale items (Total Scale Mean= 13.30; SD=9.10).

Anxiety. Anxiety was measured using the State-Trait Anxiety Index, which is a 20-item scale with 4-point Likert scale responses (Speilberger & Vagg, 1984; Spielberger, VanDercar, Greaner, Hibler, & Bloch, 1980). It is important to note that this scale is sensitive to changes in transitory anxiety. An example item from the index includes, “Right now…I am tense; I am worried.” The answer options were in a Likert scale response pattern with (1) “Almost never” to (4) “Almost always.” A total anxiety score was computed by summing all responses. Responses could range from 20-80, with higher scores indicating higher levels of anxiety. The Cronbach's alpha reliability for this scale was 0.941 suggesting excellent internal consistency of scale items (Total Scale Mean= 39.88; SD= 12.54).

Burden. Burden was measured using the Zarit Caregiver Burden Scale, which is a 22-item scale (Steven H Zarit, Reever, & Bach-Peterson, 1980). An example item from the scale is, “Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?” The items have Likert scale responses ranging from (0) “Never” to (4) “Nearly always.” A total burden score was computed by summing all responses. The range of scores could be from 0-88, with higher scores indicating higher levels of burden. The Cronbach's alpha reliability score for this scale was 0.92 indicating excellent internal consistency of scale items (Total Scale Mean= 38.70; SD= 15.90).

Perceived Stress. The outcome variable of stress was measured was through the utilization of the Perceived Stress Scale, which consists of 14 items (Salovey, Stroud, Woolery, & Epel, 2002). “In the last month, how often have you felt that you were unable to control the important things in your life,” is an example of one of the items included in the scale. The answer options are 4-point Likert scales ranging from (0) “Never” to (4) “Very Often.” The range of scores could be from 0-56, with higher scores indicating higher levels of perceived stress. Seven items needed to be recoded before computing the total perceived stress score by adding all responses for each of the 14 items. The Cronbach's alpha reliability for this scale was 0.88 suggesting good internal consistency of scale items (Total Scale Mean= 24.40; SD=8.50).

Interleukin-6 (IL-6): The second way in which the outcome variable of stress was measured was through IL-6 biomarkers levels. IL-6 is a pro-inflammatory cytokine that activates the hypothalamic-pituitary-adrenal axis as part of the stress response (Tilg & Moschen, 2008). According to Fischbach (2003), the normal range of IL-6 within adults is 1-3 pg/mL. IL-6 was measured through salivary samples collected at baseline (Mean= 0.67; SD= 0.6).

Data Collection Procedures

Each individual was screened to assess his or her eligibility for participation in the study. Additionally, cognitive capacity was assessed with the Blessed dementia screening index (Katzman et al., 1983); individuals with a score of greater than or equal to 11 (indicating cognitive impairment) were excluded. Individuals who were eligible and consented to participate in the study were given a packet of questionnaires (demographic and psychosocial) to complete and bring them to their first evaluation. Each individual was scheduled for an outpatient visit at the General Clinical Research Center (GCRC) at Emory Hospital. The participants first participated in an exercise treadmill test. The data collector was blinded to the group assignment and met with each participant in the GCRC to verify that they had fasted for the past 12 hours, reviewed all materials, examined skipped or omitted items on the forms, and clarified any responses. The GCRC staff performed a brief health history and physical with all participants. Furthermore, venipuncture for biomarkers (adiponectin, hsCRP, PAI-1, Il-6, lipids) was performed.

After all assessments were completed, participants were given scheduling information related to their group assignments (psychoeducation and exercise, exercise, or usual-care groups); the exercise specialist contacted participants in the exercise group.

Treatment of the Data

Data entry was completed using REDCap. This program has multiple checks and balances built in internally for researchers to clean data as it is entered. Once researchers enter information into the system, REDCap will label the data as “incomplete,” “unverified,” or “complete.” After the researcher verifies the data entered is complete, the researcher will check that the data is complete. After the data is deemed complete, the research team also went back and cleaned and verified the data further. If data were missing, the research team worked to track down the data or contacted the participants to receive the data. This process was only done for demographic variables. If data were missing for psychosocial scales, a mean substitution of up to 10% was incorporated into the final score. After cleaning the data, the data was transferred into the SPSS, where all statistical analyses were completed.

Preliminary Analysis

First, descriptive statistics of the population demographic characteristics were conducted. Socio-demographic variables consisted of: age, education, gender, marital status, ethnicity, co-residence, compound caregiving, family help, caregiver-patient relationship, and duration of patient care.

Second, basic frequencies were performed on scales assessing patient condition (Lawton PSMS & IADL), family cohesion (FAD), Alzheimer’s disease knowledge (ADKT), ways of coping (WOC), self-efficacy (Pearlin Caregiver Competency), burden

(Zarit-Burden), anxiety (State-Trait), depression (CES-D), and perceived stress (PSS). A frequency table for IL-6 was also conducted to collect a mean and standard deviation of the data.

Third, bivariate analyses were conducted to examine the correlations between independent variables and dependent variables. Pearson correlations were conducted for all continuous independent variables and the dependent variables. A Pearson correlation was conducted for AD knowledge, family cohesion, depression, Lawton ADL and IADL, self-efficacy, anxiety, ways of coping, burden, with the outcome variables, perceived stress, and IL-6. Additionally, Pearson correlations were performed to examine the relationship between demographic variables such as age, caregiving duration, co-residence, and the outcome variables perceived stress and IL-6. A Spearman-Rho correlation test was performed with all categorical demographic variables and the dependent variables. A Spearman-Rho correlation was conducted to examine the association between gender, education, ethnicity, marital status, caregiver/care-recipient relationship, family help, co-residence with patient, compound caregiving, with the outcome variables, perceived stress and IL-6.

Fourth, One-Way Analysis of Variances (ANOVA) were conducted with all categorical and dichotomous independent variables and the outcome variables. The ANOVA was conducted in order to determine whether there were any statistically significant differences between the categories within the demographic variables, gender, education, ethnicity, marital status, caregiver/care-recipient relationship, family help, co-residence with patient, compound caregiving, and the mean perceived stress and IL-6 scores.

Fifth, a sequential multiple linear regression was conducted to assess the association between the outcome, perceived stress, and the predictors. Block one included the following variables: caregiver/care-recipient relationship, household size, family help, gender. Block two included self-efficacy, Alzheimer's disease knowledge, and ways of coping. Additionally, a third block was added to this regression in order to examine interaction variables of gender and self-efficacy, gender and Alzheimer's disease knowledge, and gender and ways of coping.

Sixth, a multiple linear regression was conducted to assess the association between the outcome, perceived stress, and the psychological scales that were found to be associated with the outcome in preliminary analyses. These scales included CES-D, FAD communication, FAD global family functioning, FAD problem solving, self-efficacy, anxiety, ways of coping, and burden. Independent variables were entered into the regression model in sequential blocks, with block one comprised of demographic variables, block two consisting of psychosocial scales, and block three was made up of interactions between gender and psychosocial scales.

Addressing each hypothesis

Hypothesis 1: Live-in caregivers (co-residence), compound caregiving, lack of family cohesion, duration of caregiving, patient condition, education, low self-efficacy, low AD knowledge, and poor coping efforts will be identified as factors that are associated with elevated IL-6 levels and perceived stress scores in caregivers.

This hypothesis was tested by running Pearson and Spearman Rho correlations between live-in caregivers, compound caregiving, family cohesion, duration of caregiving, education, self-efficacy, Alzheimer's disease knowledge, ways of coping, and the dependent variables of perceived stress and IL-6. A Pearson correlation was conducted between continuous independent variables (duration of caregiving; family cohesion; self-efficacy; AD knowledge; ways of coping) and the dependent variables (perceived stress and IL6). A Spearman Rho correlation was conducted between the categorical and dichotomous independent variables (live-in caregivers, compound caregiving, education) and the dependent variables (perceived stress and IL-6).

Additionally, a One-Way ANOVA was performed to determine whether there were any differences between groups in the categorical/dichotomous independent variables (gender, education, ethnicity, marital status, family help, co-residence, compound caregiving, and caregiver/care-recipient relationship) and mean perceived stress scores.

Hypothesis 2: Self-efficacy will have a more profound impact on IL-6 and perceived stress levels, compared to AD knowledge and coping efforts. High self-efficacy scores will be associated with lower IL-6 levels and perceived stress scores among caregivers at baseline.

This hypothesis was tested through a sequential multiple linear regression model. Significant associations were set a value of $p=0.05$. A combination of the bivariate analyses, literature, and research hypothesis, dictated which variables would be entered into the final model. These variables included: gender, family help, self-efficacy, AD knowledge, and ways of coping. The 14-item perceived stress scale variable was the only dependent variable included in the final model.

Chapter 4

Results

Sample Characteristics

As can be seen in Table 1, the study enrolled 142 African American Alzheimer's disease and dementia caregivers. Overall, the average age of participants was 55.1 ± 9.1 years. The sample was predominantly female, 85.9% (N=122) compared to 14.1% (N=20) males. Of these participants, 3.2% (N=4) were Hispanic or Latino compared to 96.8% (N=121) of the sample that identified themselves as not Hispanic or Latino and specifically African American. Additionally, 62% (N=85) of participants were single, divorced, separated, and/or widowed compared to 38% (N=52) of participants that were married or with a domestic partner. Lastly, of the sample, 70.8% (N=97) of participants had a college of postgraduate degree, in comparison to 29.2% (N=40) of participants who only had a high school degree or tech/vocational training.

Caregiving Characteristics

Of all caregivers, the majority reported caring for a mother or father, 64.5% (N=89). Caregivers were also caring for spouses 13% (N=18), aunts and uncles 12.3% (N=17), other relatives 8% (N=11), and/or other individuals 2.9% (N=4). In total, 70.9% (N=90) stated that they lived in the same house as the Alzheimer's disease care-recipient. Additionally, 40.7% (N=55) stated that they were responsible for caring for someone else that lived in their home as well; 15.5% (N=22) were children, 13.4% (N=19) were grandchildren, and 12% (N=17) were other chronically ill individuals. When asked how helpful family and friends were in the responsibilities' that the caregiver bears, only 45.3% (N=62) of caregivers felt that family and friends offered "some" to "a great deal of help", whereas, 54.8% (N=75) of caregivers felt that family and friends offered "little help" to "no help."

Caregiving Duration and Patient Condition

Caregivers indicated that on average, the care-recipient needed attention for 4.0 ± 2.7 years. Furthermore, caregivers indicated that they themselves had been providing care for the care-recipient on average 4.0 ± 3.4 years. As for patient condition, the average score for instrumental activities of daily living was 2.2 (SD=2.0). The average score for personal self-maintenance or activities of daily living was also 2.2 (SD=2.0).

Psychosocial Assessment Scores

As can be seen in Table 2, the Alzheimer's disease knowledge mean score was 6.80 (SD=3.20). The caregivers had a mean communication score of 2.30 (SD=0.50), global family functioning score of 2.20 (SD= 0.60), and problem-solving score of 2.20 (SD=0.60). The overall mean self-efficacy score was 3.50 (SD=0.5); the mean burden score was 38.73 (SD=15.87); the mean anxiety score was 39.90 (SD= 12.50); the mean depression score was 13.30 (SD=9.06). The caregivers' ways of coping mean score was 9.3 (SD=3.2). As for the outcome variables of interest, the caregivers had a perceived stress score of 24.42 (SD=8.50) and an IL-6 mean average of 0.67 (SD=0.59).

Correlations between predictor variables and perceived stress and IL-6

The first hypothesis for this study was that live-in caregivers (co-residence), compound caregiving, lack of family cohesion, duration of caregiving, patient condition, education, low self-efficacy, low Alzheimer's disease knowledge, and poor coping efforts would be identified as factors that were associated with elevated IL-6 levels and perceived stress scores in caregivers.

As can be seen in Table 3, bivariate Pearson and Spearman Rho correlation tests were conducted in order to address this hypothesis. A Pearson correlation test was performed to examine the associations between Alzheimer's disease knowledge, depression, family cohesion, Lawton IADLs and PSM, self-efficacy, anxiety, ways of coping, burden, perceived stress, and interleukin-6 (IL-6). Results suggest that there are statistically significant associations between depression and perceived stress; family cohesion (FAD) problem solving and perceived stress; family cohesion (FAD) global family functioning and perceived stress; self-efficacy and perceived stress; anxiety and perceived stress; ways of coping and perceived stress; and burden and perceived stress.

Results indicate FAD communication ($r=0.34$; $p=<0.001$); FAD global family functioning ($r=0.476$; $p=<0.001$); FAD problem solving ($r=0.39$; $p=<0.001$) and perceived stress were all statistically significant. These values suggest that all three subscales of family cohesion and perceived stress have a positive relationship.

Self-efficacy and perceived stress were also statistically significant ($r=-0.37$; $p<0.001$). This finding indicates that there is a negative association between self-efficacy and perceived stress. Additionally, ways of coping and perceived stress were statistically significant ($r=0.20$; $p=0.02$), which suggests that there is a positive relationship between perceived stress and ways of coping. Anxiety ($r=0.73$; $p<0.001$), burden ($r=0.66$; $p<0.001$), and depression ($r=0.67$; $p<0.001$) also had a statistically significant association with perceived stress. More specifically, theses scores indicate that anxiety, burden and depression have a positive association with perceived stress.

Another Pearson correlation was conducted to examine the association between age, duration of care-recipient needed care, household size (the number of individuals living in the household), duration of caregiving, perceived stress, and IL-6. No statistically significant associations were found between the predictor variables and perceived stress or IL-6.

A Spearman Rho correlation test was conducted to examine the association between gender, education, ethnicity, relationship, family help, co-residence, compound caregiving, caregiver/care-recipient relationship, perceived stress, and IL-6. There were statistically significant associations between the following: gender and perceived stress ($r=0.264$; $p=0.002$); family help and perceived stress ($r= 0.273$; $p<0.001$); co-residence and perceived stress ($r=0.189$; $p=0.029$), and caregiver/care-recipient relationship and perceived stress ($r=-0.232$; $p=0.006$). These results suggest that females have higher levels of perceived stress. Results also indicate that family help, living with the care-recipient, caring for a spouse or parent, all had a positive relationship with perceived stress. The caregiver/care recipient relationship was negatively associated with perceived stress.

Differences between categorical/dichotomous variables and perceived stress

One-Way ANOVAs were performed to further test the first study hypothesis. They were conducted between proposed dichotomous and categorical predictor variables (gender, education, ethnicity, marital status, caregiver/care-recipient relationship, family help, co-residence, and compound caregiving) and the dependent variable, perceived stress. Education ($p=0.36$), ethnicity ($p=0.40$), and compound caregiving ($p=0.28$) did not differ in mean perceived stress scores across categories. A statistically significant difference was observed in mean perceived stress score by gender ($F =(1, 821.96)=12.32$, p<0.001); marital status (F=(4, 236.96)=3.52, p=0.01); and family help (F=(4, 283.81)=4.30, p=0.003).

Females (Total Mean Score=25.43) had an increased mean perceived stress score compared to men (Total Mean Score=18.50). Individuals that were married (Total Mean Score=23.66), single (Total Mean Score=23.17), or widowed (Total Mean Score=20.71) had very similar mean perceived stress scores, whereas individuals that were divorced or separated had a mean perceived stress score of 27.37.Only one individual out of our sample recorded that they lived with a domestic partner, therefore the total perceived stress mean was 4.00, which indicated a statistically significant difference between the groups.

For family help, the Levene Test statistic was not significant (p=0.37), which indicated that Tukey post-hoc test should be used. Tukey post hoc tests suggests that the mean perceived stress score for caregivers who received “a great deal of help” (mean=19.71; SD=7.90) is significantly lower than the mean perceived stress score for caregivers who received “a little help” (mean=26.65; SD=9.00; p=0.007) and “almost no help” from family and friends (mean=27.74; SD=8.10; p=0.003).

A statistically significant difference was also observed in mean perceived stress score by caregiver/care recipient relationship (F=(6, 300.27)=4.86, p<0.001) and co-residence (F=(1, 418.96)=5.93; p=0.02). For caregiver/care recipient relationship, the Levene Test statistic was not significant (p=0.83), which indicated that Tukey post-hoc test should be used. Tukey post hoc tests suggests that the mean perceived stress score for caregivers caring for their mother (mean=27.49; SD=7.58) is significantly higher than the mean perceived stress score for caregivers caring for their father (mean=20.20;

SD=7.48; p=0.02). Additionally, the mean perceived stress score for caregivers caring for their mother (mean=27.49; SD=7.58) was significantly higher than the mean perceived stress score for caregivers caring for other non-relatives with Alzheimer's disease or dementia-related illness (mean=13.00; SD 7.79; p=0.01). There was also a statistically significant difference in mean perceived stress scores and co-residence. The mean perceived stress score increased for individuals living with the care recipient (Total Mean Score=25.42) compared to those who did not (Total Mean Score=21.66).

Associations between predictor variables and perceived stress

The second hypothesis of the study was that self-efficacy would have a more profound impact on IL-6 and perceived stress levels, compared to Alzheimer's disease knowledge and coping efforts. It was predicted that high self-efficacy scores would be associated with lower IL-6 levels and perceived stress scores among caregivers at baseline. A sequential multiple linear regression was performed to address this hypothesis.

Bivariate analyses suggest that gender (p=0.002), family help (p<0.001), co-residence (p<0.001), caregiver/care-recipient relationship (p<0.01), self-efficacy (p<0.001), and ways of coping (p=0.02) were independently and significantly associated with perceived stress. Based on these results, these variables were chosen to be included in the final multiple linear regression. According to the research hypothesis, Alzheimer's disease knowledge (p=0.19), was chosen to also be included in the final multiple linear regression. Therefore, all 7 variables were included in a subsequent linear regression model using the Enter method.

Based on previous ANOVA analyses, a significant difference was found for gender. Therefore, the research team decided to explore this variable in the final model as it interacted with the aforementioned psychosocial scales. Three dummy variables were created to represent the interaction between gender and self-efficacy, gender and Alzheimer's disease knowledge, and gender and ways of coping.

Results of the regression model indicated that out of all demographic variables entered into block one, gender (p=0.04) was the only variable that had significant correlations with perceived stress. The total regression model accounted for 2.8% of the variance in perceived stress scores.

When self-efficacy, Alzheimer's disease knowledge, and ways of coping were incorporated into the model, "a little" family help (p=0.04), self-efficacy (p<0.001) and ways of coping (p=0.01) were the only variables that were statistically significant. Specifically, self-efficacy decreased on average by 6.23 points for each unit increase in perceived stress (B=-6.23; 95% CI= -9.35, -3.10; p<0.001). Ways of coping increased on average by 0.68 points for each unit increase in perceived stress, (B=0.68; 95% CI=0.16, 1.19; p=0.01). The total regression model accounted for 21.1% of the variance in perceived stress scores.

When the interaction variables between gender and psychosocial scales were introduced into the model, gender (p<0.001), "a little" family help (p=0.03), self-efficacy (p<0.001), and the interaction variable for gender and self-efficacy (p=0.01) was significantly associated with perceived stress. Specifically, self-efficacy decreased on average by 24.09 points for each unit increase in perceived stress (B=-24.09; 95% CI=-

38.45, -9.73; p<0.001). The total regression model accounted for 32.1% of the variance in perceived stress scores.

Bivariate analyses also suggested that CES-D (p<0.001), FAD communication (p<0.001), FAD global family functioning (p<0.001), FAD problem solving (p<0.001), self-efficacy (p<0.001), anxiety (p<0.001), burden (p<0.001), and ways of coping p=0.02) were independently and significantly associated with perceived stress. Therefore, all of these variables were included in an additional subsequent linear regression model using the Enter method. The demographic variables used in the previous multiple linear regression were also included in block one of this model. All of the significant psychosocial scales were included in block 2. Based on previous ANOVA analyses, a significant difference was found for gender. Therefore, the research team decided to explore this variable in the final model as it interacts with the aforementioned scales. Interaction variables between gender and each scale were included in block 3.

Results of the regression model indicate that out of all of the demographic variables entered into block one, only "a little" family help (p=0.03) had significant correlation with perceived stress. The total regression model accounted for 4.9% of the variance in perceived stress scores.

When all of the psychosocial scales were incorporated into the model, "some" family help (p=0.01), "a little family help" (p<0.003), burden (p<0.001), ways of coping (p=0.04), anxiety (p=0.01), and FAD global family functioning (p=0.04) were statistically associated with perceived stress. Specifically, burden increased on average by 0.21 points for each unit increase in perceived stress (B=0.21; 95% CI=0.10, 0.32; p<0.001). Anxiety increased on average by 0.20 points for each unit increase in perceived stress (B=0.20; 95% CI=0.06, 0.34; p<0.001). FAD global family functioning increased on average by 4.22 points for each unit increase in perceived stress, (B=4.22; 95% CI=0.30, 8.14; p=0.04). Coping decreased on average by 0.48 points for each unit increase in perceived stress (B=-0.48; 95% CI=-0.93, -0.03; p=0.04). The total regression model accounted for 72.4% of the variance in perceived stress scores.

When the interaction variables between gender and self-efficacy, ways of coping, CES-D, FAD communication, FAD global family functioning, FAD problem solving, anxiety and burden were introduced into the model, “some” family help (p=0.01) and “a little” family help (p<0.001) were statistically and independently associated with perceived stress. The total regression model accounted for 77.6% of the variance in perceived stress scores.

Summary of Findings

Demographic Characteristics

The study sample included 142 African American Alzheimer’s disease caregivers. These participants were predominantly Non-Hispanic (96.8%), females (85.9%) with an average age of 55.1 years old. Additionally, the majority (62%) of participants were single, divorced, or widowed with a college degree or higher (70.8%). More than half (54.8%) of the sample explained that they felt that family and friends offered “almost no help” to “a little help.”

Caregiver/Care recipient relationship and Patient Condition

Overall, the majority (70.9%) of caregivers were living in the same household for the person for whom they provided care and were caring for a mother or father (64.5%) or spouse (13%). The rest were caring for an extended family member (20.3%) or non-relative (2.9%). Less than half (40.7%) of the sample indicated that they were responsible for providing care to someone else in addition to their loved one with dementia; these other individuals were either children (15.5%), grandchildren (13.4%), or someone else that was chronically ill (12%).

Caregivers indicated that on average, the care-recipient had needed attention for four years. Furthermore, caregivers indicated that they themselves had been providing care for the care-recipient on average for four years. The Lawton IADL and Personal Maintenance Scales indicated that care-recipients ranked fairly low for independent functioning.

Psychosocial Scores

At baseline, caregivers had a low Alzheimer's disease knowledge score (Total Mean Score=6.8; SD=3.2). Caregivers also had low burden (Total Mean Score= 38.73; SD=15.87) and anxiety scores (Total Mean Score= 39.9; SD= 12.5). The caregivers scored fairly low on the ways of coping scale (Total Mean Score= 9.3; SD=3.2). As for the outcome variables of interest, caregivers had a low IL-6 mean average of 0.67 (SD=0.59).

Overall, caregivers had moderate depression scores (Total Mean Score=13.3; SD=9.06), and fairly high self-efficacy scores (Total Mean Score=3.5; SD=0.5). Based on the Family Assessment Device scores, caregivers had a mean communication score of 2.3 (SD=0.05), global family functioning score of 2.2 (SD= 0.06), and problem-solving score of 2.2 (SD=0.06). This indicates that the caregivers had good (high) family cohesion. As for the outcome variables of interest, the caregivers had moderate perceived stress scores (Total Mean Score=24.42; SD=8.50).

Perceived Stress

The study's original hypothesis of identifying variables associated with higher levels of perceived stress and IL-6 within the caregiving situation found statistically significant associations between gender, family help, co-residence, caregiver/care-recipient relationship, and perceived stress. These results also suggest that females may have higher levels of perceived stress. Additionally, family cohesion (communication, problem solving, global family functioning), self-efficacy, ways of coping, anxiety, burden, and depression were all significantly associated with perceived stress. Based on the results from the correlations, the data illustrate that live in caregivers, family help, gender, burden, ways of coping, anxiety, family cohesion, and depression are all positively associated with perceived stress. Additionally, self-efficacy and the caregiver/care recipient relationship are negatively associated with perceived stress.

The second hypothesis was also tested to examine the impact of self-efficacy, Alzheimer's disease knowledge, and ways of coping on perceived stress and IL-6. The analyses indicated that there was a statistically significant association between gender, a little family help, self-efficacy, ways of coping, and perceived stress. The analysis of the second hypothesis proved the importance of self-efficacy on perceived stress levels, in addition to ways of coping. Alzheimer's disease knowledge did not have a significant effect on perceived stress scores.

Another sequential multiple linear regression was performed to analyze other psychosocial scales not included in the original hypothesis. Results indicate that "some" family help, "a little" family help, burden, ways of coping, anxiety, FAD global family functioning and perceived stress were all significantly associated.

Chapter 5

Summary

Findings

Demographic Characteristics

As can be seen in Table 1, the study enrolled 142 African American Alzheimer's disease and dementia caregivers. Overall, the average age of participants was 55.1 ± 9.1 years. These participants were predominantly Non-Hispanic (96.8%), females (85.9%) with an average age of 55.1 years old. Additionally, the majority (62%) of participants were single, divorced, or widowed with a college degree or higher (70.8%). Of the sample, 70.8% (N=97) of participants had a college of postgraduate degree, in comparison to 29.2% (N=40) of participants who only had a high school degree or tech/vocational training. From this, the data revealed that the study's sample was a highly educated group of participants. The literature has consistently described that caregiving does not discriminate and can affect anyone at any education level, socioeconomic status, or ethnicity. Therefore, a more representative sample of a diverse community, or sample of lesser educational status, should be examined further.

These demographics are representative of the conclusions drawn from the literature that there are 2 to 2.5 times more women providing care for someone with dementia ("Alzheimer's disease facts and figures," 2014). More than half (54.8%) of the sample explained that they felt that family and friends offered "almost no help" to "a little help." Based on the literature, 70% of caregivers have no outside help; 40% provide 20 hours or more of care each week, and 80% spend at least one-year caregiving (Navaie-Waliser et al., 2001) Even though this statistic was low compared to the literature, it was still representative of a majority of the sample. For health educators and medical professionals, this sample defines a targeted population that could experience adverse health outcomes due to the lack of help and duration of caregiving that they endure.

Caregiver/Care recipient relationship

Overall, the majority (70.9%) of caregivers indicated that they lived in the same household for the person for whom they provided care. The majority of caregivers also indicated they were caring for a mother or father (64.5%) or spouse (13%). These findings support the conclusions drawn from the REGARDS study that African American adult-children were 2 times more likely to live with the parent for whom they are providing care, compared to whites (Roth et al., 2001). The rest of the caregiving sample was caring for an extended family member (20.3%) or non-relative (2.9%). Less than half (40.7%) of the sample indicated that they were responsible for providing care to someone else in addition to their loved one with dementia; these other individuals were either children (15.5%), grandchildren (13.4%), or someone else that was chronically ill (12%). These findings support the literature and suggest the majority of care for African American Alzheimer’s disease patients living in the community is family care (Zhu et al., 2008). Based on these findings, the majority of caregivers are caring for close relatives (e.g. a spouse or parent).

Caregiving Duration and Patient Condition

Caregivers indicated that on average, the care-recipient had needed attention for four years. Furthermore, caregivers indicated that they themselves had been providing care for the care-recipient on average for four years. The Lawton IADL and Personal Maintenance Scales indicated that care-recipients ranked fairly low for independent functioning. The literature consistently states that as disease symptoms worsen (e.g. as patient functionality decreases), caregiver burden tends to increase ("Alzheimer's disease facts and figures," 2014; Dauphinot et al., 2015; Iavarone et al., 2014; Kang et al., 2014; Reed et al., 2014). This burden and distress is primarily a result of patient behaviors (Deimling & Bass, 1986; Molloy et al., 1999; Pruchno & Resch, 1989a; Teri et al., 1997) and care recipient’s incontinence (Noelker, 1987), rather than the severity of cognitive impairment. However, family support is linked to delayed institutionalization for the Alzheimer’s disease patient (Gaugler et al., 1999).

This evidence should bring policymakers, healthcare professionals, and health educators’ awareness to the need for the caregivers’ participation in the patients’ care continuum. Caregivers play a critical role in the care recipient’s health and wellbeing. Medical professionals should work to incorporate the caregiver into the patient’s care team in order to ensure the upmost quality of care for the patient.

Additionally, these findings should draw the attention of health educators to the need of knowledge and skills for behavioral management. Additionally, social workers should focus more on increasing or maintaining family cohesion and long-term planning with caregivers in order to alleviate some of the burden and distress associated with this disease.

Psychosocial Assessment Scores

As can be seen in Table 2, the caregivers had a mean FAD problem-solving score of 2.2 (SD=0.6), FAD communication score of 2.3 (SD=0.5), and FAD global family functioning score of 2.2 (SD= 0.6). These scores indicate that the COOL-AD caregiving sample has fairly high family cohesion. According to the literature, dysfunction among family members is linked to greater caregiver burden (Tremont et al., 2006). The Zarit burden scores collected at baseline are in agreement with the literature and indicated that this sample had low levels of burden (Total Mean Score= 38.73; SD=15.87).

The Alzheimer's disease knowledge mean score was 6.8 (SD=3.2), which is low. When conducting data analyses, a note was made that for questions 1, 5, 7, and 11, there was a very low percentage of correct responses. This was an unexpected finding considering that the sample was highly educated. This could have major public health implications in that even the "educated" need to be educated on particular diseases, including Alzheimer's disease and dementia. As for health educators and medical professionals, this could indicate that there needs to be more education within the community about dementia, prevention strategies, and steps to take if they or a relative are experiencing symptoms.

Furthermore, caregivers had fairly low anxiety (Total Mean Score= 44.28; SD= 6.09), and moderate depression scores (Total Mean Score= 13.30; SD=9.06). A possible explanation for these findings could be related to Sun and Hodge (2014) and Heo and Koeske (2013) findings that examined the effects of spirituality and religion on depression. They found that religion might lower caregiver burden, furthermore, decreasing depression. One recruitment method utilized local African American churches as recruitment platforms for this study. However, due to the educational level, low scores could also be related to having the resources needed to obtain medication for both anxiety and depression. However, this finding should not dismiss the previous research findings indicating that many caregivers experience high levels of anxiety and depression during care continuum.

The caregivers' had a low coping score that was 9.3 (SD=3.2). This was not consistent with the literature, which states that religious beliefs and practices, that are often noted as sources of strength in African American caregivers. These beliefs and practices are critical in providing the caregiver meaning to the situation and are identified as effective coping strategies (Hebert et al., 2007). However, religious beliefs as a means of coping were not analyzed for this study. Additionally, there are many other factors that could have played as mediators and moderators along the stress and coping process. Based on these findings, among others in the literature, health educators should train caregivers in positive coping strategies to help alleviate any adverse health outcomes associated with the threat of caregiving.

The overall mean self-efficacy score was 13.87 (SD=2.09). This is a high self-efficacy score for the sample at baseline. Previous research has shown that "low coping self-efficacy was significantly related to IL-6" (Mausbach et al., 2011). This could potentially explain the low levels of IL-6 (Mean average=0.67; SD=0.59) and the inability to see significant correlations with the biomarker within the data. As for researchers and medical professionals, an accurate and reliable biomarker should be identified to assist in measuring the physiological and biological effects of stress. Where psychosocial scales can measure perceived stress, it would be beneficial to have a valid biomarker to measure the biological effects of stress.

As for the outcome variable of interest, the caregivers had a perceived stress score of 24.42 (SD=8.50). This score is a moderate score, but fairly low for caregivers. The literature stated that stress does not affect every individual equivalently. Glanz (2008) states, "Perceived stressors, rather than objective stressors, are the main determinants of effects on behaviors and on health status.” The idea of perceived stressors versus objective stressors leads to the comprehensive analysis of moderating factors within the stress and coping framework (Glanz, 2008). Based on the previous study findings, this is not surprising since caregivers had low levels of anxiety, depression, and burden in addition to high self-efficacy.

Perceived Stress

Hypothesis 1: Live-in caregivers, compound caregiving, lack of family cohesion, duration of caregiving, patient condition, education, low self-efficacy, low Alzheimer’s disease knowledge, and poor coping efforts will be identified as factors that are associated with elevated IL-6 levels and perceived stress scores in caregivers at baseline.

Bivariate analyses were conducted to examine the associations between independent variables and dependent variables. A Pearson correlation was conducted for AD knowledge, family cohesion, depression, Lawton ADL and IADL, self-efficacy, anxiety, ways of coping, burden, with the outcome variables, perceived stress, and IL-6. Additionally, Pearson correlations were performed to examine the relationship between demographic variables such as age, caregiving duration, co-residence, and the outcome variables perceived stress and IL-6.

Results suggest that there is a statistically significant positive association between depression and perceived stress ($p<0.001$); family cohesion (FAD) communication and perceived stress ($p<0.001$); family cohesion (FAD) problem solving and perceived stress ($p=<0.001$); family cohesion (FAD) global family functioning and perceived stress ($p<0.001$); anxiety and perceived stress ($p<0.001$); and burden and perceived stress

($p<0.001$). There was a statistically significant negative association between self-efficacy and perceived stress ($p<0.001$) and ways of coping and perceived stress ($p=0.02$).

A Spearman-Rho correlation was conducted to examine the association between gender, education, ethnicity, marital status, caregiver/care-recipient relationship, family help, co-residence with patient, compound caregiving, with the outcome variables, perceived stress and IL-6. There were statistically significant positive association between the following: gender and perceived stress ($p=0.002$); family help and perceived stress ($p<0.001$); and co-residence and perceived stress ($p=0.029$). However, there was a statistically significant negative association between the caregiver/care-recipient relationship and perceived stress ($p=0.006$).

One-Way ANOVAs were also conducted in order to determine whether there were any statistically significant differences between the categories within the following demographic variables: gender, education, ethnicity, marital status, caregiver/care-recipient relationship, family help, co-residence with patient, compound caregiving, and the outcome variables, perceived stress and IL-6. A statistically significant difference was observed in mean perceived stress score by gender ($p<0.001$); marital status ($p=0.01$); family help ($p=0.003$), co-residence ($p=0.02$) and the caregiver/care recipient relationship ($p<0.001$).

As for health professionals, these findings have shown a significant correlation between specified independent variables and perceived stress. Researchers should explore these variables further to analyze the moderating and mediating effects these factors may have on the stress and coping pathway. This data could help health educators, medical professionals, and policymakers in targeting specific groups of caregivers for interventions that aim to alleviate the negative outcomes associated with caregiver. Furthermore, these individuals could be an essential population needed in clinical trials research on prevention and disease progression.

Hypothesis 2: Self-efficacy will have a more profound impact on IL-6 and perceived stress levels, compared to Alzheimer's disease knowledge and coping efforts. High self-efficacy scores will be associated with lower IL-6 levels and perceived stress scores among caregivers at baseline.

A sequential multiple linear regression was conducted to assess the association between the outcome, perceived stress, and the predictors, block one, caregiver/care-recipient relationship, household size, family help, gender; block two, self-efficacy, Alzheimer's disease knowledge, and ways of coping. Additionally, a third block was added to this regression in order to examine interaction variables of gender and self-efficacy, gender and Alzheimer's disease knowledge, and gender and ways of coping.

Results of the regression model indicated that out of all demographic variables entered into block one, gender ($p=0.04$) was the only variable that had significant correlations with perceived stress. When self-efficacy, Alzheimer's disease knowledge, and ways of coping were incorporated into the model, "a little" family help ($p=0.04$), self-efficacy ($p<0.001$) and ways of coping ($p=0.01$) were the only variables that were statistically significant. Specifically, self-efficacy decreased on average by 6.23 points for each unit increase in perceived stress. Ways of coping increased on average by 0.68 points for each unit increase in perceived stress. When the interaction variables between gender and psychosocial scales were introduced into the model, gender ($p<0.001$), "a little" family help ($p=0.03$), self-efficacy ($p<0.001$), and the interaction variable for gender and self-efficacy (p=0.01) was significantly associated with perceived stress. Specifically, self-efficacy decreased on average by 24.09 points for each unit increase in perceived stress. Based on these findings, my hypothesis was supported in that self-efficacy had a more profound impact on perceived stress than ways of coping and Alzheimer's disease knowledge.

The aforementioned results indicate the importance of gender, family help, self-efficacy, and ways of coping in the caregiving situation. One-Way ANOVA tests indicated that gender had a statistically significant difference for perceived stress. Researchers should explore this finding further as health professionals may need to target interventions toward women before men. The data also illustrate the importance of self-efficacy on perceived stress. This evidence argues the importance of skills training among caregivers on all aspects of disease care from behavioral management to legal planning.

An additional sequential multiple linear regression was conducted to assess the association between the outcome, perceived stress, and the psychological scales that were found to be associated with the outcome in preliminary analyses. These scales included depression (CES-D), FAD communication, FAD global family functioning, FAD problem solving, self-efficacy, anxiety, ways of coping, and burden. Independent variables were entered into the regression model in sequential blocks, with block one comprised of demographic variables, block two consisting of psychosocial scales, and block three was made up of interactions between gender and psychosocial scales.

Results of the regression model indicate that out of all of the demographic variables entered into block one, only "a little" family help (p=0.03) had significant correlation with perceived stress. When all of the psychosocial scales were incorporated into the model, “some” family help (p=0.01), “a little family help” (p<0.003), burden (p<0.001), ways of coping (p=0.04), anxiety (p=0.01), and FAD global family functioning (p=0.04) were statistically associated with perceived stress. Specifically, burden increased on average by 0.21 points for each unit increase in perceived stress. Anxiety increased on average by 0.20 points for each unit increase in perceived stress. FAD global family functioning increased on average by 4.22 points for each unit increase in perceived stress. Coping decreased on average by 0.48 points for each unit increase in perceived stress. When the interaction variables between gender and self-efficacy, ways of coping, CES-D, FAD communication, FAD global family functioning, FAD problem solving, anxiety and burden were introduced into the model, “some” family help (p=0.01) and “a little” family help (p<0.001) were statistically and independently associated with perceived stress.

Even though the sample had low depression, anxiety, and burden scores, a statistically significant association was still found between the variables and perceived stress. Health professionals should use the variables as indicators or risk factors of perceived stress. Additionally, the results illustrate that coping efforts and family cohesion also have statistically significant associations with perceived stress. Health educators and social workers should focus on increasing coping efforts and family cohesion in order to prevent any undue stress that may result in the future.

Conclusions

The study aimed to identify factors that are associated with elevated levels of stress among African American caregivers of a family member with dementia.

Additionally, the study aimed to analyze the effects of self-efficacy, Alzheimer’s disease knowledge, and coping on perceived stress and IL-6 levels among these caregivers. The results mirrored the importance of self-efficacy and coping mechanisms on perceived stress within the caregiving situation. Additionally, the results indicated that female caregivers with no family help, who live with the care-recipient, and care for a spouse or parent, are positively associated with elevated levels of perceived stress. Additionally, anxiety, depression and burden were also significantly associated with perceived stress. These findings call for the attention of healthcare professionals and need of more targeting interventions. Based on these results, interventions should focus on increasing a caregiver’s self-efficacy and instill better ways of coping into their current caregiving situation.

Strengths and Limitations

A significant strength of this study was the utilization of multiple recruitment methods, which allowed for a large sample of African American caregivers in Atlanta, Georgia. In addition to recruitment efforts, information was collected from a sample size of 142 caregivers at baseline. Due to the large sample size, the study power was adequate to draw accurate conclusions from. This population is considered to be an “overburdened” group, so in order to collect data on 142 participants at baseline and continue to collect data on them for 6 months, was a major strength of the study.

This study was the first study known to focus on the African American Alzheimer’s disease caregiving population. Additionally, the study used an evidence-based theory to guide the development, implementation, and evaluation of the study design and data. These two strengths portray the study's innovativeness, integrity, and determination to reach an underserved and undertreated population.

This study also had limitations. Within the baseline sample, there were 10 individuals identified as "suspicious." The research staff inferred that these individuals were only participating due to the monetary incentive. The convenience sampling technique utilized in this study is prone to bias and may not be generalizable to the greater dementia caregiving population within the United States. Another limitation arose from the self-reported nature of the psychological scale; therefore, the conclusions may not be an accurate representation of African American caregivers within Atlanta, Georgia.

The eligibility criteria required caregivers to provide at least 6 hours of care per week for the care recipient. This could have limited the findings of the study, since the average amount of care per week within the literature is approximately 20 hours. However, there are no accurate ways to collect this data and therefore must reply on self-report data. With this said, the data must be analyzed with all limitations in mind.

Additionally, the study did not measure the participants' socioeconomic status. The participants were highly educated and scored low on anxiety, depression and burden scores. This could be explained by the access to resources that may allow for this sample to receive a proper medical diagnosis and purchase medications to decrease the symptoms of these mental conditions.

Recommendations and Implications

Bivariate analyses of the One-Way ANOVA test revealed distinct differences between the categories within the variables of gender, marital status, caregiver/care-recipient relationship, family help, and co-residence with perceived stress and IL-6. Only caregiver/care-recipient relationship had a statistical difference between groups with IL-6. Due to the original priorities set for this particular study, gender was the only variable explored in the final analyses models. Variables were created to explore the interaction between gender and all psychosocial scales in the final model. Gender and self-efficacy appeared to have significant effects on perceived stress. Future research studies should further explore the differences among these variables in addition to their effects on the dependent variables of perceived stress particularly. Future research should also examine the moderating and mediating effects of these predictor variables on perceived stress and IL-6.

Within this study, it was also found that the family cohesion and perceived stress were statistically significant. This suggests that there is a positive association between perceived stress and family cohesion. While these findings are statistically significant at baseline, future research should test the association using a longitudinal study.

An additional recommendation for future research would be to replicate this study to include a diverse group of caregivers with a range of races and ethnicities and explore variables that can place caregivers at elevated levels of stress, anxiety, and burden. These findings will be critical in the design of interventions for caregivers to reduce any risks for adverse health outcomes and encourage them to participate in healthy behaviors.

Overall, this research study aimed to narrow the gap on African American health disparities research and expand current knowledge regarding dementia and caregiving. Dementia is a growing concern for caregivers, healthcare professionals, and medical agencies such as Medicare and Medicaid, specifically in relation to long-term care.

However, dementia is not a disease that solely affects the individual with dementia, but incurs another patient as well, the caregiver. Both the dementia patient and caregiver experience many inequities that are compounded by the additive effects of daily stressors and pre-existing health conditions. Findings from this study can be used to guide the development of interventions to help alleviate caregiver stress levels and burden. Additionally, these findings can also inform healthcare professionals of the increased health risks caregivers face in comparison to the general population.

Table 1: COOL AD Descriptive Statistics (N=142)

Measure	**Mean ± SD or n (%)**
Age (years)	55.1 ± 9.7
Education (5 missing)	
High School/Tech-Vocational	40 (29.2)
College / Post Graduate	97 (70.8)
Gender	
Male	20 (14.1)
Female	122 (85.9)
Marital Status (5 missing)	
Married / Domestic Partner	52 (38.0)
Single / Divorced / Separated / Widow	85 (62.0)
Ethnicity: Hispanic or Latino? (17 missing)	
No	121 (96.8)
Yes	4 (3.2)
Co-residence: Do you live in the same house as the person? (8 missing)	
Yes	95 (70.9)
No	39 (29.1)
Compound Caregiving: Are you responsible for providing care for others (beside patient) in your home? (4 missing)	
Yes	58 (42.0)
Children	22 (15.9)
Grandchildren	19 (13.8)
Other chronically ill	17 (12.3)
No	80 (58.0)
Family Help: How helpful do you feel your family and friends are to you in the responsibilities you bear? (5 missing)	
A great deal of help	32 (23.4)
Some help	30 (21.9)
A little help	32 (23.4)
Not much help	19 (13.9)
Almost no help	24 (17.5)
Caregiver/Care recipient relationship: Who is the person with AD for whom you provide care? (4 missing)	
Spouse	18 (13.0)
Mother / Father	89 (64.5)
Aunt / Uncle	16 (11.6)
Other relative	11 (8.0)
Other	4 (2.9)
Duration of needed care: About how long has the person needed attention and care because of the AD/dementia? (years)	4.0 ± 2.7
Duration of caregiving: About how long have you been personally caring for your loved one? (years)	4.0 ± 3.4

Table 2. Psychosocial Scales

Scale	Mean ± SD
ADKT Total	6.8 ± 3.2
Anxiety	39.9 ± 12.5
Burden	38.7 ± 15.9
Depression (CES-D)	13.3 ± 9.1*
FAD Communication	2.3 ± 0.5
FAD Global Family Functioning	2.2 ± 0.6
FAD Problem Solving	2.2 ± 0.6
Lawton IADL	2.2 ± 2.0
Lawton PSMS (ADL)	2.2 ± 2.0
Self-efficacy	3.5 ± 0.5
Ways of Coping	9.3 ± 3.2

* 16+ is considered clinically depressed

Table 3. Outcome Variables

Variable	Mean ± SD
Perceived Stress	24.4 ± 8.5
IL-6*	0.7 ± 0.6

*Log Transformed

Table 4. Pearson Correlations of Psychosocial Scales and Dependent Variables

	Depression	FAD Commu-nication	FAD Global Family Functioning	FAD Problem Solving	IADL	PSMS (ADL)	Self Efficacy	Anxiety	Ways of Coping	Burden	Percei-ved Stress	IL-6
Alzheimer's disease Knowledge	.005	-.094	-.041	.058	-.127	-.041	.008	.077	-.038	.130	.115	-.188*
Depression		.308**	.461**	.323**	-.075	-.119	-.246*	.705**	.245*	.491**	.670**	.195
FAD Communication			.770**	.725**	.090	.004	-.246**	.316**	.015	.267**	.339**	-.037
FAD Global Family Functioning				.793**	.032	-.067	-.305**	.417**	.082	.366**	.476**	-.052
FAD Problem Solving					-.045	-.115	-.359**	.365**	-.006	.378**	.388**	-.096
IADL						.701**	-.151	-.101	.082	-.176	-.019	.008
PSMS (ADL)							-.108	-.148	.070	-.134	-.014	-.051
Self Efficacy								-.361**	.097	-.244**	-.367**	.130
Anxiety									.219*	.530**	.729**	.000
Ways of Coping										.182*	.202*	.012
Burden											.656**	.012
Perceived Stress												.015

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table 5: Pearson Correlations Between Demographic and Dependent Variables

	Duration of Needed Care	Duration of Caregiving	Household Size	Perceived Stress	IL-6
Age	.040	.040	-.032	-.111	.007
Duration of Needed Care		.532**	.049	.068	-.079
Duration of Caregiving			.060	.049	-.013
Household Size				.164	.014
Perceived Stress					.015

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table 6: Spearman’s Rho Correlations Between Demographic and Dependent Variables

	Education	Ethnicity	Marital Status	Family Help	Co-residency	Compound Caregiving	Caregiver/ Care recipient Relationship	Perceived Stress	IL-6
Gender	.096	-.087	.046	.111	.181*	.081	-.146	.264**	-.074
Education		.028	-.001	.141	.152	-.019	-.148	.054	-.143
Ethnicity			.162	.093	-.002	-.021	.024	-.085	.037
Marital Status				.149	.157	-.071	.243**	.115	-.155
Family Help					.364**	-.113	-.251**	.273**	-.021
Co-residency						-.110	-.446**	.189*	.081
Compound Caregiving							.016	-.129	.030
Caregiver/ Care recipient relationship								-.232**	-.030
Perceived Stress									-.043

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table 7: Hypothesis Specific Sequential Multiple Linear Regression

		Dependent Variable: Perceived Stress	
Model	**Independent Variables**	**B (95% CI)**	**Sig.**
1	(Constant)	19.00 (13.17, 24.62)	0.00
	Gender	5.93 (0.30, 11.56)	**.039**
	Family Help: Some	1.47 (-3.07, 6.02)	.521
	Family Help: Little	3.54 (-0.84, 7.92)	.112
	Family Help: Almost No	0.32 (-4.55, 5.20)	.896
2	(Constant)	34.60 (19.96, 49.24)	.000
	Gender	4.61 (-0.59, 9.80)	.082
	Family Help: Some	1.71 (-2.39, 5.82)	.409
	Family Help: Little	4.22 (0.23, 8.21)	**.039**
	Family Help: Almost No	1.12 (-3.34, 5.58)	.620
	Alzheimer's Disease Knowledge	0.11 (-0.44, 0.67)	.683
	Self Efficacy	-6.23 (-9.35, -3.10)	**.000**
	Ways of Coping	0.68 (0.16, 1.19)	**.011**
3	(Constant)	124.74 (72.68, 176.80)	.000
	Gender	-92.03 (-145.34, -38.72)	**.001**
	Family Help: Some	1.16 (-2.67, 4.98)	.549
	Family Help: Little	4.32 (0.46, 8.18)	**.029**
	Family Help: Almost No	1.16 (-2.67, 4.98)	.460
	Alzheimer's Disease Knowledge	-0.73 (-1.99, 0.54)	.255
	Self Efficacy	-24.09 (-38.45, -9.73)	**.001**
	Ways of Coping	-1.17 (-3.50, 1.15)	.319
	Gender*Alzheimer's Disease Knowledge	19.13 (4.46, 33.79)	.209
	Gender*Self Efficacy	0.89 (-0.51, 2.30)	.011
	Gender*Ways of Coping	2.04 (-0.36, 4.43)	.095

*Significant B's are shown in bold

Table 8: Sequential Multiple Linear Regression Among Psychosocial Scales and Perceived Stress

		Dependent Variable: Perceived Stress	
Model	**Independent Variables**	**B (95% CI)**	**Sig.**
1	(Constant)	19.1 (12.80, 25.40)	.000
	Gender	4.47 (-1.65, 10.59)	.149
	Family Help: Some	2.39 (-3.30, 8.08)	.404
	Family Help: Little	5.99 (0.54, 11.44)	**.032**
	Family Help: Almost No	0.84 (-5.15, 6.83)	.781
2	(Constant)	3.73 (-11.10, 18.56)	.615
	Gender	2.95 (-0.59, 6.50)	.100
	Family Help: Some	4.35 (1.04, 7.66)	**.011**
	Family Help: Little	5.01 (1.81, 8.22)	**.003**
	Family Help: Almost No	2.15 (-1.29, 5.59)	.215
	Burden	0.21 (0.10, 0.32)	**.000**
	Ways of Coping	-0.48 (-0.93, -0.03)	**.039**
	Anxiety	0.20 (0.06, 0.34)	**.007**
	Self Efficacy	-0.77 (-3.59, 2.05)	.585
	FAD Communication	-0.98 (-5.24, 3.29)	.647
	FAD Global Family Functioning	4.22 (0.30, 8.14)	**.035**
	FAD Problem Solving	-1.26 (-5.28, 3.29)	.533
	Depression	0.14 (-0.05, 0.34)	.142
3	(Constant)	4.79 (-156.84, 166.42)	.953
	Gender	-3.67 (-166.14, 158.79)	.964
	Family Help: Some	4.32 (0.97, 7.68)	**.013**
	Family Help: Little	6.06 (2.60, 9.51)	**.001**
	Family Help: Almost No	2.59 (-0.72, 5.90)	.122
	Burden	-0.18 (-1.21, 0.85)	.720
	Ways of Coping	-1.37 (-3.44, 0.71)	.190
	Anxiety	0.72 (-0.40, 1.83)	.201
	Self Efficacy	-3.62 (-29.53, 22.30)	.779
	FAD Communication	-1.10 (-5.47, 3.26)	.613
	FAD Global Family Functioning	22.70 (-52.53, 97.94)	.545
	FAD Problem Solving	-8.24 (-44.94, 28.47)	.652
	Depression	-0.71 (-2.53, 1.11)	.436
	Gender*Self-Efficacy	4.00 (-22.03, 30.04)	.757
	Gender*Ways Of Coping	1.05 (-1.07, 3.18)	.323
	Gender*Depression	0.85 (-0.97, 2.68)	.350
	Gender*FAD Global Family Functioning	-18.26 (-93.73, 57.20)	.627
	Gender*FAD Problem Solving	7.21 (-29.36, 43.79)	.692
	Gender*Anxiety	-0.57 (-1.69, 0.55)	.308
	Gender*Burden	0.42 (-0.61, 1.45)	.418

*Significant B's are shown in bold

References

2009 Alzheimer's disease facts and figures. (2009). *Alzheimers Dement, 5*(3), 234-270. doi:10.1016/j.jalz.2009.03.001

Alzheimer's disease facts and figures. (2014). *Alzheimers Dement, 10*(2), e47-92.

Alzheimer's disease facts and figures. (2015). *Alzheimers Dement, 11*(3), 332-384.

Aneshensel, C. S., Pearlin, L. I., & Schuler, R. H. (1993). Stress, role captivity, and the cessation of caregiving. *J Health Soc Behav, 34*(1), 54-70.

Barnes, L. L., & Bennett, D. A. (2014). Alzheimer's disease in African Americans: risk factors and challenges for the future. *Health Aff (Millwood), 33*(4), 580-586. doi:10.1377/hlthaff.2013.1353

Barnes, L. L., Mendes de Leon, C. F., Bienias, J. L., & Evans, D. A. (2004). A longitudinal study of black-white differences in social resources. *J Gerontol B Psychol Sci Soc Sci, 59*(3), S146-153.

Broadbent, S., & Gass, G. (2008). Aerobic training increases the stimulated percentage of CD4+CD25+ in older men but not older women. *Eur J Appl Physiol, 103*(1), 79-87. doi:10.1007/s00421-007-0664-8

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., . . . Clark, K. C. (1993). How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. *Journal of personality and social psychology, 65*(2), 375.

Chen, J. C., Borson, S., & Scanlan, J. M. (2000). Stage-specific prevalence of behavioral symptoms in Alzheimer's disease in a multi-ethnic community sample. *Am J Geriatr Psychiatry, 8*(2), 123-133.

Clay, O. J., Roth, D. L., Wadley, V. G., & Haley, W. E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *Int J Geriatr Psychiatry, 23*(8), 857-862. doi:10.1002/gps.1996

Cooper, C., Balamurali, T. B., Selwood, A., & Livingston, G. (2007). A systematic review of intervention studies about anxiety in caregivers of people with dementia. *Int J Geriatr Psychiatry, 22*(3), 181-188. doi:10.1002/gps.1656

Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *Int J Geriatr Psychiatry, 23*(9), 929-936.

Covinsky, K. E., Newcomer, R., Fox, P., Wood, J., Sands, L., Dane, K., & Yaffe, K. (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *J Gen Intern Med, 18*(12), 1006-1014.

Damjanovic, A. K., Yang, Y., Glaser, R., Kiecolt-Glaser, J. K., Nguyen, H., Laskowski, B., . . . Weng, N. P. (2007). Accelerated telomere erosion is associated with a declining immune function of caregivers of Alzheimer's disease patients. *J Immunol, 179*(6), 4249-4254.

Dauphinot, V., Delphin-Combe, F., Mouchoux, C., Dorey, A., Bathsavanis, A., Makaroff, Z., . . . Krolak-Salmon, P. (2015). Risk factors of caregiver burden among patients with Alzheimer's disease or related disorders: a cross-sectional study. *J Alzheimers Dis, 44*(3), 907-916. doi:10.3233/jad-142337

Deimling, G. T., & Bass, D. M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. *J Gerontol, 41*(6), 778-784.

DeKosky, S. T. (2001). Epidemiology and pathophysiology of Alzheimer's disease. *Clin Cornerstone, 3*(4), 15-26.

Demirovic, J., Prineas, R., Loewenstein, D., Bean, J., Duara, R., Sevush, S., & Szapocznik, J. (2003). Prevalence of dementia in three ethnic groups: the South Florida program on aging and health. *Ann Epidemiol, 13*(6), 472-478.

Dieckmann, L., Zarit, S. H., Zarit, J. M., & Gatz, M. (1988). The Alzheimer's disease knowledge test. *Gerontologist, 28*(3), 402-408.

Dilworth-Anderson, P., Hendrie, H. C., Manly, J. J., Khachaturian, A. S., & Fazio, S. (2008). Diagnosis and assessment of Alzheimer's disease in diverse populations. *Alzheimers Dement, 4*(4), 305-309. doi:10.1016/j.jalz.2008.03.001

Drentea, P., & Goldner, M. A. (2006). Caregiving outside of the home: the effects of race on depression. *Ethn Health, 11*(1), 41-57. doi:10.1080/13557850500286396

Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device*. *Journal of marital and family therapy, 9*(2), 171-180.

Erta, M., Quintana, A., & Hidalgo, J. (2012). Interleukin-6, a major cytokine in the central nervous system. *Int J Biol Sci, 8*(9), 1254-1266.

Faison, W. E., Schultz, S. K., Aerssens, J., Alvidrez, J., Anand, R., Farrer, L. A., . . . Mintzer, J. E. (2007). Potential ethnic modifiers in the assessment and treatment of Alzheimer's disease: challenges for the future. *Int Psychogeriatr, 19*(3), 539-558. doi:10.1017/s104161020700511x

Fillenbaum, G. G., Heyman, A., Huber, M. S., Woodbury, M. A., Leiss, J., Schmader, K. E., . . . Trapp-Moen, B. (1998). The prevalence and 3-year incidence of dementia in older Black and White community residents. *J Clin Epidemiol, 51*(7), 587-595.

Fischbach, F. T. (2003). *A Manual of Laboratory and Diagnostic Tests* (7 ed.): Lippincott Williams & Wilkins.

Fitzpatrick, A. L., Kuller, L. H., Ives, D. G., Lopez, O. L., Jagust, W., Breitner, J. C., . . . Dulberg, C. (2004). Incidence and prevalence of dementia in the Cardiovascular Health Study. *J Am Geriatr Soc, 52*(2), 195-204.

Folkman, S. (1984). Personal control and stress and coping processes: a theoretical analysis. *Journal of personality and social psychology, 46*(4), 839.

Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social science & medicine, 45*(8), 1207-1221.

Folkman, S., & Lazarus, R. S. (1988). Coping as a mediator of emotion. *Journal of personality and social psychology, 54*(3), 466.

Fredman, L., Cauley, J. A., Satterfield, S., Simonsick, E., Spencer, S. M., Ayonayon, H. N., & Harris, T. B. (2008). Caregiving, mortality, and mobility decline: the Health, Aging, and Body Composition (Health ABC) Study. *Arch Intern Med, 168*(19), 2154-2162. doi:10.1001/archinte.168.19.2154

Froehlich, T. E., Bogardus, S. T., Jr., & Inouye, S. K. (2001). Dementia and race: are there differences between African Americans and Caucasians? *J Am Geriatr Soc, 49*(4), 477-484.

Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychol Aging, 22*(1), 37-51. doi:10.1037/0882-7974.22.1.37

Gallagher-Thompson, D., Singer, L. S., Depp, C., Mausbach, B. T., Cardenas, V., & Coon, D. W. (2004). Effective recruitment strategies for Latino and Caucasian dementia family caregivers in intervention research. *Am J Geriatr Psychiatry, 12*(5), 484-490. doi:10.1176/appi.ajgp.12.5.484

Gallicchio, L., Siddiqi, N., Langenberg, P., & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *Int J Geriatr Psychiatry, 17*(2), 154-163.

Garcia-Alberca, J. M., Cruz, B., Lara, J. P., Garrido, V., Lara, A., & Gris, E. (2012). Anxiety and depression are associated with coping strategies in caregivers of Alzheimer's disease patients: results from the MALAGA-AD study. *Int Psychogeriatr, 24*(8), 1325-1334. doi:10.1017/s1041610211002948

Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (1999). Caregiving and institutionization: perceptions of family conflict and socioemotional support. *The International Journal of Aging and Human Development, 49*(1), 1-25.

Glanz, K., Rimer, B. K., and Viswanath, K. (2008). Health Behavior and Health Education Theory, Research, and Practice. *Fourth Edition* 170-186.

Gonzalez, E. W. (1997). Resourcefulness, appraisals, and coping efforts of family caregivers. *Issues Ment Health Nurs, 18*(3), 209-227.

Gonzalez, E. W., Polansky, M., Lippa, C. F., Gitlin, L. N., & Zauszniewski, J. A. (2014). Enhancing Resourcefulness to Improve Outcomes in Family Caregivers and Persons with Alzheimer’s Disease: A Pilot Randomized Trial. *International Journal of Alzheimer’s Disease, 2014*.

Gouin, J. P., Glaser, R., Malarkey, W. B., Beversdorf, D., & Kiecolt-Glaser, J. (2012). Chronic stress, daily stressors, and circulating inflammatory markers. *Health Psychol, 31*(2), 264-268. doi:10.1037/a0025536

Gouin, J. P., Hantsoo, L., & Kiecolt-Glaser, J. K. (2008). Immune dysregulation and chronic stress among older adults: a review. *Neuroimmunomodulation, 15*(4-6), 251-259. doi:10.1159/000156468

Green, R. C., Cupples, L. A., Go, R., Benke, K. S., Edeki, T., Griffith, P. A., . . . Farrer, L. A. (2002). Risk of dementia among white and African American relatives of patients with Alzheimer disease. *Jama, 287*(3), 329-336.

Gurland, B. J., Wilder, D. E., Lantigua, R., Stern, Y., Chen, J., Killeffer, E. H., & Mayeux, R. (1999). Rates of dementia in three ethnoracial groups. *Int J Geriatr Psychiatry, 14*(6), 481-493.

Haaland, D. A., Sabljic, T. F., Baribeau, D. A., Mukovozov, I. M., & Hart, L. E. (2008). Is regular exercise a friend or foe of the aging immune system? A systematic review. *Clin J Sport Med, 18*(6), 539-548. doi:10.1097/JSM.0b013e3181865eec

Haley, W. E., West, C. A., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., . . . Roth, D. L. (1995). Psychological, social, and health impact of caregiving: a comparison of black and white dementia family caregivers and noncaregivers. *Psychol Aging, 10*(4), 540-552.

Hausmann, L. R., Jeong, K., Bost, J. E., & Ibrahim, S. A. (2008). Perceived discrimination in health care and health status in a racially diverse sample. *Med Care, 46*(9), 905-914. doi:10.1097/MLR.0b013e3181792562

Hebert, R. S., Dang, Q., & Schulz, R. (2007). Religious beliefs and practices are associated with better mental health in family caregivers of patients with dementia: Findings from the REACH study. *The American Journal of Geriatric Psychiatry, 15*(4), 292-300.

Helzner, E. P., Scarmeas, N., Cosentino, S., Tang, M. X., Schupf, N., & Stern, Y. (2008). Survival in Alzheimer disease: a multiethnic, population-based study of incident cases. *Neurology, 71*(19), 1489-1495. doi:10.1212/01.wnl.0000334278.11022.42

Heo, G. J., & Koeske, G. (2013). The role of religious coping and race in Alzheimer's disease caregiving. *J Appl Gerontol, 32*(5), 582-604. doi:10.1177/0733464811433484

Hepburn, K. a. P., M. . COOL-AD Grant.

Huang, H.-L., Shyu, Y.-I. L., Chen, M.-C., Huang, C.-C., Kuo, H.-C., Chen, S.-T., & Hsu, W.-C. (2015). Family caregivers' role implementation at different stages of dementia. *Clinical interventions in aging, 10*, 135.

Husaini, B. A., Sherkat, D. E., Moonis, M., Levine, R., Holzer, C., & Cain, V. A. (2003). Racial differences in the diagnosis of dementia and in its effects on the use and costs of health care services. *Psychiatr Serv, 54*(1), 92-96.

Iavarone, A., Ziello, A. R., Pastore, F., Fasanaro, A. M., & Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer's disease. *Neuropsychiatr Dis Treat, 10*, 1407-1413. doi:10.2147/ndt.s58063

Janevic, M. R., & Connell, C. M. (2004). Exploring self-care among dementia caregivers:the role of perceived support in accomplishing exercise goals. *J Women Aging, 16*(1-2), 71-86. doi:10.1300/J074v16n01_06

Kang, H. S., Myung, W., Na, D. L., Kim, S. Y., Lee, J. H., Han, S. H., . . . Kim, D. K. (2014). Factors associated with caregiver burden in patients with Alzheimer's disease. *Psychiatry Investig, 11*(2), 152-159. doi:10.4306/pi.2014.11.2.152

Katzman, R., Brown, T., Fuld, P., Peck, A., Schechter, R., & Schimmel, H. (1983). Validation of a short Orientation-Memory-Concentration Test of cognitive impairment. *Am J Psychiatry, 140*(6), 734-739. doi:10.1176/ajp.140.6.734

Kiecolt-Glaser, J. K., Marucha, P. T., Malarkey, W. B., Mercado, A. M., & Glaser, R. (1995). Slowing of wound healing by psychological stress. *Lancet, 346*(8984), 1194-1196.

Knight, B. G., Longmire, C. V., Dave, J., Kim, J. H., & David, S. (2007). Mental health and physical health of family caregivers for persons with dementia: a comparison of African American and white caregivers. *Aging Ment Health, 11*(5), 538-546. doi:10.1080/13607860601086561

Knight, B. G., Silverstein, M., McCallum, T., & Fox, L. S. (2000). A sociocultural stress and coping model for mental health outcomes among African American caregivers in Southern California. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 55*(3), P142-P150.

Krishnan, L. L., Petersen, N. J., Snow, A. L., Cully, J. A., Schulz, P. E., Graham, D. P., . . . Kunik, M. E. (2005). Prevalence of dementia among Veterans Affairs medical care system users. *Dement Geriatr Cogn Disord, 20*(4), 245-253. doi:10.1159/000087345

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist, 9*(3), 179-186.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*: Springer publishing company.

Lee, S., Colditz, G. A., Berkman, L. F., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in U.S. women: a prospective study. *Am J Prev Med, 24*(2), 113-119.

Leggett, A. N., Zarit, S. H., Kim, K., Almeida, D. M., & Klein, L. C. (2015). Depressive Mood, Anger, and Daily Cortisol of Caregivers on High- and Low-Stress Days. *J Gerontol B Psychol Sci Soc Sci, 70*(6), 820-829. doi:10.1093/geronb/gbu070

Livingston, G., Johnston, K., Katona, C., Paton, J., & Lyketsos, C. G. (2005). Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *Am J Psychiatry, 162*(11), 1996-2021. doi:10.1176/appi.ajp.162.11.1996

Manly, J. J., Tang, M. X., Schupf, N., Stern, Y., Vonsattel, J. P., & Mayeux, R. (2008). Frequency and course of mild cognitive impairment in a multiethnic community. *Ann Neurol, 63*(4), 494-506. doi:10.1002/ana.21326

Mausbach, B. T., Aschbacher, K., Mills, P. J., Roepke, S. K., von Kanel, R., Patterson, T. L., . . . Grant, I. (2008). A 5-year longitudinal study of the relationships between stress, coping, and immune cell beta(2)-adrenergic receptor sensitivity. *Psychiatry Res, 160*(3), 247-255. doi:10.1016/j.psychres.2007.09.006

Mausbach, B. T., von Känel, R., Roepke, S. K., Moore, R., Patterson, T. L., Mills, P. J., . . . Allison, M. (2011). Self-efficacy buffers the relationship between dementia caregiving stress and circulating concentrations of the proinflammatory cytokine interleukin-6. *The American Journal of Geriatric Psychiatry, 19*(1), 64-71.

Mayo Clinic, T. (2014, November 22, 2014). Diseases and Conditions: Dementia Definition

McCallum, T. J., Sorocco, K. H., & Fritsch, T. (2006). Mental health and diurnal salivary cortisol patterns among African American and European American female dementia family caregivers. *Am J Geriatr Psychiatry, 14*(8), 684-693. doi:10.1097/01.jgp.0000225109.85406.89

Mehta, K. M., Yaffe, K., Perez-Stable, E. J., Stewart, A., Barnes, D., Kurland, B. F., & Miller, B. L. (2008). Race/ethnic differences in AD survival in US Alzheimer's Disease Centers. *Neurology, 70*(14), 1163-1170. doi:10.1212/01.wnl.0000285287.99923.3c

Miller, S. M., & Mangan, C. E. (1983). Interacting effects of information and coping style in adapting to gynecologic stress: should the doctor tell all? *Journal of personality and social psychology, 45*(1), 223.

Molloy, D. W., Bédard, M., Pedlar, D., & Lever, J. A. (1999). Institutionalization in cognitively-impaired older individuals: A longitudinal study. *Clinical gerontologist, 20*(2), 3-22.

Musa, D., Schulz, R., Harris, R., Silverman, M., & Thomas, S. B. (2009). Trust in the health care system and the use of preventive health services by older black and white adults. *AM J Public Health, 99*(7), 1293-1299. doi:10.2105/ajph.2007.123927

Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2001). The experiences and challenges of informal caregivers: common themes and differences among whites, blacks, and hispanics. *Gerontologist, 41*(6), 733-741.

Noelker, L. S. (1987). Incontinence in elderly cared for by family. *Gerontologist, 27*(2), 194-200.

Noelker, L. S., & Wallace, R. W. (1985). The organization of family care for impaired elderly. *Journal of Family Issues, 6*(1), 23-44.

Nogales-Gonzalez, C., Romero-Moreno, R., Losada, A., Marquez-Gonzalez, M., & Zarit, S. H. (2015). Moderating effect of self-efficacy on the relation between behavior problems in persons with dementia and the distress they cause in caregivers. *Aging Ment Health*, 1-9. doi:10.1080/13607863.2014.995593

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist, 30*(5), 583-594.

Piazza, J. R., Almeida, D. M., Dmitrieva, N. O., & Klein, L. C. (2010). Frontiers in the use of biomarkers of health in research on stress and aging. *J Gerontol B Psychol Sci Soc Sci, 65*(5), 513-525. doi:10.1093/geronb/gbq049

Pinquart, M., & Sorensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci, 58*(2), P112-128.

Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist, 45*(1), 90-106.

Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *J Gerontol B Psychol Sci Soc Sci, 61*(1), P33-45.

Poon, I., Lal, L. S., Ford, M. E., & Braun, U. K. (2009). Racial/ethnic disparities in medication use among veterans with hypertension and dementia: a national cohort study. *Ann Pharmacother, 43*(2), 185-193. doi:10.1345/aph.1L368

Pot, A., Deeg, D., Van Dyck, R., & Jonker, C. (1998). Psychological distress of caregivers: the mediator effect of caregiving appraisal. *Patient education and counseling, 34*(1), 43-51.

Pruchno, R. A., & Resch, N. L. (1989a). Aberrant behaviors and Alzheimer's disease: mental health effects on spouse caregivers. *J Gerontol, 44*(5), S177-182.

Pruchno, R. A., & Resch, N. L. (1989b). Mental health of caregiving spouses: coping as mediator, moderator, or main effect? *Psychol Aging, 4*(4), 454-463.

Radloff, L. S. (1977). The CES-D scale a self-report depression scale for research in the general population. *Applied psychological measurement, 1*(3), 385-401.

Reed, C., Belger, M., Dell'agnello, G., Wimo, A., Argimon, J. M., Bruno, G., . . . Vellas, B. (2014). Caregiver Burden in Alzheimer's Disease: Differential Associations in

Adult-Child and Spousal Caregivers in the GERAS Observational Study. *Dement Geriatr Cogn Dis Extra, 4*(1), 51-64. doi:10.1159/000358234

Reeve, B. B., Hays, R. D., Bjorner, J. B., Cook, K. F., Crane, P. K., Teresi, J. A., . . . Cella, D. (2007). Psychometric evaluation and calibration of health-related quality of life item banks: plans for the Patient-Reported Outcomes Measurement Information System (PROMIS). *Med Care, 45*(5 Suppl 1), S22-31. doi:10.1097/01.mlr.0000250483.85507.04

Roepke, S. K., Mausbach, B. T., Aschbacher, K., Ziegler, M. G., Dimsdale, J. E., Mills, P. J., . . . Grant, I. (2008). Personal mastery is associated with reduced sympathetic arousal in stressed Alzheimer caregivers. *Am J Geriatr Psychiatry, 16*(4), 310-317. doi:10.1097/JGP.0b013e3181662a80

Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: the role of race. *J Gerontol B Psychol Sci Soc Sci, 59*(4), P185-190.

Rohleder, N., Aringer, M., & Boentert, M. (2012). Role of interleukin-6 in stress, sleep, and fatigue. *Ann N Y Acad Sci, 1261*, 88-96. doi:10.1111/j.1749-6632.2012.06634.x

Romero-Moreno, R., Losada, A., Mausbach, B. T., Marquez-Gonzalez, M., Patterson, T. L., & Lopez, J. (2011). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging Ment Health, 15*(2), 221-231. doi:10.1080/13607863.2010.505231

Roth, D. L., Haley, W. E., Owen, J. E., Clay, O. J., & Goode, K. T. (2001). Latent growth models of the longitudinal effects of dementia caregiving: a comparison of African American and White family caregivers. *Psychol Aging, 16*(3), 427-436.

Rozario, P. A., & DeRienzis, D. (2008). Familism beliefs and psychological distress among African American women caregivers. *Gerontologist, 48*(6), 772-780.

Salovey, P., Stroud, L. R., Woolery, A., & Epel, E. S. (2002). Perceived emotional intelligence, stress reactivity, and symptom reports: Further explorations using the trait meta-mood scale. *Psychology and health, 17*(5), 611-627.

Sandu, R. E., Buga, A. M., Uzoni, A., Petcu, E. B., & Popa-Wagner, A. (2015). Neuroinflammation and comorbidities are frequently ignored factors in CNS pathology. *Neural Regen Res, 10*(9), 1349-1355. doi:10.4103/1673-5374.165208

Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use: lessons from focus groups with racially and ethnically diverse family caregivers. *J Gerontol Soc Work, 47*(1-2), 133-156. doi:10.1300/J083v47n01_09

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Jama, 282*(23), 2215-2219.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry, 12*(3), 240-249.

Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist, 35*(6), 771-791.

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Am J Nurs, 108*(9 Suppl), 23-27; quiz 27. doi:10.1097/01.NAJ.0000336406.45248.4c

Schwartz, M. D., Lerman, C., Miller, S. M., Daly, M., & Masny, A. (1995). Coping disposition, perceived risk, and psychological distress among women at increased risk for ovarian cancer. *Health Psychology, 14*(3), 232.

Selwood, A., Johnston, K., Katona, C., Lyketsos, C., & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *J Affect Disord, 101*(1-3), 75-89. doi:10.1016/j.jad.2006.10.025

Smith, S. M., & Vale, W. W. (2006). The role of the hypothalamic-pituitary-adrenal axis in neuroendocrine responses to stress. *Dialogues in clinical neuroscience, 8*(4), 383.

Speilberger, C. D., & Vagg, P. R. (1984). Psychometric properties of the STAI: a reply to Ramanaiah, Franzen, and Schill. *Journal of personality assessment, 48*(1), 95-97.

Spielberger, C., VanDercar, D., Greaner, J., Hibler, N., & Bloch, S. (1980). A description and analysis of the operation and validity of the psychological stress evaluator. *Journal of Forensic Science, 25*(1), 174-188.

Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R., & Verhey, F. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: a meta-analysis. *J Am Geriatr Soc, 56*(6), 1116-1128. doi:10.1111/j.1532-5415.2008.01705.x

Steadman, P. L., Tremont, G., & Davis, J. D. (2007). Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of geriatric psychiatry and neurology, 20*(2), 115-119.

Stowell, J. R., Kiecolt-Glaser, J. K., & Glaser, R. (2001). Perceived stress and cellular immunity: when coping counts. *J Behav Med, 24*(4), 323-339.

Sun, F., & Hodge, D. R. (2014). Latino Alzheimer's disease caregivers and depression: using the stress coping model to examine the effects of spirituality and religion. *J Appl Gerontol, 33*(3), 291-315. doi:10.1177/0733464812444462

Tang, M. X., Cross, P., Andrews, H., Jacobs, D. M., Small, S., Bell, K., . . . Mayeux, R. (2001). Incidence of AD in African-Americans, Caribbean Hispanics, and Caucasians in northern Manhattan. *Neurology, 56*(1), 49-56.

Teri, L., Logsdon, R. G., Uomoto, J., & McCurry, S. M. (1997). Behavioral treatment of depression in dementia patients: a controlled clinical trial. *J Gerontol B Psychol Sci Soc Sci, 52*(4), P159-166.

Tilg, H., & Moschen, A. R. (2008). Inflammatory mechanisms in the regulation of insulin resistance. *Molecular Medicine, 14*(3-4), 222-231.

Tremont, G., Davis, J. D., & Bishop, D. S. (2006). Unique contribution of family functioning in caregivers of patients with mild to moderate dementia. *Dement Geriatr Cogn Disord, 21*(3), 170-174.

Truman, B. I., Smith, K. C., Roy, K., Chen, Z., Moonesinghe, R., Zhu, J., . . . Zaza, S. (2011). Rationale for regular reporting on health disparities and inequalities - United States. *MMWR Suppl, 60*(1), 3-10.

Ulstein, I., Wyller, T. B., & Engedal, K. (2008). Correlates of intrusion and avoidance as stress response symptoms in family carers of patients suffering from dementia. *Int J Geriatr Psychiatry, 23*(10), 1051-1057.

van Zuuren, F. J., Grypdonck, M., Crevits, E., Walle, C. V., & Defloor, T. (2006). The effect of an information brochure on patients undergoing gastrointestinal endoscopy: a randomized controlled study. *Patient education and counseling, 64*(1), 173-182.

Vitaliano, P. P., Russo, J., Carr, J. E., Maiuro, R. D., & Becker, J. (1985). The ways of coping checklist: Revision and psychometric properties. *Multivariate behavioral research, 20*(1), 3-26.

von Kanel, R., Dimsdale, J. E., Mills, P. J., Ancoli-Israel, S., Patterson, T. L., Mausbach, B. T., & Grant, I. (2006). Effect of Alzheimer caregiving stress and age on frailty markers interleukin-6, C-reactive protein, and D-dimer. *J Gerontol A Biol Sci Med Sci, 61*(9), 963-969.

Weintraub, D., Raskin, A., Ruskin, P. E., Gruber-Baldini, A. L., Zimmerman, S. I., Hebel, J. R., . . . Magaziner, J. (2000). Racial differences in the prevalence of dementia among patients admitted to nursing homes. *Psychiatr Serv, 51*(10), 1259-1264.

Wilkins, C. H., Wilkins, K. L., Meisel, M., Depke, M., Williams, J., & Edwards, D. F. (2007). Dementia undiagnosed in poor older adults with functional impairment. *J Am Geriatr Soc, 55*(11), 1771-1776. doi:10.1111/j.1532-5415.2007.01417.x

Willenberg, H. S., Path, G., Vogeli, T. A., Scherbaum, W. A., & Bornstein, S. R. (2002). Role of interleukin-6 in stress response in normal and tumorous adrenal cells and during chronic inflammation. *Ann N Y Acad Sci, 966*, 304-314.

Williams, D. R. (1999). Race, socioeconomic status, and health. The added effects of racism and discrimination. *Ann N Y Acad Sci, 896*, 173-188.

Williams, I. C. (2005). Emotional health of black and white dementia caregivers: a contextual examination. *J Gerontol B Psychol Sci Soc Sci, 60*(6), P287-p295.

Wilson, R. S., Li, Y., Aggarwal, N. T., McCann, J. J., Gilley, D. W., Bienias, J. L., . . . Evans, D. A. (2006). Cognitive decline and survival in Alzheimer's disease. *Int J Geriatr Psychiatry, 21*(4), 356-362. doi:10.1002/gps.1472

Wimo, A., Jonsson, L., & Winblad, B. (2006). An estimate of the worldwide prevalence and direct costs of dementia in 2003. *Dement Geriatr Cogn Disord, 21*(3), 175-181. doi:10.1159/000090733

Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., & Covinsky, K. E. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *Jama, 287*(16), 2090-2097.

Zarit, S. H., & Femia, E. E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging Ment Health, 12*(1), 5-13. doi:10.1080/13607860701616317

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist, 20*(6), 649-655.

Zhu, C. W., Scarmeas, N., Torgan, R., Albert, M., Brandt, J., Blacker, D., . . . Stern, Y. (2006). Longitudinal study of effects of patient characteristics on direct costs in Alzheimer disease. *Neurology, 67*(6), 998-1005. doi:10.1212/01.wnl.0000230160.13272.1b

Zhu, C. W., Torgan, R., Scarmeas, N., Albert, M., Brandt, J., Blacker, D., . . . Stern, Y. (2008). Home health and informal care utilization and costs over time in Alzheimer's disease. *Home Health Care Serv Q, 27*(1), 1-20. doi:10.1300/J027v27n01_01

Zuckerman, I. H., Ryder, P. T., Simoni-Wastila, L., Shaffer, T., Sato, M., Zhao, L., & Stuart, B. (2008). Racial and ethnic disparities in the treatment of dementia among Medicare beneficiaries. *J Gerontol B Psychol Sci Soc Sci, 63*(5), S328-333.

Zuliani, G., Guerra, G., Ranzini, M., Rossi, L., Munari, M. R., Zurlo, A., . . . Fellin, R. (2007). High interleukin-6 plasma levels are associated with functional impairment in older patients with vascular dementia. *Int J Geriatr Psychiatry, 22*(4), 305-311. doi:10.1002/gps.1674

Appendices

Emory Institutional Review Board (IRB) Determination Letter

Activity Details (Log Comment To Study Team) Logs a comment to the study team on the submission

Author:	Tabitha Flint (*Institutional Review Board)
Logged For (IRB Study):	Distance Savvy
Activity Date:	5/12/2015 12:32 PM EDT

The comments added in this form will be visible to the Principal Investigator and other Study Staff on this project:

Comments:
Effective as of 5/11/15, Lindsey Blevins was added as study personnel, per request.

Upload documents:

Name	Description
There are no items to display	

COOL-AD
Caregiver Opportunities for Optimizing Lifestyles

Date:______ Time: Baseline/Follow up Subject ID: AD__ __ __

African American Family Dementia Caregivers Study
Family Questionnaire

Please complete the following questionnaire to give us a better understanding of your caregiving experience.

1. Your Age_____

2. Who is the person with Alzheimer's for whom you provide care? (circle all applicable choices)

Spouse	Mother	Father
Aunt	Uncle	Other Relative
Other (please specify):		

3. How old is this person? _________Years

4. Do you live in the same house as the person? ____Yes ___No

5. About how long has the person needed attention and care because of the Alzheimer's disease/dementia? __________ Years.

6. About how long have you been personally caring for your loved one?
________Years __________Months

7. If others in your family or community help with caring for this person, please indicate who they are (by relationship – for example, son, sister, church member) and rate how much help you can depend on from them (use additional sheet if necessary):

Person/ Group	**Amount of help they provide in the caregiving**				
	A great deal of help	Some help	A little help	Not much help	Almost no Help
	1	2	3	4	5
	1	2	3	4	5
	1	2	3	4	5

8. Thinking about your life as a caregiver, overall: How helpful do you feel your family and friends are to you in the responsibilities you bear?

Amount of help your family and friends provide in your overall caregiving experience				
A great deal of help	Some help	A little help	Not much help	Almost No Help
1	2	3	4	5

9. A. Are there others in your family or among your friends and neighbors for whom you also feel responsible to provide care or other kinds of support (e.g., financial, legal, emotional, logistical, etc)?

____Yes (Go to 9. B) ____No (Skip to question 11)

B. If Yes, please indicate their relationship to you (e.g., child, other relative, friend), whether they live with you (Y/N), rate how much of your time this provision of care and/or support occupies, and answer question 10:

Person/ Group	**Lives with you?**		**Amount of time you put into caring for or offering support**				
			A great deal of time	Some time	A little time	Not much time	Almost No time
	Y	N	1	2	3	4	5
	Y	N	1	2	3	4	5
	Y	N	1	2	3	4	5
	Y	N	1	2	3	4	5
	Y	N	1	2	3	4	5
	Y	N	1	2	3	4	5

10. If you are caring for or supporting others, please indicate the kind(s) of problems or conditions you are dealing with:

11. Thinking about your family and friends and about your caregiving and support responsibilities: How much strife and disagreement have family and friends added to the difficulties you may face in your overall caregiving experience:

Amount of strife and disagreement your family and friends have added to difficulties in your caregiving experience				
They have only been helpful	Hardly any problems	Occasional strife or problems	Some serious difficulties	A main source of difficulties
1	2	3	4	5

COOL-AD
Caregiver Opportunities for Optimizing Lifestyles

Date:_______ Time: Baseline/Follow up Subject ID: AD__ __ __

Zarit Burden Scale

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid of what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent upon you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4

11. Do you feel that you don’t have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don’t have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative’s illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4

21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
	Not at All	A Little	Moderately	Quite A Bit	Extremely
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Date:______ Time: Baseline/Follow up Subject ID: AD___ ___ ___

Ways of Coping Questionnaire

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation that you have experienced in the *past week.*

By “stressful” we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something else important to you. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. **Read each statement carefully and indicate by circling 0, 1, 2, or 3, to what extent you used it in the situation.**

	Does not apply or not used	Used Somewhat	Used Quite a Bit	Used a great deal
1. I just concentrated on what I had to do next – the next step	0	1	2	3
2. I tried to analyze the problem in order to understand it better	0	1	2	3
3. I turned to work or another activity to take my mind off things	0	1	2	3
4. I felt that time would have made a difference – the only thing was to wait	0	1	2	3
5. I bargained or compromised to get something positive from the situation	0	1	2	3
6. I did something that I didn’t think would work, but at least I was doing something	0	1	2	3
7. I tried to get the person responsible to change his or her mind	0	1	2	3

8. I talked to someone to find out more about the situation	0	1	2	3
9. I criticized or lectured myself	0	1	2	3
10. I tried not to burn my bridges, but leave things open somewhat	0	1	2	3
11. I hoped for a miracle	0	1	2	3
12. I went along with fate; sometimes I just have bad luck	0	1	2	3
13. I went on as if nothing had happened	0	1	2	3
14. I tried to keep my feelings to myself	0	1	2	3
15. I looked for the silver lining, so to speak; I tried to look on the bright side of things	0	1	2	3
16. I slept more than usual	0	1	2	3
17. I expressed anger to the person (s) who caused the problem	0	1	2	3
18. I accepted sympathy and understanding from someone	0	1	2	3
19. I told myself things that helped me feel better	0	1	2	3
20. I was inspired to do something creative about the problem	0	1	2	3
21. I tried to forget the whole thing	0	1	2	3
22. I got professional help	0	1	2	3
23. I changed or grew as a person	0	1	2	3
24. I waited to see what would happen before doing anything	0	1	2	3
25. I apologized or did something to make up	0	1	2	3
26. I made a plan of action and followed it	0	1	2	3

27. I accepted the next best thing to what I wanted	0	1	2	3
28. I let my feelings out somewhat	0	1	2	3

29. I realize that I had brought the problem on myself	0	1	2	3
30. I came out of the experience better than when I went in	0	1	2	3
31. I talked to someone who could do something concrete about the problem	0	1	2	3
32. I tried to get away from it for a while by resting or taking a vacation	0	1	2	3
33. I tried to make myself feel better by eating, drinking, smoking, using drugs, or medications, etc	0	1	2	3
34. I took a big chance or did something very risky to solve the problem	0	1	2	3
35. I tried not to act too hastily or follow my first hunch	0	1	2	3
36. I found new faith	0	1	2	3
37. I maintained my pride and kept a stiff upper lip	0	1	2	3
38. I rediscovered what is important in life	0	1	2	3
39. I changed something so things would turn out all right	0	1	2	3
40. I generally avoided being with people	0	1	2	3
41. I didn't let it get to me; I refused to think too much about it	0	1	2	3
42. I asked advice from a relative or friend I respected	0	1	2	3
43. I kept others from knowing how bad things were	0	1	2	3

44. I made light of the situation; I refused to get too serious about it	0	1	2	3
45. I talked to someone about how I was feeling	0	1	2	3
46. I stood my ground and fought for what I wanted	0	1	2	3
47. I took it out on other people	0	1	2	3
48. I drew on my past experiences; I was in a similar situation before	0	1	2	3
49. I knew what had to be done, so I doubled my efforts	0	1	2	3
50. I refused to believe that it had happened	0	1	2	3
51. I promised myself that things would be different next time	0	1	2	3
52. I came up with a couple of different solutions to the problem	0	1	2	3
53. I accepted the situation, since nothing could be done	0	1	2	3
54. I tried to keep my feeling about the problem from interfering with other things	0	1	2	3
55. I wished that I could change what had happened or how I felt	0	1	2	3
56. I changed something about myself	0	1	2	3
57. I daydreamed or imagined a better time or place than the one I was in	0	1	2	3
58. I wished that the situation would go away or somehow be over with	0	1	2	3
59. I had fantasies or wishes about how things might turn out	0	1	2	3
60. I prayed	0	1	2	3
61. I prepared myself for the worst	0	1	2	3

62. I went over in my mind what I would say or do	0	1	2	3
63. I thought about how a person I admire would handle this situation and used that as a model	0	1	2	3
64. I tried to see things from the other person's point of view	0	1	2	3
65. I reminded myself how much worse things could be	0	1	2	3
66. I jogged or exercised	0	1	2	3

COOL-AD
Caregiver Opportunities for Optimizing Lifestyles

Date:_______ Time: Baseline/Follow up Subject ID: AD___
___ ___

Self Evaluation Questionnaire (STAI Form Y-1)

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel *right* now, that is, at *this* moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately so	Very much so
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I am tense	1	2	3	4
4. I feel strained	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel satisfied	1	2	3	4
9. I feel frightened	1	2	3	4
10. I feel comfortable	1	2	3	4
11. I feel self-confident	1	2	3	4
12. I feel nervous	1	2	3	4
13. I am jittery	1	2	3	4
14. I feel indecisive	1	2	3	4
15. I am relaxed	1	2	3	4
16. I feel content	1	2	3	4
17. I am worried	1	2	3	4
18. I feel confused	1	2	3	4

19. I feel steady	1	2	3	4
20. I feel pleasant	1	2	3	4

Date:______ Time: Baseline/Follow up Subject ID: AD___ ___ ___

Perceived Stress Scales

Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by checking how often you felt or thought a certain way. Please check the most appropriate box for each question.

	Never	**Almost Never**	**Some-times**	**Fairly Often**	**Very Often**
1. Been upset because of something that happened unexpectedly?	**0**	**1**	**2**	**3**	**4**
2. Felt that you were unable to control the important things in your life?	**0**	**1**	**2**	**3**	**4**
3. Felt nervous and stressed?	**0**	**1**	**2**	**3**	**4**
4. Dealt successfully with irritating life hassles?	**0**	**1**	**2**	**3**	**4**
5. Felt that you were effectively coping with important changes that were occurring in your life?	**0**	**1**	**2**	**3**	**4**
6. Felt confident about your ability to handle your personal problems?	**0**	**1**	**2**	**3**	**4**
7. Felt that things were going your way?	**0**	**1**	**2**	**3**	**4**
8. Found that you could not cope with all the things you had to do?	**0**	**1**	**2**	**3**	**4**
9. Been able to control irritations in your life?	**0**	**1**	**2**	**3**	**4**
10. Felt that you were on top of things?	**0**	**1**	**2**	**3**	**4**
11. Been angered because of things that happened that were outside of your control?	**0**	**1**	**2**	**3**	**4**
12. Found yourself thinking about things that you had to accomplish?	**0**	**1**	**2**	**3**	**4**

13. Been able to control the way you spend your time?	**0**	**1**	**2**	**3**	**4**
14. Felt difficulties were piling up so high that you could not overcome them?	**0**	**1**	**2**	**3**	**4**

COOL-AD
Caregiver Opportunities for Optimizing Lifestyles

Date:_______ Time: Baseline/Follow up Subject ID: AD___ ___ ___

Caregiver Stress Scales

1. Caregiving Competence

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

	Very much	Somewhat	Just a little	Not at all
A. Believe that you've learned how to deal with a very difficult situation	4	3	2	1
B. Feel that all in all, you're a good caregiver	4	3	2	1

B. Think now of all the things we've been talking about: the daily ups and downs that you face as a caregiver; the job you are doing; and the ways you deal with the difficulties. Putting all these things together, how (WORD) do you feel?

	Very	Fairly	Just a little	Not at all
C. Competent	4	3	2	1
D. Self-confident	4	3	2	1

COOL-AD
Caregiver Opportunities for Optimizing Lifestyles

Date:______ Time: Baseline/Follow up Subject ID: AD__ __ __

Family Assessment Device

Think about each statement and how your family has been functioning during the PAST TWO MONTHS. Pick how strongly you agree or disagree.

	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
1. Planning family activities is difficult because we misunderstand each other.				
2. We resolve most everyday problems around the house.				
3. When someone is upset the others know why.				
4. In times of crisis we can turn to each other for support.				
5. We cannot talk to each other about the sadness we feel.				
6. We usually act on our decisions regarding problems.				
7. You can't tell how a person is feeling from what they are saying.				
8. Individuals are accepted for what they are.				
9. People come right out and say things instead of hinting at them.				
10. We avoid discussing our fears and our concerns.				
11. It is difficult to talk to each other about tender feelings.				

12. After our family tries to solve a problem, we usually discuss whether it worked or not.				
13. We can express feelings to each other.				
14. We talk to people directly rather than through go-betweens.				

15. There are lots of bad feelings in my family.				
16. We often don't say what we mean.				
17. We feel accepted for what we are.				
18. We resolve most emotional upsets that come up.				
19. Making decisions is a problem for our family.				
20. We are frank with each other.				
21. We are able to make decisions about how to solve problems.				
22. We confront problems involving feelings.				
23. We don't get along well enough together.				
24. We don't talk to each other when we are angry.				
25. We confide in each other.				
26. When we don't like what someone has done, we tell them.				
27. We try to think of different ways to solve problems.				

COOL-AD
Caregiver Opportunities for Optimizing Lifestyles

Date:_______ Time: Baseline/Follow up Subject ID: AD___ ___ ___

CES-D

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way **<u>during the past week</u>**. Place an “X” in the box to indicate your answer.

During the <u>past week</u> . . .	**Rarely or none of the time** (less than 1 day)	**Some or a little of the time** (1-2 days)	**Occasionally or a moderate amount of time** (3-4 days)	**Most or all of the time** (5-7-days)
1. I was bothered by things that usually don’t bother me.				
2. I did not feel like eating; my appetite was poor.				
3. I felt that I could not shake off the blues even with help from my family or friends.				
4. I felt I was just as good as other people.				
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort.				
8. I felt hopeful about the future.				
9. I thought my life had been a failure.				
10. I felt fearful.				
11. My sleep was restless.				

12. I was happy.				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly.				
16. I enjoyed life.				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people dislike me.				
20. I could not get “going”.				

COOL-AD
Caregiver Opportunities for Optimizing Lifestyles

Date:_______ Time: Baseline/Follow up Subject ID: AD___ ___ ___

Alzheimer ’s disease Knowledge Test

We have some questions about Alzheimer’s disease. Select <u>one</u> response for each question. Don't worry if you are not sure of the answers; just do the best you can.

1. The percentage of people over 65 who have dementia caused by Alzheimer’s disease or a related disorder is estimated to be:
a. less than 2 %
b. about 5%
c. about 10%
d. 20-25%
f. I don’t know

2. The prevalence of Alzheimer’s disease in the general population of the United States is expected to:
a. decrease slightly
b. remain approximately the same.
c. increase in proportion to the number of people over 65.
d. nearly triple by the year 2000.
f. I don’t know.

3. The cause of Alzheimer’s disease is:
a. old age
b. hardening of the arteries
c. senility
d. unknown
f. I don’t know

4. Preliminary research concerning the role of heredity in Alzheimer’s disease suggest that:
a. a person with a close relative with Alzheimer’s disease have an increased risk of becoming afflicted.
b. Alzheimer’s disease is always transmitted genetically.
c. Alzheimer’s disease is only inherited if both parents are carriers of the disease.
d. Alzheimer’s disease is never inherited.
f. I don’t know.

5. Larger than normal amounts of aluminum have been found in the brains of some people with Alzheimer's disease. Studies investigating the role of aluminum in causing Alzheimer's disease:
a. have determined that it is the major cause
b. have established that it plays a role in the onset of the diabetes
c. are in conclusive
d. have proven that it is not a cause
f. I don't know

6. A person suspected of having Alzheimer's disease should be evaluated as soon as possible because:
a. prompt treatment of Alzheimer's disease may prevent worsening of symptoms
b. prompt treatment of Alzheimer's disease may reverse symptoms.
c. it is important to rule out and treat reversible disorders.
d. it is best to institutionalize an Alzheimer's disease patient in the early course of the disease.
f. I don't know.

7. Which of the following procedures is required to confirm that symptoms are due to Alzheimer's disease?
a. mental status testing
b. Autopsy
c. CT scan
d. blood test
f. I don't know

8. Which of the following conditions sometimes resembles Alzheimer's disease?
a. depression
b. delirium
c. stroke
d. all of the above
f. I don't know.

9. Which of the following is always present in Alzheimer's disease?
a. loss of memory
b. loss of memory, incontinence
c. loss of memory, incontinence, hallucinations
d. none of these
e. I don't know

10. Although the rate of progression of Alzheimer’s disease is variable, the average life expectancy after onset is:
a. 6 months to a year
b. 1-5 years
c. 6-12 years
d. 15-20 years
e. I don’t know

11. Most researchers investigating the use of lecithin as a treatment for Alzheimer’s disease have concluded that it:
a. reverses symptoms
b. prevents further decline
c. reverses symptoms that prevent further decline
d. has no effect on the disease
e. I don’t know

12. Which of the following statements describes a reaction an Alzheimer’s disease patients may have to their illness?
a. They are unaware of their symptoms
b. They are depressed
c. They deny their symptoms
d. All of the above
e. I don’t know

13. Sometimes Alzheimer’s disease patients wander away from home. Caregivers can best manage this problem by:
a. reasoning with the patient about the potential dangers of wandering
b. sharing feelings of concern with the patient in a calm and reassuring manner.
c. making use of practical solutions such as locked doors.
d. remaining with the patient at all times
e. I don’t know

14. Which statement is true concerning treatment of Alzheimer’s disease patients who are depressed?
a. It is usually useless to treat them for depression because feelings of sadness and inadequacy are a part of the disease process.
b. treatments of depression may be effective in alleviating depressive symptoms.
c. Poor nutrition can make symptoms of Alzheimer’s disease worse.
d. Proper medication may alleviate symptoms of depression and prevent further intellectual decline.
e. I don’t know

15. What is the role of nutrition in Alzheimer’s disease?
a. Proper nutrition can prevent Alzheimer’s disease
b. Proper nutrition can reverse the symptoms of Alzheimer’s disease
c. Poor nutrition can make the symptoms of Alzheimer’s disease worse
d. Nutrition plays no role in Alzheimer’s disease.

16. What is the effect of orienting information (i.e., reminders of the date and the place) on Alzheimer’s disease patients?
a. It produces permanent gains on memory.
b. It will slow down the course of the disease.
c. In increases confusion in approximately 50% of patients.
d. It has no lasting effects on the memory of patients
e. I don’t know

17. People sometimes writes notes to themselves as reminders. How effective is this technique for Alzheimer’s disease patients?
a. It can never be used because reading and comprehension are too severely impaired.
b. It may be useful for the widely demented patients.
c. It is a crutch which may contribute to further decline.
d. It may produce permanent gains in memory.
e. I don’t know

18. When an Alzheimer’s disease patient begins to have difficulty performing self care activities, many mental health professionals recommend that the caregiver:
a. allow the patient to perform the activities regardless of the outcome
b. assist with the activities so the patient can remain as independent as possible
c. take over the activities right away to prevent accidents
d. make plans to have the patient moved to a nursing home
e. I don’t know

COOL-AD
Caregiver Opportunities for Optimizing Lifestyles

Date:______ Time: Baseline/Follow up Subject ID: AD__ __ __

Lawton ADL/IADL scale

We have some questions about the person you care for ability to handle day to day activities of daily living. Select <u>one</u> response for each item. Please answer all questions.

<u>Physical Self-Management Scale:</u>

1. Toilet:
a. Cares for self at toilet completely, no inconvenience.
b. Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most) accidents
c. Soiling or wetting while sleep more than once a week
d. Soiling or wetting while awake more than once a week
f. No controls of bowls or bladder

2. Feeding:
a. Eats without assistance
b. Eats with minor assistance at meal times and/or with special preparation of food, or help in cleaning up after meals.
c. Feeds self with moderate assistance and is untidy
d. Requires extensive assistance for all meals.
f. Does not feed self at all and resists efforts of others to feed them.

3. Dressing:
a. Dresses, undresses, and selects clothes from own wardrobe
b. Dresses and undresses self with minor assistance
c. Needs moderate assistance in dressing or selection of clothes
d. Needs major assistance in dressing, but cooperates with efforts of others to help
f. Completely unable to dress self and resists efforts of others to help

4. Grooming (neatness, hair, nails, hands, face, and clothing):
a. Always neatly dressed, well-groomed, without assistance.
b. Grooms self adequately with occasional minor assistance, e.g., shaving.
c. Needs moderate and regular assistance or supervision in grooming.
d. Needs total grooming care, but can remain well-groomed after help from others.
f. Actively negates all efforts of others to maintain grooming.

5. Physical Ambulation:
a. Goes about grounds or city
b. Ambulates within residence or about one block distance.
c. Ambulates with assistance of (circle one)
  i. Another person
  ii. Raining
  iii. Cane
  iv. Walker
  v. Wheel Chair
d. Sits unsupported in a chair or a wheel chair, but cannot propel self without help.
f. Bedridden more than half the time.

6. Bathing:
a. Bathes self (tub, shower, sponge bath) without help.
b. Bathes self with help in getting in and out of tub.
c. Washes face and hands only, but cannot bathe rest if body.
d. Does not wash self but is cooperative with those who bathe him/her.
f. Does not try to wash self and resist efforts to keep him/her clean.

7. Which of the following procedures is required to confirm that symptoms are due to Alzheimer’s disease?
a. mental status testing
b. Autopsy
c. CT scan
d. blood test
f. I don’t know

<u>Physical Self-Management Scale:</u>

8. Ability to use telephone:
a. Operates telephone on own initiative-looks up and dials numbers, etc.
b. Dials a few well known numbers.
c. Answers telephone but does not dial
d. Does not use telephone

9. Shopping:
a. Takes care of all shopping needs independently.
b. Shops independently for small purchases.
c. Needs to be accompanied on any shopping trip
d. Completely unable to shop

10. Food preparation
a. Plan, prepares, and serves adequate meals independently.
b. Prepares adequate meals if supplied with ingredients.
c. Heats and serves prepared meals, or prepares meals but does not maintain adequate diet.
d. Needs to have meals prepared and served.

11. Housekeeping:
a. Maintains house alone or with occasional assistance (e.g. "heavy work-domestic help").
b. Performs light daily task such as dishwashing and bed making.
c. Performs light daily task but cannot maintain acceptable levels of cleanliness.
d. Needs help with all home maintenance tasks.
e. Does not participate in any housekeeping tasks.

12. Laundry:
a. Does personal laundry completely.
b. Launder small items-rinse socks, stockings, etc.
c. All laundry must be done by others.

13. Mode of transportation:
a. Travels independently of public transportation or drives own car.
b. Arranges own travel via taxi, but does not otherwise use public transportation.
c. Travels on public transportation when assisted or accompanied by another.
d. Travel limited to taxi or automobile with assistance of another.
e. Does not travel at all

14. Responsibility for own medications
a. Is responsible for taking medication in correct dosage at correct time.
b. Takes responsibility if medications are prepared in advance in separate dosages.
c. Is not capable of dispensing own medication.

15. Ability to handle finances:
a. Manages financial matters independently, (budget, writes checks, pays rent, bills, goes to bank), collects and keeps track of income
b. Manage day to day purchases, but needs help with banking, major purchases, etc.
c. Incapable of handling money.

Lindsey Nicole Blevins

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QUALIFICATION SUMMARY

- **Master Public Health:** Emory University, Rollins School of Public Health, May 2016
- **Experience:** Over 2 years of applied public health experience collaborating with multiple community organizations in Atlanta, California, and Virginia on various projects including survey design, training, and evaluation
- **Financial Planning:** Developed and managed $1,000,000+ budget for organization research grant
- **Leadership:** Currently serving as Vice President of Communications for Emory Healthcare Improvement Chapter
- **Project Management:** Possess strong project and program management skills through multiple internships
- **Communication:** Experience working with diverse cultures; Excellent oral and written communication skills cultivated by experience working with diverse populations
- **SAS:** One year of experience working with SAS through class projects
- **SPSS:** One and a half years' experience working with SPSS through class projects and thesis
- **Evaluation/Analytic Skills:** Conducted an extensive evaluation for two organizations in Atlanta and presented the results and recommendations formally in written and oral formats to the stakeholders
- **Data/Research/Analysis:** Experience designing qualitative and quantitative research protocols and data collection instruments; collecting data in person and over the phone; evaluating data; and presenting findings to stakeholders via written and oral formats
- **Client Presentations:** Experience presenting data and evaluation findings to stakeholders via written and oral formats
- **Technical/Computer:** Excel, PowerPoint, MaxQDA, FluidSurveys, SurveyMonkey, MailChimp, RedCap, Piktochart, Prezi

PROFESSIONAL EXPERIENCE

Emory University Alzheimer's Disease Research Center **Atlanta, GA**
Evaluation Intern **January 2016- May 2016**

- Conduct on-site evaluation of caregiver needs to inform future outreach initiatives and improve existing services currently at the ADRC
- Utilize quantitative, qualitative, and analytical skill sets to develop, disseminate, collect, and analyze data
- Create and present recommendations in written and oral formats to stakeholders

Emory University Alzheimer's Disease Research Center **Atlanta, GA**
Project Coordinator of Outreach **August 2014- May 2016**

- Analyze pre and post surveillance data of 500+ respondents to assess health-related knowledge, attitudes and behaviors; Present reports to funding partners and lead neurologists at ADRC
- Coordinate and prioritize existing projects; Develop agendas and timelines; Organize and coordinate team meetings
- Manage event logistics for The Spirit Lives On Program
- Design, implement, and evaluate culturally-appropriate health promotion interventions to improve healthy behaviors for community brain health and movement disorder forums of which 400+ attendees participated

- Organize 2 community memory screenings for 100+ participants, recruit and train 8 medical students to perform memory screenings (MiniCog and MoCA) per event, evaluate data collected (demographics and test performance)
- Assist in publicity and marketing and apply for continuing education credit certification for community events

Cognitive Disorders Specialty Center of Excellence- Atlanta VAMC **Atlanta, GA**
Evaluation Intern **August 2015- December 2015**

- Conducted an on-site evaluation to explore the needs of caregivers of veterans with Mild Cognitive Impairment (MCI) and Dementia using qualitative and quantitative skill sets to develop, collect, and analyze the data
- Presented results in oral and written formats to stakeholders

The Solace Foundation **Orange County, CA**
Grant Writer **August 2015- December 2015**

- Developed a grant to request funding for educational trainings regarding opioid abuse and overdose, particularly using Naloxone as an agent to prevent adverse outcomes associated with overdose

Tele-Savvy, a Distance Dementia Family Caregiver Education Program **Atlanta, GA**
Research Assistant **August 2014- August 2015**

- Developed checklists to ensure integrity and fidelity during the participant enrollment process for 40 participants
- Obtained IRB consent, interviewed, and gathered baseline and post-program data using validated instruments and formative evaluations; Assisted research team in writing reports for formal publications and presentations

Portal de Salud **Lilburn, GA**
Curriculum Developer **January 2015- May 2015**

- Developed a health curriculum designed to provide 29,000 Hispanic/Latino individuals with an understanding of how to practice preventive health behaviors and manage chronic health conditions
- Created an evaluation plan to assess knowledge gained for each lesson within the curriculum

Marion Middle School **Marion, VA**
6th Grade Science Teacher **February 2014- June 2014**

- Taught 100 students the standards of learning requirements for force, motion and energy; living systems; interrelationships in Earth/Space systems; and resources; Created an evaluation plan for each academic unit to assess knowledge at both pre and post lessons

Psychology/Neuroscience Lab **Williamsburg, VA**
Lab Manager **January 2012-December 2013**

- Developed schedules for 20 lab members; Trained new members; Created extensive learning assignments for lab members and oversaw lab integrity for all experiments and injections
- Studied animal learning and cognition, neural basis of learning and memory; Analyzed how nicotine affects anxiety in adolescents through using light enhanced startle paradigm with rats

LEADERSHIP AND SERVICE

Institute for Healthcare Improvement Emory Open School Chapter **Atlanta, GA**
Vice President of Communications **May 2015- May 2016**

- Coordinate operations team (VP of Communications, Secretary, and Treasurer); Assist president in efforts to encourage and expand chapter membership; Improve healthcare quality and patient safety through leadership
- Manage incoming chapter e-mails; Update chapter website and Facebook page; Publicize chapter events via e-mail; Compose monthly newsletter; Maintain a list of chapter alumni and maintains quarterly communication with them

Outreach360 **Jinotega, Nicaragua**
Team Leader **August 2010-January 2014**

- Organized and planned the trip to Nicaragua for 15 individuals; Interviewed and evaluated applications for new team members; Planned weekly meetings to discuss cultural norms, social injustices, organization's mission, and logistics of the trip; Engaged members in reorientation upon return
- Supervised and assisted fundraising chair and treasurer; Taught English literacy to underprivileged children

Virginia Alcoholic Beverage Control **Richmond, VA**
Program Coordinator **July 2009- July 2013**

- Developed Youth Alcohol and Drug Abuse Prevention Conference for the year of 2012 for 400+ staff and participants
- Trained staff regarding leadership, group development, experiential learning activities, and classroom management

EDUCATION

Rollins School of Public Health **Atlanta, GA**
Master of Public Health, Behavioral Science and Health Education **May 2016**

The College of William & Mary **Williamsburg, VA**
Bachelor of Science, Neuroscience **January 2014**

PROFESSIONAL MEMBERSHIP

Member of Georgia Society for Public Health Education