

# Walden University

College of Health Sciences and Public Policy

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has been found to be complete and satisfactory in all respects,  
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Walden University  
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Abstract

The Association of Depression, Respite Care, Socialization, and Self-Rated Health for  
African American Family Caregivers

by

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MPH, Loma Linda University, 1990

BS, Columbia Union College, 1988

Doctoral Study Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Public Health

Walden University

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## Abstract

Alzheimer's disease is a brain disorder caused by nerve damage that slowly destroys memory and thinking skills, as well as the ability to carry out the simplest tasks. The burden of care often lies with family caregivers who are essential to healthcare providing care and support to over 6.5 million individuals suffering from Alzheimer's dementia and related dementias, allowing them to thrive in familiar surroundings. For the family caregiver, the strain experienced can lead to stress and decreased quality of life, leading to a negative impact on health and well-being. The purpose of this study, using data from the 2017 National Health and Aging Trends Study/National Study of Caregiving (NHATS/NSOC) was to examine the association between the variables. The chi-square test was used to examine the associations between depression levels, age, gender, race, ethnicity, and the self-rated health of African American caregivers; between receiving respite help from family members to care for the subject person and self-rated health of the caregiver; and between participating in social activities with other people and the self-rated health of the caregiver. There were significant associations between depression levels, being female, being over 50 years old, participating in social activities, and the self-reported health of African American caregivers. African American caregivers are often overlooked in research, so this study was intended to generate provider and community support for caregivers and create solutions and resources to help to relieve their burden and health challenges.

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## Dedication

To my Mum, Agnes Francis, for believing in me, and never allowing me to give up or fail. I wish that you could have seen my educational journey to its fruition.

To Adriann Fraser-Johnson, for being open and honest and sharing your personal experiences as a family caregiver with me. You are the impetus for this research journey.

Thank you, both. With much love.

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## Section 1: Foundation of the Study and Literature Review

### **Introduction**

Alzheimer's disease is a brain disorder caused by nerve damage that slowly destroys memory and thinking skills, and eventually, the ability to carry out the simplest tasks (National Institute on Aging, 2021). When Alzheimer's changes first occur, the brain initially compensates, enabling the individual to function normally. As time passes and nerve damage increases, cognitive function and other areas are affected leading to cognitive decline, memory loss, confusion, behavioral symptoms, personality changes, and eventually basic bodily functions (Alzheimer's Association, 2022). Alzheimer's disease is the most common type of dementia. Approximately 6.5 million people in the United States have Alzheimer's disease and related dementias (ADRD). The disease is ranked the sixth leading cause of death in the United States, and the third leading cause of death among older adults (Alzheimer's Association, 2022). Because the cognitive decline is progressive, patients with Alzheimer's become dependent on caregivers for daily help and survival.

Older non-Hispanic African Americans and Hispanic Americans are disproportionately more likely than older Whites to have ADRD (Alzheimer's Association, 2022). For the family caregiver responsible to care for the patient with ADRD, the burden of being a carer means a long-term commitment with the knowledge that the person with Alzheimer's dementia will evolve into a different person and become debilitated leading to loss of judgment, orientation, and the ability to understand or communicate effectively (National Institute on Aging, 2021). The burden experienced by

the caregiver can lead to stress and decreased quality of life, leading to a negative impact on health and well-being (Anderson et al., 2019). Caregivers experience physical, emotional, financial, and social burdens from taking care of their family members with ADRD. African American caregivers, however, are disproportionately affected by dementia (Epps et al., 2021; Samson et al., 2016). They have a higher rate of unmet health needs such as depression, tend to be isolated, and utilize less social support, community resources, and services (Abramsohn et al., 2019).

In this study, I examined the association of depression, gender, age, respite care, socialization, and the self-rated health of African American family caregivers as they care for individuals with Alzheimer's. The focus was on African American caregivers as culturally appropriate studies are often overlooked, in order to create solutions for potential positive social change. The intent was to generate more support from policymakers and the community for caregivers and help create policies in the future to relieve their health problems.

This section covers the problem statement, purpose of the study, research questions, theoretical framework for the study, nature of the study, literature search strategy, and literature review.

### **Problem Statement**

Alzheimer's disease is a progressive brain disorder that slowly destroys memory and thinking skills and is the most common type of dementia. Current estimates indicate that 6.5 million people in the United States have ADRD. The percentage of people with Alzheimer's dementia increases with age so, of the 6.5 million people with ADRD, 81

percent are aged 75 and older. However, Alzheimer's dementia is often underdiagnosed, so it is likely that a large portion of Americans with Alzheimer's may not know that they have it. The disease is ranked as the sixth leading cause of death in the United States, and the third leading cause of death among older adults (Alzheimer's Association, 2022; National Institutes of Health, n.d.).

For the family caregiver responsible for caring for the patient with ADRD, the strain experienced can lead to stress and decreased quality of life, leading to a negative impact on health and well-being (Anderson et al., 2019). Caregivers experience physical, emotional, financial, and social burdens from taking care of their family members with ADRD and are also likely to be working at least a part-time job (Jenkins, 2023). These burdens can impact the quality of care and health of a person with dementia. However, African American caregivers are disproportionately affected by dementia (Epps et al., 2021; Samson et al., 2016), have a higher rate of unmet health needs such as depression, tend to be isolated, and utilize less social support, community resources, and services (Abramsohn et al., 2019). Studies of caregivers often lack sufficient numbers of diverse participants to confirm these findings or delve deeper into them for important insights (Alzheimer's Association, 2022), so little is known from the research about how much African American caregivers utilize specialty help, services, or social interactions to enhance their health and well-being (Alzheimer's Association, 2022).

There is, therefore, a need to study how African American caregivers perceive their health, including their depression levels, respite care that they receive from other family members, their ability to maintain a social life, and the impact on the care

recipient. Brewster et al. (2020) and Cothran et al. (2020) indicated that the toll on the caregiver coupled with the health disparities of African Americans places the caregivers at higher risk for morbidity and mortality and that community services may enhance their health and ultimately the health of the care recipient.

### **Purpose of the Study**

The purpose of this secondary data study was to examine the association between levels of depression, available respite care, socialization, and self-rated health among African American family caregivers. Caregivers are affected by the burdens of caring for their care recipient with dementia as their ability to function decreases and the caregiver obtains more responsibility. From a public health perspective, this can promote the need for and awareness of culturally appropriate interventions to improve the health and quality of life of African American caregivers (Kally et al., 2014). The focus of this study was to investigate how factors such as the level of depression, availability of respite care, and social interactions affect the perception of health among African American caregivers. I investigated the problem by considering questions that compare the association between these factors.

### **Research Questions**

The following research questions were adopted for this study:

RQ1: Is there an association between depression levels, and the self-rated health of African American caregivers while controlling for age and gender?

$H_01$  – There is no association between depression levels and the self-rated health of African American caregivers while controlling for age and gender.

$H_{A1}$  – There is an association between depression levels and the self-rated health of African American caregivers while controlling for age and gender.

RQ2: Is there an association between receiving respite help from family members to care for the care recipient and the self-rated health of the caregiver?

$H_{02}$  – There is no association between receiving respite help from family members to care for the care recipient and the self-rated health of the caregiver.

$H_{A2}$  – There is an association between receiving respite help from family members to care for the care recipient and the self-rated health of the caregiver.

RQ3: Is there an association between participating in social activities with people other than the care recipient, and the self-rated health of the caregiver?

$H_{03}$  – There is no association between participating in social activities with people other than the care recipient, and the self-rated health of the caregiver.

$H_{A3}$  – There is an association between participating in social activities with people other than the care recipient and the self-rated health of the caregiver.

### **Theoretical Framework of the Study**

The ecological systems theory explains the development of a child as a complex system of relationships involving the interaction of multiple levels of the environment. (Guy-Evans, 2020; Hayes et al., 2017). Bronfenbrenner (1977) proposed that the child's development was influenced by five levels of the system contained within the other: (a) microsystem – the immediate family, religious organizations, and health services; (b) mesosystem – the interaction between the parties of the microsystem; (c) exosystem – formal and informal social structures such as neighbors, extended family, and mass

media; (d) macrosystem – ethnicity, geography, and ideologies; and (e) chronosystem – historical events, environmental changes, and life transitions. Using Bronfenbrenner’s model as the foundation and the original World Health Organization (WHO, 2022) definition of health as physical, mental, and social well-being, the Centers for Disease Control and Prevention (CDC, 2022) created a four-part model for health promotion programs to use to engage with communities called the social-ecological model. The levels are individual, relationship, community, and societal. At the individual level, the age of the caregiver, their socioeconomic status, and health status may be factors that influence their health. Family dynamics and competing work demands may be factors at the relationship level. At the community level, changes in the healthcare workforce and lack of access to services may influence a caregiver’s decisions, and at the societal level, insufficient policies or no policies can factor into the caregiver’s decisions related to their health (Ali et al., 2021). For African American family caregivers, both Bronfenbrenner and the CDC’s model identify factors that can influence them and contribute to their perception of good or poor health. These factors, however, ultimately affect not only the caregiver’s personal attitudes, philosophies, and health, but also the health of the care recipient, extended family members, social circles, and the community.

### **Conceptual Framework of the Study**

Family caregiving of dementia patients has become a common concept as dementia rates have increased, and research indicates the need for caregivers to be as prepared as possible (American Association of Retired Persons [AARP], 2022). However, utilizing culturally appropriate interventions for ethnically diverse caregivers is

not as common, and this study builds from this premise to consider how African American caregivers can benefit from enhancing their reported health. Solutions are varied, but those that are culturally appropriate allow the caregiver to practice self-care and utilize external influencers that support their health and make it a priority. Pope et al. (2017) conducted research on caregiver self-care and stated that little is known about the self-care practices of caregivers as caregiver research tends to focus on negative health outcomes. The study investigated self-care practices among family caregivers and the relationships between personal self-care, perceived stress, and other health variables. Personal self-care was most strongly associated with emotional well-being, pain, perceived stress, and general health.

Merrilees's (2016) study of family caregivers of dementia patients provided insight into the need for a relationship between the caregiver and the provider to enhance caregiver peace of mind. Samson et al.'s (2016) study of African American caregivers explores how culture and race can be incorporated into interventions. Themes such as the tradition of family care, caregiver and caregiving issues, culturally appropriate care, and navigating without a map were considered. A similar study by Kally et al. (2014), of an intervention for ethnically diverse caregivers, showed more competence, reduced depression, greater tolerance for care recipients' memory problems, better management of their overall situation, and improved perception of their situation 6 months and 12 months post-enrollment.

### **Nature of the Study**

To address the research questions in this quantitative study, the specific research design included secondary data using the National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC) with a cross-sectional design to understand the association between depression levels, available respite care, and socialization and self-rated health of African American family caregivers. The study design was both descriptive and analytical.

For RQ1, self-rated health is the dependent variable, and depression levels, age, and gender are the independent variables. The dependent variable for RQ2 is also self-rated health, and the independent variable is the availability of receiving respite care. For RQ3, the dependent variable is self-rated health and the independent is participating in social activities with people other than the care recipient.

This study is based on the data from Round 7 (2017) of the NSOC, which is a supplement to the NHATS, a nationally representative study of Medicare beneficiaries 65 years and older. The NSOC consists of a sample of 1453 informal caregivers identified by the NHATS participants in 2017. Respondents to the NHATS and the NSOC represent all 50 states including the District of Columbia and U.S. Territories. For this study, I will extract information from the Round 7 2017 NSOC, convert it from the original SAS program, and analyze it using IBM SPSS statistical software (Version 29.0, 2023).

### **Literature Search Strategy**

The articles reviewed in this search were researched from libraries including the Walden University Library, Google Scholar, Medline, PubMed, CINAHL, and Thoreau.

Beyond the library searches, facts from other sources included the National Alliance for Caregiving, the Family Caregiving Alliance, the AARP, the Alzheimer's Association, the CDC, and the National Center on Caregiving websites. A thorough review of the literature on previous studies on caregiving was conducted using Boolean keyword searches with terms such as *health, depression, Alzheimer's, caregiver mental health, Alzheimer's informal and family caregivers, African American caregivers, self-care, and social support.*

The literature review includes relevant articles known and published on the topic of Alzheimer's Disease from 2017 to 2022. Any relevant articles published prior to 2017 were reviewed and included only if the research was considered to be seminal in nature.

### **Literature Review**

This literature review section incorporated articles published on Alzheimer's dementia caregivers and African American family caregivers that support this study using different library databases. The last section includes a summary of the literature review and discusses the research gaps.

### **Facts and Prevalence of Alzheimer's Disease**

Alzheimer's disease is a brain disorder caused by nerve damage that slowly destroys memory and thinking skills, and eventually, the ability to carry out the simplest tasks (National Institute on Aging, 2021). When changes to the brain due to Alzheimer's first occur, the brain initially compensates, enabling the individual to function normally. As time passes and nerve damage increases, cognitive function, and other areas are affected leading to cognitive decline, memory loss, confusion, behavioral symptoms,

personality changes, and eventually basic bodily functions (Alzheimer's Association, 2022). The disease is ranked the sixth leading cause of death in the United States, and the third leading cause of death among older adults (Alzheimer's Association, 2022).

Alzheimer's disease is the most common type of dementia and may contribute to 60%–70% of cases (WHO, 2022). Since the beginning of the disease, as seen by changes in the brain, can occur many years before the onset of symptoms, it is estimated that approximately 6.5 million people in the United States have Alzheimer's disease. This estimate includes 6.3 million people aged 65 years and older and 200,000 under age 65 with early-onset Alzheimer's (Alzheimer's Association, 2022). There is less certainty regarding the estimate of early-onset Alzheimer's, as younger people in their 30s may get the disease, but it is less common. What is known is that more than 1 in 9 people (10.7%) ages 65 and older have ADRD, and the number of people doubles every 5 years beyond age 65 to a projection of 14 million people by 2050 (Alzheimer's Association, 2022). Because those who meet the diagnostic criteria for ADRD are generally not diagnosed by physicians, ADRD remains underdiagnosed outside of the research setting (Healthy People 2020, 2015).

The prevalence of ADRD in the United States among those older than 65 is greater in females: 4 million women versus 2.5 million men (Rajan et al., 2021). The reason for this varied in literature. Women tend to live longer than men on average, and older age is the primary risk factor for Alzheimer's. Some studies, Rajan et al. (2021) noted, did not find a significant difference between the sexes, whereas others suggest that men might die of other health complications, so the remaining older men are healthier.

Older non-Hispanic African Americans and Hispanic Americans are disproportionately more likely than older Whites to have ADRD. Variations in health, lifestyle, and socioeconomic status such as cardiovascular disease, diabetes, poverty rates, adversity, and discrimination are associated with an increased risk of Alzheimer's and other dementias (CDC, 2020). These disparities influence factors such as where people can live, quality of care, employment opportunities, and occupational safety, and directly or indirectly impact the quality of life. Studies have shown that missed or delayed diagnoses of ADRD are more common among Black and Hispanic older adults than among White older adults (Alzheimer's Association, 2022). According to the Alzheimer's Association (2022) report, 19% of Blacks and 14% of Hispanics age 65 and older have ADRD compared to 10% of Whites, and Matthews et al. (2019) predicted that Hispanic and African Americans in the United States will see the largest increases in ADRD between 2015 and 2060.

### **Cost of Alzheimer's Disease**

Dementia care is costly to society. Dementia-related diseases cost more than three times that of other health expenses for seniors. The Alzheimer's Association (2022) estimated the cost of caring for those with ADRD to total \$321 billion, with \$206 billion being paid by Medicare and Medicaid. Costs include health care and long-term care. Out-of-pocket costs are about 25% of expenditures or \$81 billion and include expenses such as Medicare copayments, other insurance premiums, deductibles and copayments, and any additional services. By 2050 the total costs will rise to nearly \$1 trillion. (Alzheimer's Association, 2022). The 2022 estimated cost does not include the \$271.6

billion in unpaid caregiving by over 11 million family and friends, accounting for 16 billion hours of informal assistance.

People with Alzheimer's or other dementias have twice as many hospital stays, increased skilled nursing facility stays, and home health care visits than other older people (Alzheimer's Association, 2022). This is the case if the person with dementia also has comorbidities such as coronary artery disease, diabetes, kidney disease, chronic obstructive pulmonary disease, stroke, or cancer. These conditions not only contribute to the increase in healthcare costs but also increase the burden on the caregiver.

### **Family Caregivers**

Caregiving refers to providing support for another person's health needs and well-being (AARP, 2021). This can entail activities of daily living such as assisting in bathing, dressing, feeding, or mobility. Caregiving can also include instrumental activities of daily living such as conducting household chores, preparing meals, administering medications, providing transportation, arranging doctor's appointments, care coordination, or managing finances and legal affairs. Perhaps of more importance to the person with ADRD is the emotional support provided by the caregiver that ensures safety at home and elsewhere (Mollica et al., 2020).

The family caregiver is typically either the spouse or child of the care recipient. Occasionally, it is an extended family member or a combination of carers. Most family caregivers are unpaid (Kourakos et al., 2016). For the family caregiver, the burden of being a carer aiding in the aforementioned tasks means that they have a long-term commitment to the family member who is the care recipient. The benefit to the care

recipient is that they are safe and in familiar surroundings—their own home or a family member’s home. However, the caregiver takes on this responsibility (hopefully) with the knowledge that the care recipient with Alzheimer’s dementia will evolve into a different person and become debilitated leading to loss of judgment, orientation, and the inability to understand or communicate effectively (National Institute on Aging, 2021). The burden and stress experienced by the family caregiver can lead to decreased quality of life and a negative impact on their health and well-being (Anderson et al., 2019; Sheehan et al., 2021). Caregivers experience physical, emotional, financial, and social burdens from taking care of their family members with ADRD as they juggle their own lives which may include a job and/or family (Jenkins, 2023).

In studies conducted by Pristavec (2019) and Pristavec et al. (2020), caregivers’ perceptions of health were considered to be critical to their own well-being as well as the mental health of their care recipients. Lindeza et al. (2020) concluded that insights into the positive and negative aspects of the caregiving role should focus on enhancing the positive experiences such as mental health and community interventions as a means to improve the quality of life of both the care recipient with dementia and the family caregiver. Focusing on the positives is not easy, and utilizing services even if they are needed does not always happen. Studies by Brodaty and Donkin (2022) stated that despite feeling overloaded and reporting low levels of life satisfaction, caregivers were reluctant to utilize services. Some did not consider that they needed services, whereas others were unaware that services existed for them. The most successful caregivers were those that affiliated with a provider. Despite feeling like the “invisible second patient,” a

comprehensive partnership between the health provider and the family caregiver, reduced the burden of physical ill-health, social isolation, and financial hardship, and in turn, improved the overall well-being of the care recipient.

### **Caregiving Across Diverse Populations**

The concept of caregiving and the expectation of the caregiver varies from one ethnic group to another. Dilworth-Anderson et al. (2020) stated that supporting caregivers by understanding their culture and philosophy and providing appropriate resources through the lens of diversity, inclusivity, and intersectionality can enhance services and provide evidence for practice and policy change. Roche et al. (2021) indicated that within diverse groups there are differences that researchers should be aware of, and integrate in their questions, analysis, interpretation of data, and interventions. Haley et al. (1995) concurred that foreign-born caregivers have a unique appraisal of their responsibilities as caregivers and so do not experience the burden of care as other cultures. Therefore, their needs and resources differ (Haley et al., 1995; Liu et al., 2020; Moon et al., 2020).

W.E. Haley, a renowned researcher, has researched and published on ADRD caregiving for over 40 years. His expertise includes the effects of ADRD on the stress, health, and well-being of caregivers, racial/ethnic differences in caregiving, and the mechanisms of change in caregiver interventions (Haley, 2020). Studies by Haley and colleagues comparing the experiences, physical health, depression levels, and life satisfaction of African American, Hispanic, and White family caregivers revealed that although all races experienced increased physical symptoms over time, levels of

depression and life satisfaction varied significantly. African American caregivers noted more resilience in their experiences (Liu et al., 2020; Roth et al., 2001).

The cultural differences of the caregivers also affected their perceived health. For African American caregivers, studies by Rote et al. (2019) determined that their perception of health and distress was related to the intensity of their commitment to caregiving and their faith. Self-rated health was connected to their relationship with the care recipient and the support they received from family, their church, and friends. The better the connection with the recipient, community, and family, the better their reported health. This determination was not as strong with White caregivers who preferred to utilize non-family or formal support and reported no impact on their health, or Mexican American caregivers who reported a decrease in health status by utilizing formal support.

### **African American Family Caregivers**

Approximately 10% of dementia caregivers are African American (Parker & Fabius, 2020). ADRDs have a significant impact on African American family caregivers. Studies indicate that African American care recipients are disproportionately affected by dementia compared to other races, and so too are their caregivers, also placing them at high health risk (Epps et al., 2021; Samson et al., 2016). The majority of African American caregivers are a spouse or child who lives with their care recipient and considers their care to be an expression of love and devotion for the care recipient rather than a burden. According to the AARP (2022), although African American caregivers feel that they had little choice in taking the role, they have a sense of purpose. Having an

outsider care for their loved one is not typically done and may be perceived as being disrespectful to the elder.

Little is known from the research about the need for caregivers to use specialty help, services, or social interactions to enhance their health and well-being and the health of their care recipients. African American caregivers aid their care recipients, often to the detriment of their own physical health, and therefore have a higher rate of unmet health needs (Abramsohn et al., 2019). Parker and Fabius (2020) found that Black dementia caregivers were 69% less likely than White caregivers to use respite services. Because they choose not to seek outside help or formal services and tend to be isolated, they indicate to have greater depression. In a survey conducted by the AARP (2022), caregivers' response to not utilizing formal services was that they were unaware that services were available and did not believe that they needed them. Bonds and Lyons (2018) concurred that services that are not culturally appropriate are not as appealing to African American caregivers, so they are not valued or utilized. Studies conclude that culturally congruent, family-centered, and specifically tailored interventions supported the health and well-being and improved the competence of African American caregivers (Brewster et al., 2020; Epps et al., 2020). However, it is vital that African American caregivers see the value of needing resources.

### **Solutions and Caregiver Self-Care**

Caregivers provide practical and emotional support to their care recipients but also need to make their own health a priority. How can caregivers fulfill the needs of their care recipient and themselves? Lloyd et al. (2019) stated that caregivers with higher

levels of self-compassion reported lower levels of burden and had higher coping strategies. Self-compassion is defined as being kind to oneself despite things going wrong. When self-compassion is used by caregivers, their ability to cope with stressors and caregiver burden increases leading to positive well-being, self-care, and personal health outcomes.

Other strategies associated with caregiver self-care and well-being include education about dementia, training, and utilizing respite care (Parker et al., 2020), case management, counseling, and psychotherapeutic approaches (Alzheimer's Association, 2022), having a strong family or support network (Alzheimer's Association, 2022), being physically active, and joining a support group (National Institute on Aging, 2021). Support groups can be a critical lifeline for caregivers, allowing them to share their experiences, express concerns, garner knowledge, and receive emotional support. Self-care may not be top-of-mind for the caregiver, but Anderson et al. (2018), using caregiver blogs to explore self-care strategies, determined that caregiver self-care reduces the caregiver burden and provides physical and emotional benefits for both the caregiver and the care recipient.

### **Caregiver Policies and Laws**

The National Institute on Aging and the Administration for Community Living (ACL) are the primary federal agencies through the U.S. Department of Health and Human Services (DHHS) dedicated to caregiving services. There are three current laws that refer to support for caregivers: the 2011 National Alzheimer's Project Act, the 2014 Model Caregiver Advise Record and Enable (CARE) Act, and the 2018 Recognize,

Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. The National Alzheimer's Project Act mandates improved coordination of care for those with ADRD giving special attention to racial populations that are at higher risk to reduce disparities (AARP, 2022). For caregivers, reducing the barriers to accessing services enables them to also focus on their own care (Abramsohn et al., 2019). Since caregivers provide basic medical care such as wound care, giving injections, and medication administrations to their care recipients, the Model CARE Act requires hospitals to retain the caregiver's contact information as part of the recipient's medical record for follow-up and to educate or train the caregiver to perform medical tasks at home (AARP, 2014). The CARE Act has been signed into law in 42 states, the District of Columbia, Puerto Rico, and the US Virgin Islands. The RAISE Family Caregivers Act, tasks the DHHS with establishing a national strategy for family caregivers. The Family Caregiving Advisory Council developed 26 recommendations for consideration, and the next step is to develop implementation strategies that support and reward family caregivers for the work that they do (AARP, 2022).

State laws related to caregiving have been approved in Arizona, California, Connecticut, Nebraska, New York, Pennsylvania, and Washington. These laws vary from establishing a public insurance fund for in-home services, establishing caregiver resource centers, and providing reimbursement programs, to expanding the Family and Medical Leave Act to include family caregivers (AARP, 2021). All of these state laws lead to family caregivers having more options to assist their loved ones.

For African American caregivers one change in policy that may make a difference in their ability to access services and resources is being included in caregiver research. Since the majority of those with dementia are Non-Hispanic White, the research conducted for caregivers rarely includes caregivers of color. According to Dilworth-Anderson et al. (2020), capturing the needs and dementia care experiences of caregivers of color makes the research richer as these groups continue to grow. If representation is not achieved, researchers' ability to generalize and determine findings by subgroups will not be possible and the progress of Alzheimer's research will be hindered. The AARP (2022) and the Alzheimer's Association (2022) consider the lack of representation to be a systemic problem. Policymakers ask for data to show the extent of the problem, but if certain groups are not included in the research, then the extent of the problem will not be realized, and caregiving cannot be improved. Culturally informed theories and research guide the work of the future for caregivers of color.

### **Definition of Terms**

*Alzheimer's dementia:* The progression of Alzheimer's disease over time where the individual's ability to perform everyday activities is diminished (Alzheimer's Association, 2022).

*Care recipient:* The individual receiving care from the caregiver.

*Caregiving burden:* The physical stress of caregiving for a recipient with Alzheimer's dementia is very high. These demands can increase the caregiver's health problems and susceptibility to diseases (Alzheimer's Association, 2022).

*Caregiving duties:* Assistance provided by a caregiver to the care recipient. It includes daily living activities from bathing and dressing to administering medication, wound care, managing finances, and coordinating healthcare (AARP, 2021).

*Family caregiver:* A relative who attends to the health and personal needs of an individual.

*Respite care:* Providing care to an individual as an alternative to a caregiver (AARP, 2021).

### **Assumptions**

There are several assumptions made related to this study. One assumption is that the health of caregivers is affected by taking care of a loved one who has Alzheimer's dementia. Another assumption is that an association exists between the health status of the caregiver and the ability to socialize and have help in taking care of the loved one. The final assumption is that the data have been validated by using the 2017 NHATS/NSOC survey results and that the participant responses used in this study were truthful and honest.

### **Scope and Delimitations**

The scope of the study is based on the 2017 NHATS/NSOC survey data results. The data examined are dependent on the researchers who collected the primary data; thus, only variables available in the dataset were used. These results, therefore, are limited due to the use of secondary data from these existing databases.

The burden of caregiving is increasing as adults age and Alzheimer's dementia increases. This research study specifically focuses on the African American family

caregiver's levels of depression, opportunities for respite care, and the ability to socialize as they care for their loved ones with Alzheimer's dementia. The study focus was chosen because previous studies examined implementation implications for the majority (White) population and limited culturally appropriate implementations for caregivers of color, particularly African Americans.

### **Significance of the Study**

The significance of the study is to increase the awareness of the gaps in the literature between the variables and to give African American family caregivers a voice for their experiences with the intent to advance professional practice. Public health practitioners and educators need to be informed of the value of accessible and culturally appropriate interventions and support services for African American family caregivers so that their knowledge and quality of care improve. As the number of individuals with Alzheimer's dementia and related diseases increases, the public health impact will also increase, so providers and practitioners will need to find innovative approaches to address how to engage African American caregivers and connect them to resources (Alzheimer's Association, 2022).

It is also important that the voice of African American caregivers also reaches the policymakers. Whether professionals advocate or caregivers advocate for themselves, it is vital that policies and financial resources are created for African American families to access needed services. Communities may then be confident that they are better equipped to support their loved ones and be prepared to reduce the stress of the disease.

### **Significance to Social Change**

Family caregivers of individuals with Alzheimer's dementia provide vital care for their care recipient allowing them to remain in familiar surroundings and thrive as much as possible. The number of individuals with Alzheimer's dementia will continue to increase. The Alzheimer's Association (2022) has estimated that by 2050 over 15 million individuals in the United States will have dementia, increasing the burden on caregivers and the public health system.

The social change contribution of this study is to increase the understanding of the health practitioners, advocates, and policymakers of the value of African American caregivers having access to culturally appropriate resources. The intent is that by identifying the specific needs of African American caregivers and including them in research opportunities, more policies will recognize their contributions. If these caregivers continue to lack representation in research, they will not receive the benefits of prevention, treatment, or innovations in care, and ultimately hinder the progress of Alzheimer's disease information in diverse populations and their quality of life.

### **Summary**

ADRD is a brain disorder that can initially be compensated for but progresses to cognitive decline, confusion, and loss of bodily function. The care recipient becomes dependent on the caregiver for aid and support. It is estimated that 6.5 million individuals in the United States have ADRD (Alzheimer's Association, 2022). The demand for caregiving has increased as the number of individuals with ADRD has increased. Caregiving varies from feeding and bathing to administering medications, household

chores, and medical appointments. The burden can be demanding, to the detriment of the physical and mental health of the caregiver.

African American care recipients are disproportionately affected by Alzheimer's dementia compared to other races, and their susceptibility to other maladies such as high blood pressure, diabetes, and coronary heart disease exacerbates their risk. Family caregivers are also impacted as their burden increases with additional recipient health problems. According to Abramsohn et al. (2019), African American caregivers have a higher rate of unmet health needs from caring for their recipients to the detriment of their own health. Seeking and utilizing implementation services such as dementia education, professional counseling, case management, group therapy, and respite care would help to alleviate the stress of caregiving. However, there are limited culturally appropriate programs available for African American caregivers, and they tend to not utilize services such as respite care assuming that if it is available that it is not for them.

Research studies that might provide solutions for the challenges of African American caregivers are scarce. The Alzheimer's Association (2022) and the AARP (2022) consider the lack of representation in research to be a systemic problem that practitioners, administrators, and policymakers need to realize and resolve quickly for the future health of caregivers of color to be brighter.

The next section presents the research procedures that were used in the study.

## Section 2: Research Design and Data Collection

### **Introduction**

Family caregivers are essential to healthcare, providing care and support to over 6.5 million individuals suffering from ADRD in the United States, thus allowing them to thrive in familiar surroundings.

The dependent variable for this study is the self-reported health of the family caregivers and the independent variables are age, gender, race, ethnicity, receiving respite help from family members, and participation in social activities with other people. The purpose of this study is to fill a gap in the literature regarding the above variables and to give African American caregivers a voice for their experiences with the intent to inform and advance professional practice.

This section provides an explanation of the rationale and design of the research, the methodology, the data analysis plan, threats to validity, and ethical procedures.

### **Research Design and Rationale**

A research design should bring a philosophical worldview with a methodology and procedures that can translate into approaches that are applicable to practice (Creswell & Creswell, 2018). The design for this study was cross-sectional and examined the association between the multiple variables. The data were retrieved from the 2017 NHATS/NSOC database and were analyzed using a chi-square test. Results from this study may be used to inform health providers and practitioners of the health needs of African American caregivers. Providers and practitioners can also use the information to

craft policies and find innovative approaches to address how to engage African American caregivers and connect them to necessary resources and research.

### **Methodology**

I analyzed the 2017 NHATS/NSOC database using the chi-square test to determine the association, if any, between the variables. According to Wagner (2017), the chi-square test is used when comparing categorical variables to determine whether the variables are related to each other. IBM (2022) further qualified the chi-square test by stating that it summarizes the difference between the frequencies observed and what is expected.

In this study, the dependent variable is the self-reported health of African American caregivers. In RQ1, the independent variables are depression levels, age, gender, race, and ethnicity. In RQ2, the independent variable, receiving respite help is a categorical variable, and in RQ3, the independent variable, participating in social activities with other people who are not the care recipient, is also a categorical variable. I used the 2017 NHATS/NSOC database to verify and validate the hypotheses that the self-rated health of African American family caregivers is related to and impacted by their depression levels, ability to receive respite help from other family members, and their ability to socialize outside of their caregiving duties.

### **Population**

The data source for this study is the data from Round 7 (2017) of the NSOC, which is a supplement to the NHATS, a nationally representative study of Medicare beneficiaries 65 years and older. According to NSOC (2022), a sample of 2652 informal

caregivers were identified by their recipients and interviewed using a survey. The caregivers comprised 1659 Non-Hispanic White caregivers, 685 Non-Hispanic African American/Black caregivers, 160 Hispanic caregivers, 63 Non-Hispanic other races (Native American, Asian/Pacific Islander, and other) caregivers, and 85 did not know their race or refused to answer the question.

### **Sampling**

The NHATS conducts a thorough screening of its participants, and these participants recommend the caregivers for the study. Respondents to the NHATS and the NSOC represent all 50 states including the District of Columbia and U.S. Territories.

### **Power Analysis**

The power analysis, according to Creswell and Creswell (2018), helps to determine whether the result of a survey is due to chance or is genuine and significant. It is the probability of a hypothesis test detecting a true effect if there is an effect to be found. For this study, the minimum accepted power of 80% was used to estimate the sample size with an alpha level of 0.01 and a  $p$  value of .001. Calculating the power using G\*Power 3.1.9.6 software (Heinrich Heine Universität Dusseldorf, 2022), I determined that the minimum sample needed for a small effect size of 0.15 (since effect size and sample size work inversely) is 108 participants (see Figures 1 and 2). The sample size for this study is 685, which is considered acceptable. Determining the margin of error is beneficial as it provides a clearer understanding of what a survey's estimate of a population characteristic means and tells how accurate the survey results are (Creswell & Creswell, 2018). Therefore, with a confidence level of 95%, a population size of 2652

caregivers, a sample size of 685 African American caregivers, and a population proportion of 26%, the margin of error is  $\pm 2.79\%$ . This means that for this study, there is a 95% chance that the real value is within  $\pm 2.79\%$  of the surveyed value (Calculator.net, 2022).

### Figure 1

#### *Linear Multiple Regression t Test for Sample Size*

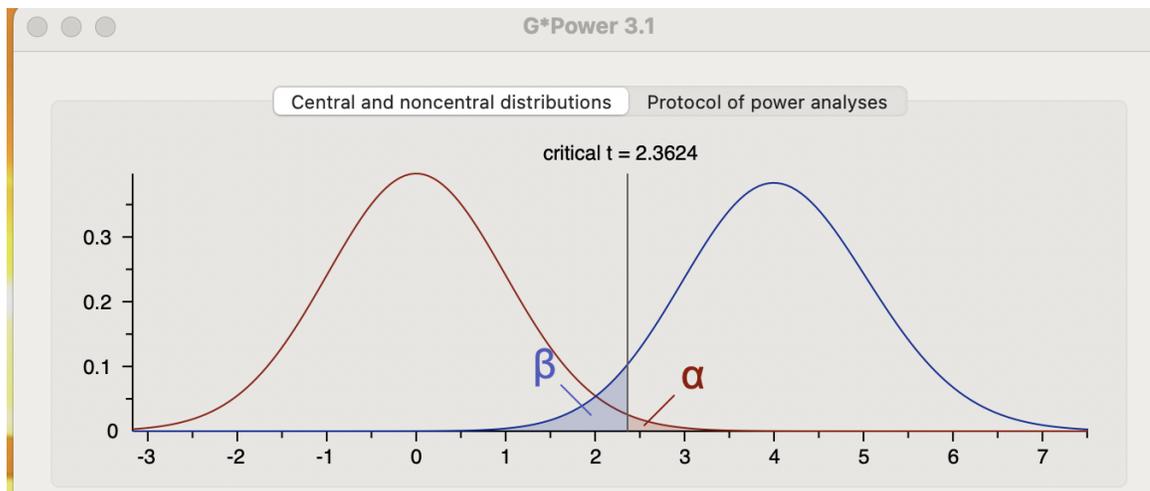


Figure 2

*Protocol for Power Analysis Using Linear Multiple Regression*

The screenshot displays the G\*Power 3.1 software interface. The window title is "G\*Power 3.1". There are two tabs: "Central and noncentral distributions" and "Protocol of power analyses". The "Protocol of power analyses" tab is active, showing a terminal-style output window with the following text:

```
[1] -- Wednesday, November 30, 2022 -- 13:10:40
t tests - Linear multiple regression: Fixed model, single regression coefficient

Analysis: A priori: Compute required sample size
Input:    Tail(s)                = One
          Effect size f²         = 0.5
          α err prob             = 0.05
          Power (1-β err prob)   = 0.95
          Number of predictors    = 2
Output:   Noncentrality parameter δ = 3.4641016
          Critical t              = 1.7207429
          Df                      = 21
          Total sample size       = 24
          Actual power            = 0.9558557
```

Below the terminal window, there are several control panels:

- Test family:** A dropdown menu set to "t tests".
- Statistical test:** A dropdown menu set to "Linear multiple regression: Fixed model, single regression coefficient".
- Type of power analysis:** A dropdown menu set to "A priori: Compute required sample size - given α, power, and effect size".
- Input parameters:** A panel with a "Determine" button and several input fields:
  - Tail(s): One
  - Effect size f²: 0.15
  - α err prob: 0.01
  - Power (1-β err prob): 0.95
  - Number of predictors: 2
- Output parameters:** A panel displaying the results of the calculation:
  - Noncentrality parameter δ: 4.0249224
  - Critical t: 2.3623875
  - Df: 105
  - Total sample size: 108
  - Actual power: 0.9501580

At the bottom right, there are two buttons: "X-Y plot for a range of values" and "Calculate".

## Operationalization of Variables

Table 1 represents the operational definitions of variables that were used in the data analysis. The variables were depression levels, age, gender, receiving respite help, participating in social activities, and self-reported health.

**Table 1**

### *Operationalization of Variables*

Name of variables	Type of variable	Level of measurement
Depression levels	Independent variable	Ordinal categorical
Caregiver age	Independent variable	Continuous
Caregiver gender	Independent variable	Nominal categorical
Receiving respite help	Independent variable	Nominal categorical
Participating in social activities	Independent variable	Nominal categorical
Self-reported health	Dependent variable	Ordinal categorical

## Data Analysis Plan

I used SPSS (Version 29.0) software to perform the statistical analysis. The NHATS/NSOC database is only available in SAS, so I converted the data to SPSS by opening the SAS files in SPSS so that they could be read using the syntax ‘.sas7bdat’. The data were input into SPSS and all three research questions were addressed using linear multiple regression. The plan was to first apply descriptive statistics to the nominal variables and utilize chi-square tests to determine the association between variables.

## Research Questions

The following research questions were considered for this study:

RQ1: Is there an association between depression levels, and the self-rated health of African American caregivers while controlling for age and gender?

$H_{01}$  – There is no association between depression levels and the self-rated health of African American caregivers while controlling for age and gender.

$H_{A1}$  – There is an association between depression levels and the self-rated health of African American caregivers while controlling for age and gender.

RQ2: Is there an association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver?

$H_{02}$  – There is no association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver.

$H_{A2}$  – There is an association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver.

RQ3: Is there an association between participating in social activities with people other than the care recipient, and the self-rated health of the caregiver?

$H_{03}$  – There is no association between participating in social activities with people other than the care recipient, and the self-rated health of the caregiver.

$H_{A3}$  – There is an association between participating in social activities with people other than the care recipient and the self-rated health of the caregiver.

### **Analysis Techniques**

A descriptive analysis was conducted to determine the frequency of health levels of African American caregivers. For RQ1, there were three independent variables and one dependent variable, and analysis was performed using the chi-square test. For RQ2 and RQ3, the independent and dependent variables were analyzed using the chi-square test since these variables were categorical.

### **Threats to Validity**

A threat to validity elevates the concern about whether a test or survey measures what it is designed to measure (Terrell, 2016). Utilizing secondary data for a study can be a threat to validity. According to Creswell and Creswell (2018), there are several threats that can raise a question about whether the manipulated variables affect an outcome and not another factor. Examining the internal and external threats can resolve these questions. Internal threats are relevant when procedures, treatment, performance, and experiences of participants impact their responses and the researcher's ability to make inferences and therefore impact the outcomes of the study (Creswell & Creswell, 2018). For this study, no contact was made with the participants to influence their responses, so the secondary data set stands as is. External threats ask whether the characteristics of individuals, unique settings, or timing of the surveys in a study are generalizable to the population or to future situations (Terrell, 2016). The purpose of the NSOC is to learn about the needs of family caregivers to draw inferences that are generalized for the population. This study utilized the responses of the caregivers to learn more about the needs of the African American caregiver's subset. The NHATS/NSOC 2017 data were collected using in-person interviews (NHATS, 2022). Because this data set is from a nationally representative sample of Medicaid recipients aged 65 and older and their caregivers, who voluntarily participated in the survey, it can be considered a reputable source with generalizable outcomes and limited internal and external threats for this study.

### **Ethical Procedures**

The 2017 NHAT/NSOC is a public database supported by the National Institute on Aging; therefore, no direct contact with participants was made for this study. Permission to access and use these data was granted in April 2022 by NHATS/NSOC on the condition that findings were shared with the NHATS/NSOC researchers. The permission to use the data extended to sensitive files of the participants, but no personal identifiers were necessary to answer the current study's research questions.

### **Treatment of Data**

The NHATS/NSOC data were used in this secondary data study without needing personal identifiers. To avoid any ethical breaches, the data were saved and stored in compliance with the Institutional Review Board (IRB) requirements of Walden University and made available to research quality staff as needed to assess this study.

### **Ethical Concerns**

Ethical concerns in research are essential to ensure that the well-being and decisions of the participants are respected (Terrell, 2016). The secondary data that were collected in this study were used exclusively to determine whether an association exists between the independent and dependent variables.

### **Summary**

Section 2 of this study presented the research design and rationale for the study, the methodology including the population, sampling, and power analysis. The software to analyze the NHATS/NSOC data were included as well as threats to validity and ethical

concerns and considerations related to the treatment of the data. Section 3 will present the interpretation of the results and summarize the answers to the research questions.

### Section 3: Presentation of the Results and Findings

#### Introduction

The purpose of this study was to examine the association between depression levels, available respite help, going out for enjoyment (also referred to in the analysis as socialization or social activity), and self-reported health among African American caregivers. I also considered how demographic factors such as age and gender impact the caregivers' perception of health. Section 3 shows the results of the statistical analysis from the NHATS/NSOC Round 7 (2017) using SPSS software (Version 29). The chi-square test was used for RQ1, RQ2, and RQ3. The results for each research question are displayed in this section including descriptive statistical results. The statistical significance is considered at  $p < .05$ .

The research questions and hypotheses for this study were:

RQ1: Is there an association between depression levels, and the self-rated health of African American caregivers while controlling for age and gender?

$H_{01}$  – There is no association between depression levels and the self-rated health of African American caregivers while controlling for age and gender.

$H_{A1}$  – There is an association between depression levels and the self-rated health of African American caregivers while controlling for age and gender.

RQ2: Is there an association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver?

$H_{02}$  – There is no association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver.

*H<sub>A2</sub>* – There is an association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver.

RQ3: Is there an association between participating in social activities with people other than the care recipient, and the self-rated health of the caregiver?

*H<sub>03</sub>* – There is no association between participating in social activities with people other than the care recipient, and the self-rated health of the caregiver.

*H<sub>A3</sub>* – There is an association between participating in social activities with people other than the care recipient and the self-rated health of the caregiver.

### **Data Collection of Secondary Data**

The NHATS/NSOC Round 7 (2017) was used as data for this study. The NSOC is a supplement to the NHATS, which is a nationally representative study of Medicare beneficiaries 65 years and older. Respondents to the NHATS and the NSOC represent the 50 states in the United States, the District of Columbia, and the U.S. Territories. Starting in 2011, the NHATS has conducted an annual survey of a representative sample of the population. Designed as a scientific study of late-life disability trends, the research reduces disability, maximizes independent functioning, and enhances the quality of life among older adults. The NSOC is conducted periodically to provide the perspective of the family and friends that care for and help the older adults and addresses limitations in their daily life. Both the NHATS and the NSOC are supported by the National Institute on Aging (NHATS/NSOC, 2022). The data were collected by NHATS/NSOC from January to December 2017. The data collected for the variables were ethnicity, self-rated health, depression level, respite help, going out for enjoyment, age, and gender.

As a requirement and to comply with the ethics of the research project, permission to proceed with this research was granted by the Walden University IRB. The IRB approval number for this study is 02-17-2023-0983029. The analysis of data retrieved from the 2017 NHATS/NSOC is presented in this section.

### **Demographic/Profiles of Participants**

There were 2,652 total participating caregivers in the cross-sectional study, and 685 (26.4%) identified as Non-Hispanic Black/African American. Using the software package G\*Power (Heinrich Heine Universität Dusseldorf, 2022), I conducted a priori power analysis, and the minimal number of participants needed was equal to or greater than 108 (see Figures 1 and 2). This study, therefore, complies with the number of participants needed.

The data set included demographic information such as sex and age. Of the 685 African American caregivers included in this study, 480 (70.1%) were female. The age range of caregivers was from 18 years old to 92 years old with a mean age of 57.78 years (see Figure 3).

**Figure 3**

*Histogram Showing the Distribution of Age of African American Caregivers*

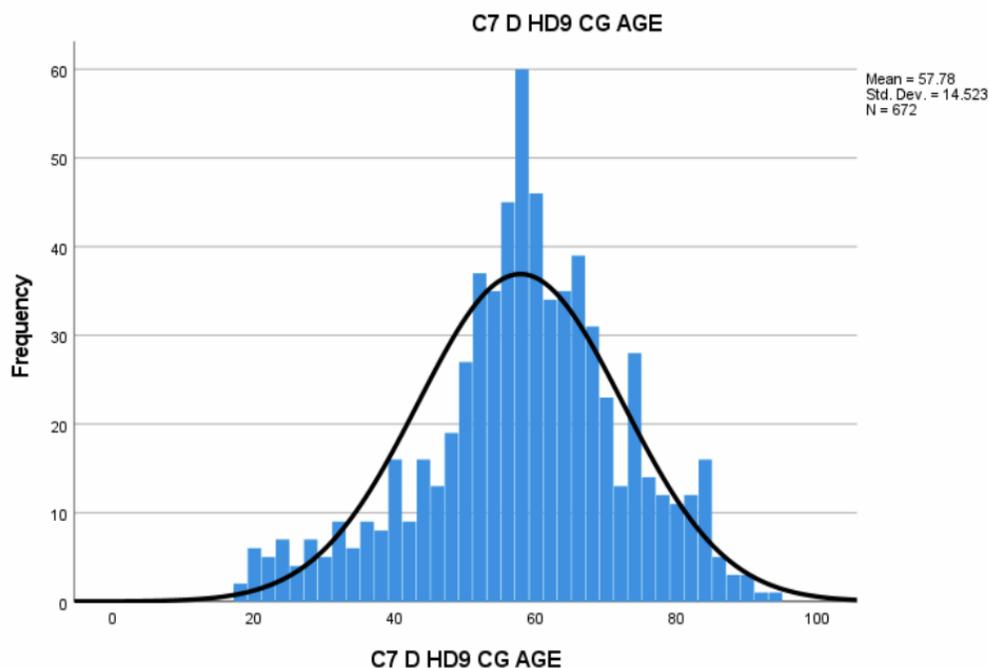


Table 2 shows the other characteristics of the variables related to African American caregivers. For self-rated health, 479 (69.9%) caregivers rated their health as good, very good, or excellent. For depression, over 70% ( $n = 481$ ) of the caregivers indicated that they did not experience it, 14% ( $n = 96$ ) experienced depression every day, 4.7% ( $n = 32$ ) experienced depression more than half of the days (of the week), and 3.2% ( $n = 22$ ) experienced depression nearly every day. 73.4% ( $n = 503$ ) of the African American caregivers reported that they receive respite help from others with their care recipient, and 66.7% ( $n = 457$ ) go out for enjoyment or social activities.

**Table 2***Characteristics of African American Caregivers*

Variables	African American caregivers
Age (mean $\pm$ SD) in years	57.7 $\pm$ 14.5
Female sex (n, %)	480 (70.1)
Self-rated health (n, %)	
Excellent	94 (13.7)
Very good	182 (26.6)
Good	203 (29.6)
Fair	136 (19.9)
Poor	20 (2.9)
Other	50 (7.3)
Depression level (n, %)	
Not at all	481 (70.2)
Several days	96 (14.0)
More than half the days	32 (4.7)
Nearly every day	22 (3.2)
Other	54 (7.9)
Respite help (n, %)	
Yes	503 (73.4)
No	129 (18.8)
Other	53 (7.7)
Social activity (n, %)	
Yes	457 (66.7)
No	178 (26)
Other	50 (7.3)

For each variable selected for this study, a variable type was identified as ordinal, nominal, or continuous. Table 3 includes the variables and the corresponding NSOC codes. The self-reported health and depression levels of African American caregivers were captured as an ordinal variable in the data set. Those caregivers that received respite help from other family members and friends, and whether caregivers went out for enjoyment were captured as a nominal variable in the data set. Age was captured as a continuous variable.

**Table 3***Variables and Corresponding NSOC Codes*

Variable Name (Code)	Dependent/Independent Variable	Type of Variable
Self-rated health (che7health)	Dependent	Ordinal
Depression level (che7fltdown)	Independent	Ordinal
Respite help (cse7frfamhlp)	Independent	Nominal
Social activity (cpp7go4fun)	Independent	Nominal
Age (chd7dage)	Independent	Continuous
Sex (c7dgender)	Independent	Nominal

In order to comply with the assumptions for the chi-square test (see below), the variables were re-coded for analysis. For the dependent variable self-rated health, the categories were combined into “fair” and “good.” For the independent variable depression level, the categories were collapsed into “not all days,” “several days,” and “most of the days.” The variable age was collapsed into three categories: “less than 50 years old,” “51–60 years,” and “61–92 years.” This allowed for a better spread of the data and ensured that there were more than five counts per cell. This also allowed the variable age to be considered as a categorical variable.

Table 4 shows the frequencies for the variables related to African American caregivers. The missing data for respite help, social activity, and depression level was noted and accounted for in the analysis.

**Table 4***Frequencies for African American Caregivers*

	Felt Down	Social Act	Self-R Hlt	Age	Gender	Respite Hp
<i>N</i> Valid	631	635	635	685	685	632
Missing	54	50	50	0	0	53
Mean	1.32	1.28	1.606	1.941	1.70	1.20
Median	1.00	1.00	2.00	2.00	2.00	1.00
Mode	1	1	2.00	2.00	2	1
Std. Dev	.625	.450	.489	.635	.458	.403
Minimum	1	1	1.00	1.00	1	1
Maximum	3	2	2.00	3.00	2	2

### Assumptions

According to Frankfort-Nachmias and Leon-Guerrero (2018), the chi-square test is used to test for significant relationships or associations between two variables and is organized in a bivariate table. There are several assumptions made when using the chi-square test:

- The data comes from a large sample.
- The data cells should be frequencies.
- The data is displayed as counts rather than percentages, with more than five counts per cell.
- The categories of the variables are mutually exclusive.
- The variables are categorical.

All assumptions for the chi-square test discussed in the sections above were met in this data analysis.

### Research Question 1: Results

RQ1: Is there an association between depression levels, and the self-rated health of African American caregivers while controlling for age and gender?

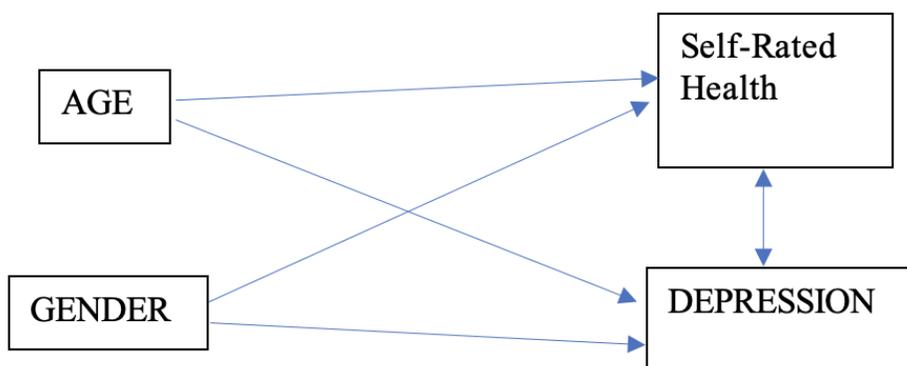
$H_01$  – There is no association between depression levels and the self-rated health of African American caregivers while controlling for age and gender.

$H_{A1}$  – There is an association between depression levels and the self-rated health of African American caregivers while controlling for age and gender.

The chi-square test was used to examine the association between the caregiver's depression levels and their self-rated health while controlling for age and gender. The interaction between depression levels, age, gender, and self-reported health can be understood using the illustration shown in Figure 4:

**Figure 4**

*Interaction Between Depression Level, Age, Gender, and Self-Rated Health*



Both gender and age interact and impact depression and self-rated health, and depression and self-rated health affect each other.

Of the total of 631 participants who responded to the survey question related to depression levels, 481 respondents indicated that with fair or good health they experienced depression for not many days. There were 96 respondents who experienced depression several days per month and 54 indicated that they experienced depression most days in the month. Table 5 shows that the association between depression levels and self-rated health of African American caregivers was significant overall,  $X^2(2, N = 685) = 22.95, p < .001$ . Those participants who reported good health were more likely to not have many days where they felt depressed. Figure 5 shows the bar chart reflecting the significance.

**Table 5**

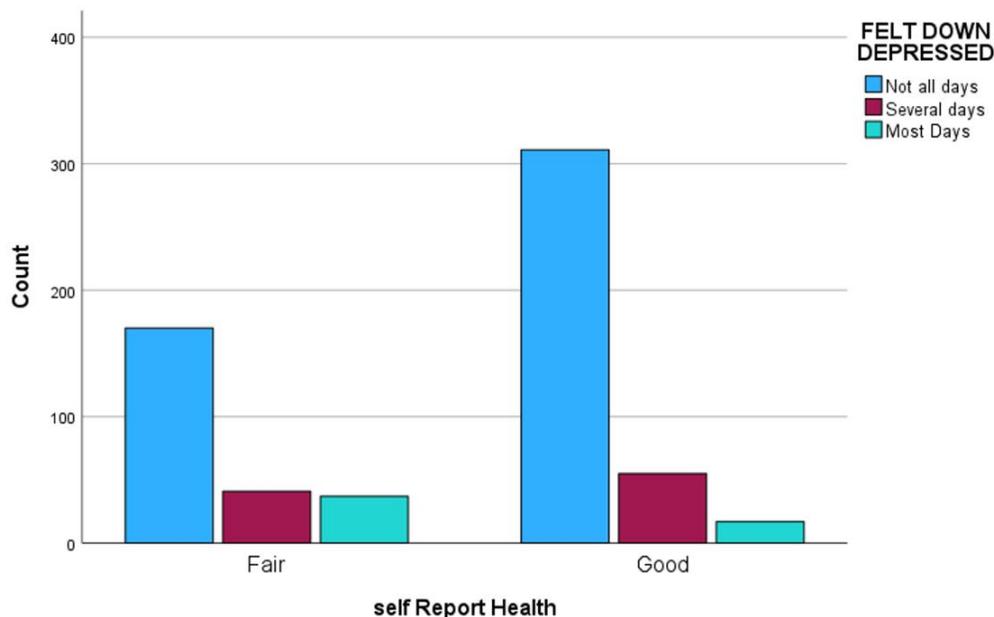
*Chi-Square Test for Self-Rated Health and Depression*

	Value	df	Asymptotic Significance (2- sided)
Pearson Chi-Square	22.949	2	<.001
N of Valid Cases	631		

0 cells (0.0%) have expected count less than 5. The minimum expected count is 21.22.

**Figure 5**

*Bar Chart of Self-Rated Health and Depression*



The second consideration for this research question is gender. Of the 631 respondents, 438 were female and 193 were male. Three hundred and thirty-three females and 148 males indicated that with fair or good health they experienced depression for a few days. Sixty-four females and 32 males experienced depression for several days, and 41 females and 13 males indicated that they experienced depression for most days of the month. Further, the association between depression levels and self-rated health was significant by gender, where females were significantly more likely than males,  $X^2(2, N = 685) = 18.715, p < .001$  to report good health and not many days where they felt depressed (see Table 6). Figure 6 is the bar chart reflecting the significance for females.

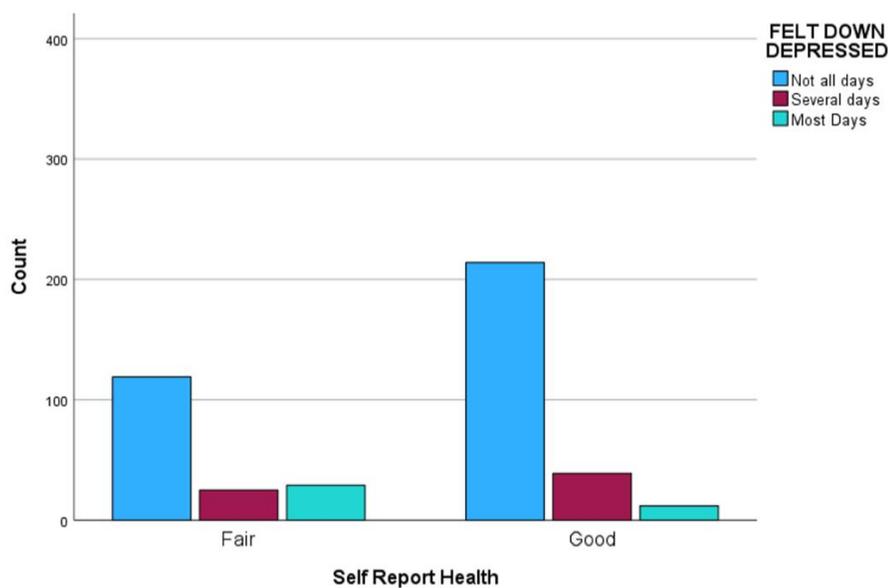
**Table 6***Chi-Square Test for Gender, Self-Rated Health, and Depression*

		Value	df	Asymptotic Significance (2-sided)
Male	Pearson Chi-Square	5.692 <sup>b</sup>	2	.058
	N of Valid Cases	193		
Female	Pearson Chi-Square	18.715 <sup>c</sup>	2	<.001
	N of Valid Cases	438		
Total	Pearson Chi-Square	22.949 <sup>a</sup>	2	<.001
	N of Valid Cases	631		

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 21.22.

b. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 5.05.

c. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 16.19.

**Figure 6***Bar Chart of Female Gender, Self-Rated Health, and Depression*

The final consideration for this research question was the caregiver's age. There were 181 caregivers between the ages of 18 years and 49 years, 194 aged 50–60, and 256 above the age of 60. The association between depression levels and self-rated health of African American caregivers was also significant by age, where caregivers aged 50–60 years and over 60 years,  $X^2(2, N = 685) = 10.600, p < .005$  and  $X^2(2, N = 685) = 13.465, p < .001$ , respectively, were more likely to report good health and not many days where they felt depressed (see Tables 7 and 8). Figures 7 and 8 are bar charts reflecting the significance for ages 50-60 years and over 60 years.

Using the chi-square test, these results show that there is a positive association between self-reported health and depression when considering caregiver gender and age. As a result, for H01, the null hypothesis was rejected, and the alternative hypothesis was accepted.

**Table 7**

*Caregiver Age, Self-Reported Health, and Depression Levels*

CG Age			Depression not all days	Depression several day	Depression most days	Total
Below 50	Self-Rep	Fare	51	7	11	69
	Health	Good	87	20	5	112
	Total		138	27	16	181
50 to 60	Self-Rep	Fair	63	10	14	87
	Health	Good	90	14	3	107
	Total		153	24	17	194
Above 60	Self-Rep	Fair	56	24	12	92
	Health	Good	134	21	9	164
	Total		190	45	21	256
Total	Self-Rep	Fair	170	41	37	248
	Health	Good	311	55	17	383
	Total		481	96	54	631

**Table 8**

*Chi-Square Test for Caregiver Age, Self-Reported Health, and Depression*

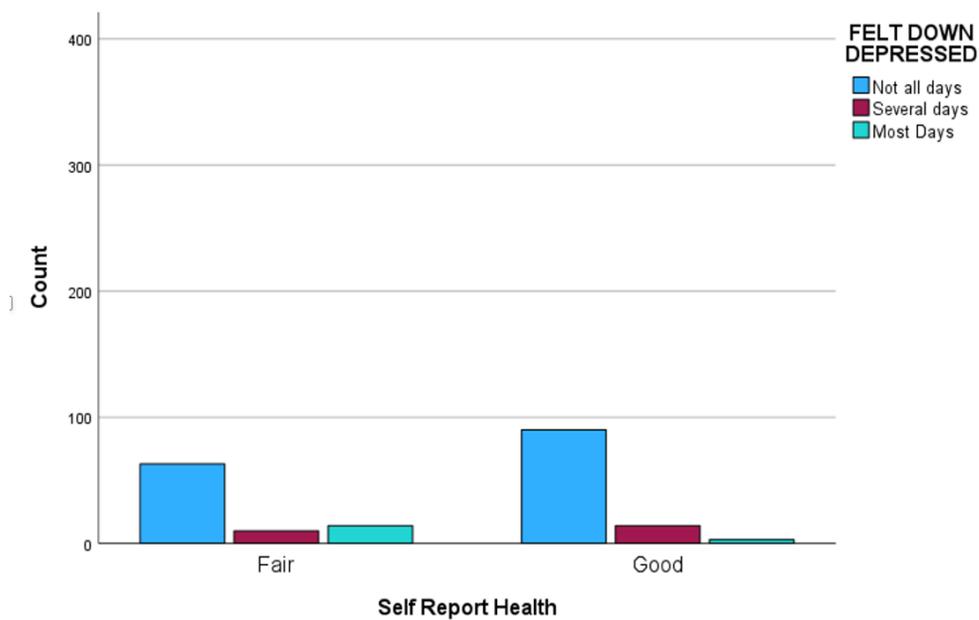
*A Sample Table Showing Correct Formatting – Caregiver Age*

		Value	df	Asymptotic Significance (2-sided)
Below 50	Pearson Chi-Square	8.15 <sup>b</sup>	2	.017
	N of Valid Cases	181		
50-60	Pearson Chi-Square	10.600 <sup>c</sup>	2	.005
	N of Valid Cases	194		
Above 60	Pearson Chi-Square	14.465 <sup>d</sup>	2	.001
	N of Valid Cases	256		
Total	Pearson Chi-Square	22.949 <sup>a</sup>	2	<.001
	N of Valid Cases	631		

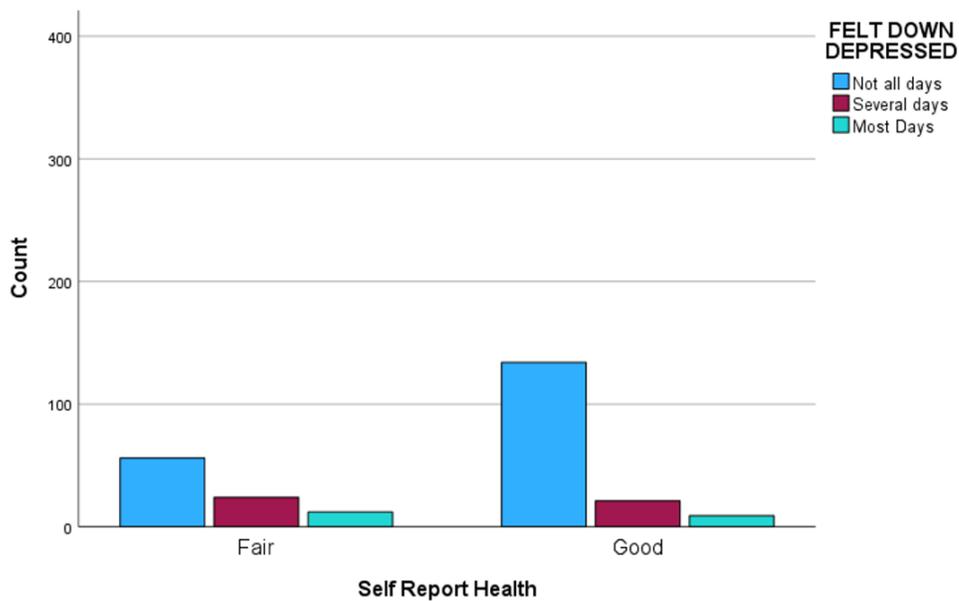
- a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 21.22.
- b. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 6.10.
- c. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 7.62.
- d. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 7.55.

**Figure 7**

*Bar Chart of Caregivers Aged 50–60 Years, Self-Reported Health, and Depression Levels*

**Figure 8**

*Bar Chart of Caregivers Aged Above 60 Years, Self-Reported Health, and Depression Levels*



## Research Question 2: Results

RQ2: Is there an association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver?

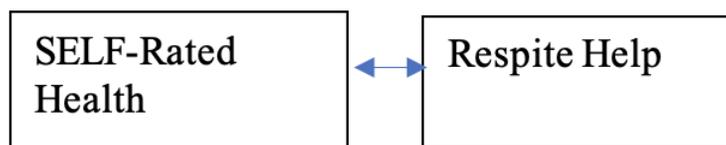
H02 – There is no association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver.

HA2 – There is an association between receiving respite help from family members to care for the care recipient and self-rated health of the caregiver.

The chi-square test was used to examine the association between the caregiver receiving respite help from family members and their self-rated health. The following illustration shows the interaction between self-rated health and receiving respite help:

**Figure 9**

*Interaction Between Receiving Respite Help and Self-Rated Health*

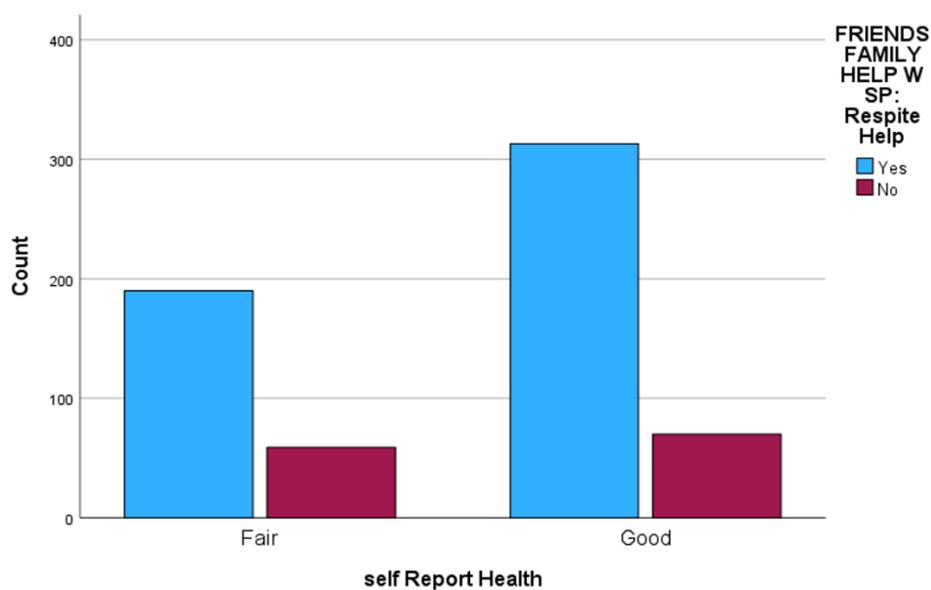


There were 632 African American caregiver responses to this survey question, with 503 indicating that with fair or good reported health they receive respite help from family or friends. Table 9 and Figure 10 indicate that the association between respite help from family members and the self-rated rated health of African American caregivers was not significant,  $X^2 (2, N = 685) = 2.727, p = .099$ . Using these results for H02, because there is no significant association between caregivers receiving respite help and self-reported health, I failed to reject the null hypothesis.

**Table 9***Chi-Square Test for Respite Help and Self-Reported Health*

	Value	df	Asymptotic Significance (2- sided)
Pearson Chi-Square	2.727	1	.099
N of Valid Cases	632		

0 cells (0.0%) have expected count less than 5. The minimum expected count is 50.82.

**Figure 10***Bar Chart of Caregiver Respite Help and Self-Reported Health*

### Research Question 3: Results

RQ3: Is there an association between participating in social activities with people other than the care recipient, and the self-rated health of the caregiver?

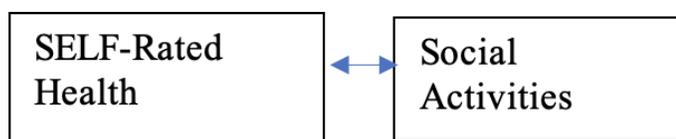
H03 – There is no association between participating in social activities with people other than the care recipient, and the self-rated health of the caregiver.

HA3 – There is an association between participating in social activities with people other than the care recipient and the self-rated health of the caregiver.

I used the chi-square test to examine the association between caregivers going out and participating in social activities with other people and their self-rated health. The relationship between self-rated health and caregivers participating in social activities is illustrated below:

#### Figure 11

*Interaction Between (Going Out for) Social Activities and Self-Reported Health*



There were 635 African American caregivers that responded to this survey question with 459 indicating that they did go out and participate in social activities. Table 10 and Figure 12 shows that the association between going out for enjoyment (social activities) and the self-reported health of African American caregivers was significant overall,  $X^2(2, N = 685) = 11.708, p < .001$ . Those who reported good health were more likely to participate in social activities. Using the chi-square test, these results show that

there is a positive association between African American caregivers' self-reported health and going out for enjoyment. As a result, for H03, the null hypothesis was rejected, and the alternative hypothesis was accepted.

**Table 10**

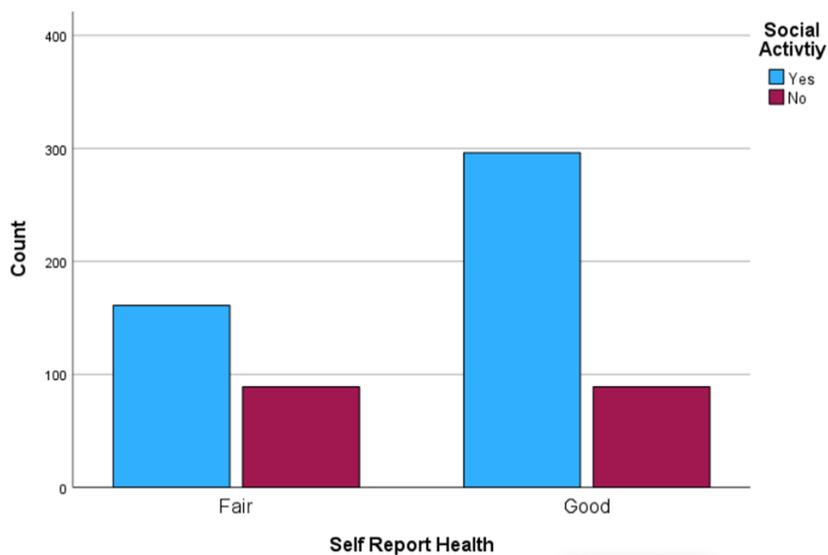
*Chi-Square Test for Going Out for Enjoyment and Self-Reported Health*

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	11.708	2	<.001
N of Valid Cases	635		

0 cells (0.0%) have expected count less than 5. The minimum expected count is 70.08.

**Figure 12**

*Bar Chart of Caregivers Going Out for Enjoyment and Self-Reported Health*



## Summary

The secondary data collected for this research study was used to determine whether an association exists between the dependent variable, self-reported health, and the independent variables, depression, age, gender, receiving respite help, and going out for enjoyment with others for African American caregivers. The study is to inform healthcare providers, administrators, policymakers, and community advocates about the variables as they make decisions, as this impacts the health outcomes of caregivers. Conducting this quantitative study validates the need for continued and future studies involving African Americans and other caregivers of color, as they navigate the healthcare system and seek resources for themselves and their sick loved ones.

The 2017 NHAT/NSOC data were analyzed using IBM SPSS Version 29. The responses from 685 African American caregivers were used for analysis in this study, and the results were presented. A descriptive analysis of the variables was conducted, and recoding of the data was necessary in order to be compliant with the assumptions of the chi-square test.

This section provided the detailed results for each research question. In summary: A chi-square test was used to evaluate the three research questions. For Research Question 1, the following factors made a significant impact on self-reported health: participants who reported good health were less likely to report depression for many days, females were more likely than males to report good health and fewer days of depression, and those caregivers between 50-60 years old and over 60 years that reported good health were also less likely to have as many days of depression. For Research

Question 2, there were no significant factors associated with those who received respite help from family members and self-reported health. Lastly, for Research Question 3, significance was found in the association between going out for enjoyment with others and self-reported health.

The next section provides an interpretation and discusses the limitations of the findings. Recommendations for additional study will also be discussed. Finally, the professional implications and implications for social change will be explored.

## Section 4: Application to Professional Practice and Implications for Social Change

### **Introduction**

The purpose of this quantitative cross-sectional study was to inform health professionals, administrators, policymakers, and advocates and provide a better understanding of the support needed by African American caregivers, especially as the number of individuals with ADRD rises and the demand for family caregivers increases. Secondary data was used to determine the association between depression levels, age, gender, the ability to receive respite help, and going out for enjoyment, and the self-reported health of African American caregivers. The purpose of this quantitative cross-sectional study was to inform health professionals, administrators, policymakers, and advocates and provide a better understanding of the support needed by African American caregivers, especially as the number of individuals with ADRD rises and the demand for family caregivers increases. The study advances professional practice by also increasing the awareness of the gaps in the literature and the variables. By informing health professionals, administrators, and advocates of the advantages that policy change or enhancement can have, this study gives a voice to the experiences of African American caregivers and increases the status of the overall health of the caregiver and therefore the quality of health of the care recipient.

### **Interpretation of the Findings**

The three research questions were presented to evaluate the association between certain variables and the self-reported health of African American caregivers. Secondary data used in this study were from 685 caregivers who responded to the survey questions

on the 2017 NHATS/NSOC. To interpret the analysis of the results, I used the chi-square test for RQ1 to determine if there is a statistically significant association between depression levels, gender, age, and the self-reported health of African American caregivers. According to Epps et al. (2021) and Samson et al. (2016), African American care recipients are disproportionately affected by dementia, thus impacting the burden to their caregivers. Abrahsohn et al. (2019) noted that African American caregivers have a higher rate of unmet health needs, choosing to care for their loved ones to the detriment of their own health. The results of this study did not support these views. The association between depression levels and self-rated health was significant with those caregivers who reported good health being more likely to not have many days where they felt depressed. Similarly, the association between depression levels and self-rated health was significant with females being more likely than males to report good health and not many days that they felt depressed. Finally, the age of the caregiver was considered. The age of the African American caregivers in the study spanned from 18 years to 92 years. The association between depression levels and self-reported health was significant by age, where caregivers aged 50 years and over were more likely to report good health and not many days of feeling depressed.

For RQ2, I used the chi-square test to determine if there was a statistically significant association between receiving respite help from family members or friends and the self-reported health of African American caregivers. Parker and Fabius (2020) noted that African Americans typically do not ask for help, nor do they utilize health and community services, even if they are available. However, the AARP (2022) countered

that African American caregivers are unaware of the services available to them. The results of this study indicated that there was no significant association between caregivers receiving respite help and self-reported health. The chi-square test was also used to interpret RQ3 to determine if there was a statistically significant association between going out for enjoyment with others and self-reported health. According to Parker and Fabius (2020), because African American caregivers choose not to utilize services, they tend to be isolated and suffer depression. Bonds and Lyons (2018) added that the available services are not culturally appropriate and therefore not utilized. The results from this study showed a positive association between caregivers' self-reported health and going out for enjoyment. In fact, those caregivers who reported good health were more likely to participate in social activities.

### **Methodological, Theoretical, and Empirical Implications**

A quantitative cross-sectional research design was used in this study to determine the association between depression levels, use of respite help, and going out for enjoyment (socializing with others), the independent variables, and the self-reported health, the dependent variable, of African American caregivers responsible for a loved one with Alzheimer's dementia. The independent and dependent variables were appropriate, and the use of cross-sectional survey data is in line with empirical implications for this secondary study.

Bronfenbrenner's 1977 ecological systems theory states that the development of a child involves interactions on multiple levels, including family and relatives, religious organizations, health providers, the community, and society. Similarly, adults form

opinions, are influenced, and make decisions based on a similar structure. The CDC (2022) calls this structure the Social-Ecological Model and created four components that educators could use in their health promotion programming. For African American caregivers, both Bronfenbrenner and the CDC's models identify factors that can contribute to their perception of good or poor health. Therefore, their health is influenced by not only their personal philosophies, but also their care recipient, extended family members, social circles, religious groups, mass media, ethnicity, and the political climate.

### **Limitations of the Study**

The results of this study were obtained from analysis of the 2017 NHATS/NSOC data with a population of African American caregivers aged 18 years and older. Some of the limitations of this study include those inherent in the use of secondary data and the self-reported activities of the caregivers.

The survey questions were not developed to answer my specific research hypotheses. Without direct involvement in the research design and instrument selection, the responses in this study are the best responses under the current circumstances that could be used for a study using secondary data. Providing the self-rated health information of the caregivers may capture perceptions of health but can also result in biased results. Latkin et al. (2018) defined this bias as *social acceptability bias*, a type of response bias that occurs when survey respondents provide or distort answers based on society's expectations rather than their own beliefs or experiences, resulting in overreporting expected "good" behavior and underreporting expected "bad" behavior.

These responses are seen in situations where sensitive questions, such as those related to mental health or depression, are asked.

Caregivers may have other responsibilities that affect their caregiving. Adult children taking care of their parents with dementia might also have a spouse or children that they also need to take care of. This is called “sandwich generation caregiving” (Ali et al., 2021). It is unknown how these family dynamics may have impacted their caregiving, depression levels, or perception of health.

### **Recommendations**

Caregiving is an important need in the lives of people advancing in age, especially those suffering from ADRD, the third leading cause of death among older adults (Alzheimer’s Association, 2022). The study results showed that there is a statistically significant association between depression levels, gender (females), age (50–60 years of age and above 60 years), going out for enjoyment, and the self-reported health of African American caregivers. There are a few questions that further research can explore: Could caregiver training have impacted their responses? Would knowing about and utilizing services have a bearing on their health status? These are questions that were not addressed in the study but are also important questions for policymakers to consider.

### **Policies/Legislation**

Caregivers of color need to be involved more in research and have access to available resources. Currently, African Americans are the least considered for research, and the AARP (2022) and Alzheimer’s Association (2022) consider this to be a systemic issue. If policymakers do not realize the extent of the problem, and the richness of

involving African Americans is not included, caregiving nationally cannot be improved. Similarly, advocates for caregivers of color can learn of and promote available resources and research. Policymakers need to ensure that existing legislation such as the RAISE Act of January 2018, which requires the DHHS to develop integrated services for family caregivers and improve coordination across federal government programs, is enforced and available for all families.

According to Ali et al. (2021), some states compensate eligible family caregivers through their Medicaid expansion program. Policymakers should consider this expansion and eligibility of caregivers for all states rather than just a few.

### **Healthcare Providers**

Communication between healthcare providers and African American family caregivers is key and should be a standard of care. Healthcare providers can be the gateway to caregivers accessing desperately needed resources. Providers assessing the needs of the care recipient should also assess the needs of the caregiver. This caregiver assessment addresses the competencies and health of the caregiver and determines the need for skills training, counseling, social services, and follow-up. Culturally competent resources that promote evidence-based practices can ease the burden on caregivers and promote health that benefits both the caregiver and the recipient (Ali et al., 2021; Brewster et al., 2020; Epps et al., 2020).

At the point where the healthcare provider is no longer able to provide the necessary resources for the caregiver, a referral can be made to other allied health services such as a caregiver family care therapist. Family care therapy is a treatment

model that guides families through transitions of later life, addressing the needs of the care recipient, the caregiver, and their family members, including self-care and social concerns (Ali et al., 2021).

### **African American Caregivers**

Caregiving for African American care recipients who may have previously been the foundation for the family is difficult. The family caregiver is now making health, medical, insurance, financial, and end-of-life decisions for the loved one who raised them. Preparing for this role by being trained and receiving support is key. Considering the multiple levels of influence may be helpful. Communicating with other family members, and remaining connected to the community, local church, or social group enables normalcy for the care recipient and provides resources for the caregiver. According to Adriann Fraser-Johnson, having a plan, knowing when to ask for help, and realizing the importance of self-care is vital. The people that were the most important for her as she took care of her mother with dementia were a spiritual leader (priest), a Gerontologist, a financial advisor, a lawyer, and a therapist (A. Fraser-Johnson, African American Family Caregiver, personal communication, June 27, 2023). It is imperative that African American caregivers maintain their personal health so that they can improve the health of their loved ones.

### **Implications for Professional Practice**

Implications for professional practice include knowledge and education useful for healthcare providers, advocates, healthcare administrators, specialty providers, and health researchers who provide care to persons with Alzheimer's and want to lessen the burden

of their caregivers. Perhaps the greatest challenge for providers is coordinating the care of the care recipients and their family caregivers. Services needed for a care recipient can vary from medical, health and wellness, and potentially rehabilitation to transportation, social, financial, and legal. A health professional with knowledge and experience can help the family navigate the healthcare system, coordinate care, and locate services, ensuring that needs are identified and addressed, especially if the caregiver has another job (Ali et al., 2021). A health professional who knows the care recipient and the caregiver and has assessed the family can refer them to specialty services that focus on the long-term care of the dementia patient and the needs of the family. Access to information such as a local gerontologist, alternative services such as adult day centers, advocacy, counseling, support groups, and financial assistance, can help the family as they transition to their different life.

Lastly, being aware of pending and ongoing policies that impact the ADRD population and their families ensures that research and new services are utilized quickly and efficiently (AARP, 2022). Results from this study may help health professionals to educate their African American caregivers to access the resources, help, and support that they need to increase their quality of health and the health of their care recipient.

### **Implications for Social Change**

Positive social change is considered a deliberate process to create and apply strategies and actions to promote the health and dignity of individuals, the community, and society. Positive social change leads to an improvement in the community and society as a whole. As the population of persons with dementia continues to increase,

creative interventions are necessary to support family caregivers, especially those of color. Social change implications of this study for public health practitioners and providers may include collaborating with advocates, community organizations, and churches to develop or adapt culturally appropriate education, resources, and interventions that prioritize and support family caregivers of color. Health policy planners, religious leaders, health care professionals, and stakeholders may utilize the study findings to conduct health promotion campaigns targeting African American family caregivers which may assist with improving caregiver health outcomes.

The significance of this study is that it may provide a better understanding of the support needed by African American family caregivers. This study may contribute to public health by providing evidence that family caregivers have a normal level of depression yet consider their personal health to be high, particularly among female caregivers and those over the age of 50. It highlights the support disparities that may be experienced by African American caregivers. Findings from this study may foster the development of culturally appropriate interventions and research to meet the specific needs of African American caregivers. Through increased knowledge about the importance of self-care, strategies can be identified to reduce the risk of depression, fatigue, stress, and other related health disorders. Although personal self-care is vital for health, community interventions, and targeted research need to be developed that appreciates the uniqueness of the culture of African American families and offers solutions to improve their health and health outcomes.

## Conclusion

Studies have indicated that African American family caregivers are burdened and stressed from the impact of being the carer for their loved ones affected by ADRD, especially as the population ages, those suffering from ADRD increase, and healthcare funds decrease. Their quality of life can negatively impact their health and well-being (Anderson et al., 2019; Sheehan et al., 2021). This research contributes to the increasing body of knowledge addressing African American family caregiver health and shows that their responsibility to the care recipient does not waver, their perceived health is satisfactory, and that there is an information gap that can be filled.

The significance of this quantitative secondary study can guide healthcare providers, administrators, advocates, community leaders, policymakers, and the community that the voice of African American family caregivers must be acknowledged and heard to address and resolve the long-term challenge of including caregivers of color in their programming. African American family caregivers are resilient (Liu et al., 2020), and healthcare providers can help to make the caregivers' navigation of the healthcare system easier by being educated about local resources and coordinating the care of the recipient and the caregivers to maximize efforts. Evidence collected and data analyzed from this study can educate policymakers who can also provide federal funding and resources to support family caregivers in all states.

This doctoral study opened my eyes to the misperceptions and challenges that African American family caregivers have in navigating the healthcare system to provide the best quality of life for themselves and their loved ones suffering from ADRD. During

my research, I became more aware of the need for African American caregivers to have access to appropriate information and support to acquire the resources that they need. I also learned that research such as this is vital for African American family caregivers to be invited to the research arena and have their opinions valued. Without their inclusion in research, we may never have a true picture of how important the contribution of family caregivers actually is.

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## Appendix: Permission to Use the Dataset

National Health and Aging Trends Study (NHATS):  
Sensitive Data Investigator Form

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**Investigator:**

Dr. Claire Robb, PhD, MPH

NAME

SIGNATURE

claire.robb@mail.waldenu.edu

EMAIL ADDRESS

2/2/2022

DATE OF SIGNATURE

941-587-2954

PHONE CONTACT

Check here if Investigator is applying on behalf of a student pursuing a terminal degree and indicate student name below:

STUDENT'S NAME: Ruth Francis, MPH, MCHES

STUDENT'S USERNAME: Ruth Francis (FrancisRE@F)

Candidate for (check one):  PhD  MD  MPH  MS/MHS/MA  other DrPH (specify)  
(Note: student must sign the Sensitive Data Supplemental Agreement with Research Staff)

**Institution where Investigator holds appointment:**

Walden University

NAME

100 Washington Avenue South, Suite 900

STREET ADDRESS

Minneapolis, MN 55401

CITY, STATE, ZIP

<https://www.waldenu.edu/>

LINK to WEBSITE or URL of INSTITUTION

## National Health and Aging Trends Study (NHATS): Sensitive Data Use Agreement

Data Set Requested (Check one or more):

NHATS Sample Person Sensitive Demographic File		NHATS Other Person Sensitive Demographic File	
<input type="checkbox"/> Round 1	<input type="checkbox"/> Round 7	<input type="checkbox"/> Round 1	<input type="checkbox"/> Round 7
<input type="checkbox"/> Round 2	<input type="checkbox"/> Round 7 DBS	<input type="checkbox"/> Round 2	<input type="checkbox"/> Round 8
<input type="checkbox"/> Round 3	<input type="checkbox"/> Round 8	<input type="checkbox"/> Round 3	<input type="checkbox"/> Round 9
<input type="checkbox"/> Round 4	<input type="checkbox"/> Round 9	<input type="checkbox"/> Round 4	<input type="checkbox"/> Round 10
<input type="checkbox"/> Round 5	<input type="checkbox"/> Round 10	<input type="checkbox"/> Round 5	
<input type="checkbox"/> Round 6		<input type="checkbox"/> Round 6	
<input type="checkbox"/> NHATS Round 10 COVID-19 Family Members and Friends File			
<input type="checkbox"/> NHATS Round 1 National Study of Caregiving (NSOC) files			
<input type="checkbox"/> NHATS Round 5 National Study of Caregiving (NSOC) Files			
<input type="checkbox"/> NHATS Round 7 National Study of Caregiving (NSOC) Cross-Sectional Files			
<input checked="" type="checkbox"/> NHATS Round 7 National Study of Caregiving (NSOC) Cross-Sectional and Time Diary Files			
<input checked="" type="checkbox"/> NHATS Round 7 National Study of Caregiving (NSOC) Longitudinal Files			

By signing this form and obtaining the requested data set(s) from NHATS, the User agrees:

1. To use the data set solely for statistical reporting and analysis.
2. Not to share these data with, or provide copies of these data to, any other person or organization. Note: Each individual working on the research project, such as a research assistant/associate or graduate or undergraduate student, must sign the Supplemental Agreement with Research Staff form.
3. To return or destroy the data set, and any derivative data files, upon request from NHATS.
4. To make no attempt to link this data set with individually identifiable records from any source, or in any other way to attempt to identify the persons in this or other NHATS datasets.
5. That if the identity of any person in this data set is inadvertently discovered, then (a) no use will be made of this knowledge, (b) the Director of NHATS will be advised of this incident immediately [email [nhatsdata@westat.com](mailto:nhatsdata@westat.com); subject line: Director of NHATS], (c) the information that would identify any individual will be safeguarded or destroyed, as requested by NHATS, and (d) no one else will be informed of the discovered identity.
6. To employ the following guidelines when producing tabulations for distribution:
  - Magnitude Data: Ensure that no cells/strata with  $n < 5$  are produced.
  - Frequency Data: Ensure that no cells or categories with  $n < 5$  are produced.
7. Aggregate statistical summaries of the data and analyses (frequency tabulations, magnitude tabulations, means, variances, regression coefficients, and correlation coefficients) are approved under this agreement and may be freely published by the User, subject to the provisions above.
8. To cite NHATS as the data source in any publications or research based upon these data. The following citation should be included in any research reports, papers, or publications based on these data:
 

*In text:* "National Health and Aging Trends Study (NHATS) is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by the Johns Hopkins University."  
*In references:* "National Health and Aging Trends Study. Produced and distributed by [www.nhats.org](http://www.nhats.org) with funding from the National Institute on Aging (grant number NIA U01AG32947)."
9. To provide citations for any publications (and PMCID) from these data to NHATS ([nhatsdata@westat.com](mailto:nhatsdata@westat.com); subject line: NHATS citations).
10. To the extent permitted by law, to hold harmless and indemnify NHATS and the Johns Hopkins University, its agents and employees, for any claims of breaches of confidentiality arising out of his/her research, defined as failure to abide by any section of this agreement or any accidental or intentional violation of privacy of any contributor to any NHATS data resource.

User ID from NHATS data registration at ([www.nhats.org](http://www.nhats.org)):

Investigator Signature  
 Dr. Claire Robb, PhD, MPH  
 Name (printed or typed)

Contributing Faculty  
 Title  
 Walden University  
 Employer/Institutional Affiliation

## National Health and Aging Trends Study (NHATS): Sensitive Data Use Agreement

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The undersigned Research Staff, in consideration of their use of Sensitive Data from the National Health and Aging Trends Study, agree:

- A. That they have read the associated Data Use Agreement for the Use of Sensitive Data from the National Health and Aging Trends Study
- B. That they are "Research Staff" within the meaning of the Sensitive Data Use Agreement.
- C. To comply fully with the terms of the Agreement.

The Investigator named in the Sensitive Data Use Agreement agrees that the persons designated herein are Research Staff within the meaning of the associated Data Use Agreement for Sensitive Data from the National Health and Aging Trends Study.

Investigator agrees to ensure that each Research Staff person signs this Supplemental Agreement.

**Research Staff**

Ruth Francis

NAME TYPED OR PRINTED

FrancisRE@F

User ID

  
SIGNATURE

2/2/2022

DATE

NAME TYPED OR PRINTED

SIGNATURE

DATE

User ID

NAME TYPED OR PRINTED

SIGNATURE

DATE

User ID

**Investigator**

NAME TYPED OR PRINTED

SIGNATURE

DATE

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