Examining the Relationship Between Community-Based Support Services Use and Mental Health in Black Family Caregivers of Persons Living with Dementia

by

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Dedication

This dissertation is dedicated to my heartbeats, my children: Whitney, Andrew, Chris, Sydney, and Stephen; my grandchildren: Amiyah, Cameron, Mason, and Andrew Jr. I love you with all my being.

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Abstract

Background: Without remuneration or training, spouses, family members, and friends provide 83% of dementia patients' basic personal care. Caring for a person living with dementia is stressful and can negatively impact the caregiver's health. Caregiver stress is a major issue for Black family caregivers. Black family caregivers' stress-related mental health issues can be addressed through community support services (CSS) such as support groups, help-seeking, respite, and dementia training. CSS can help the person living with dementia and their community-dwelling caregivers delay or avoid institutionalization and stay safe in their homes. This study examines how using CSS affects Black family caregivers' mental health.

Framework: The study utilized Pearlin's caregiver stress model to guide the analysis, highlighting the importance of support services in moderating the relationship between stress and mental health outcomes.

Method: This mixed-method study used logistic regression, bivariate, and multivariate models to analyze the nationally representative 2015 NHATS Round 5 and NSOC Rd II datasets (n= 2,204) caregivers using Stata 17. The RaDAR method was used to analyze and develop themes from the focus group (n=6) participant interview.

Results/Conclusion: One-quarter (25%) of the Black caregivers reported feeling anxious, and over a fifth (23%) reported feeling depressed. Fewer than 5% of the dementia caregivers participated in support groups: only 7% received training. Regardless of dementia classification, neighborhood cohesion is lower for both White and Black caregivers. The results suggest that

Black caregivers may be experiencing more anxiety and depression than their White counterparts. Further, there was no distinction between Black and White family caregiver stress or use of support services. The focus group (n = 6) participants validated the quantitative findings that Black caregivers are less likely to use CSS, particularly respite and support groups. The focus group participants reported that financial constraints and lack of free time were the main barriers to support group and respite use.

Chapter 1 Introduction

1.1 Introduction

Every 65 seconds, someone is diagnosed with Alzheimer's disease (Alzheimer's Association, 2021), a brain disorder that most frequently causes dementia, accounting for 60-80% of cases (CDC, 2019). It is projected that approximately 12.7 million older adults aged 65 and older will be diagnosed with Alzheimer's dementia by 2050, according to the Alzheimer's Association (2022). Cognitive disorders such as Alzheimer's affect brain regions that regulate cognition, memory, and language. (Alzheimer's Association, 2021 & CDC, 2019; NIH/NIA, 2021). A common term used to describe Alzheimer's disease and a variety of other degenerative neurological illnesses is dementia (Alzheimer's Association, 2022). Each form of dementia is distinct, though there is an overlap in symptomology and disease trajectory. Although there will be unique symptoms, the core cause of dementia, degenerative changes in the brain, is the most distinguishing factor. People with dementia have difficulty processing and remembering new information. They may struggle to find the appropriate words, become lost in their thoughts, and find it difficult to articulate their ideas.

Dementia greatly impairs cognition; therefore, the person's recall deficits related to time and location frequently become obvious early in the disease process (Hillis, 2022). It severely impairs a person's ability to perform daily tasks and often begins with moderate memory loss. It progresses to a loss of the capacity to carry on a conversation and react to the environment (Alzheimer's Association, 2022 & CDC, 2019; NIH/NIA, 2021). In its later stages, persons living with dementia cannot perform even the most basic personal care tasks and require the support of caregivers—often family members (Shepherd et al., 2009; NIA/NIH, 2021; Gaugler et al., 2013). Due to the significant increase in the number of people diagnosed with dementia and cared for by untrained, overwhelmed family members who lack supportive resources, dementia family caregiving has been the subject of many research studies in the caregiving literature. (Schulz & Martire, 2004).

A family caregiver is an adult family member who provides a wide range of assistance and care to a person living with dementia (Merriless, 2016). Unpaid and untrained spouses, other family members, and friends provide 83% of the essential personal care persons with dementia receive (Alzheimer's Association, 2021; CDC, 2019; Merrilees, 2016; Rifin et al., 2017; Snyder et al., 2015; Sorensen et al., 2006; van den Kieboom et al., 2020). Almost half of all unpaid caregivers assist older adults who live with dementia (Alzheimer's Association, 2020). In 2020, more than 11 million Americans provided unpaid care for people with dementia, totaling an estimated 15.3 billion hours of help worth close to $250 billion (Alzheimer' Association, 2021; NAC, 2021). Dementia can cause people to become physically reliant and may manifest in challenging behavioral symptoms such as constant questioning, verbal or physical aggressiveness, and refusal of care (Merrilees, 2016). The care provided by family caregivers is difficult, unpredictably complex, and physically, emotionally, and financially taxing (Merriless, 2016).

Care recipients and caregivers have recently advocated for a more equitable and inclusive phrase because they understand that caring is a two-way street and that both parties have possibilities to offer and receive (Mallery, 2020). A caregiver is someone who gives care to someone who is unable to take care of themselves; a care partner is someone who supports the care receiver. The term "caregiver" implies that there is only one way for two people to interact:

one gives and the other receives (Mallery, 2020). For the purposes of this study, the term caregiver will be used.

The stress and burden associated with caring for someone with the gradual progressive degeneration of dementia can negatively impact the CGs' physical and mental health (Penning & Wu, 2016; Sorensen et al., 2006). A new dementia diagnosis can result in the caregiver mourning over the loss of a personal connection, changes in family responsibilities, changes in employment, and transition to a more formal caregiving role as the person living with dementia (PLWD) becomes increasingly dependent (Cabote et al., 2015; Reinhard et al., 2008). Unfortunately, the amount of time CGs spend providing care, 69 to 117 hours per week, often leaves them with little time or money to attend to their own health-promoting activities and healthcare requirements (APA, 2015; Johnson et al., 2004; Sorensen et al., 2006; Elliott et al., 2010). Although there has been increased focus on dementia family caregiving, there is a gap in the study of Black dementia family caregiving.

1.2 The Black Family Caregiver

Older Black adults are twice likely to have higher rates of dementia and are diagnosed later in the disease process, which increases the workload for their family caregivers (Robinson-Lane et al., 2020). They provide care to PLWD with higher degrees of dementia-related behavioral symptoms, report more unmet requirements, and give care with more intensity (Aranda et al., 2021). Black family dementia caregivers commonly absorb the health consequences of decreased physical and psychological wellbeing, productivity, and income (IOM, 2001). Though Black caregivers are at a higher risk of developing dementia and other comorbid diseases, more frequently report work-related issues, and generally carry more care load, they have remained underrepresented and understudied in objective stress studies, limiting the researchers’ understanding (Cothran et al., 2021). There is an urgent need to engage the Black dementia caregiver if scientists want to fully understand how the combination of high prevalence, greater severity, and late diagnosis of dementia in older Black adults differentially impacts the Black family caregivers of those living with dementia in the community (Chin et al., 2011).

Although dementia is a condition involving cognitive decline, the non-cognitive aspects, often known as behavioral and psychological symptoms associated with dementia (BPSD), are more difficult for caregivers to manage and have the most significant influence on whether the individual is institutionalized (Ornstein et al., 2013). Healthcare access and quality discrepancies between races and ethnic groups have been well-documented (Johnson et al., 2004). High-stress levels occur daily for many Black people, especially Black dementia family caregivers who experience it more (Cothran et al., 2021). Structural socioeconomic injustices such as racism and discrimination are well-documented recurring sources of chronic stress (Cothran et al., 2021).

Black older adults face adverse social determinants of health and are disproportionately represented among the uninsured, contributing significantly to racial and ethnic inequities in healthcare and support services access (Beancourt & Maina, 2004). In 2021, the Alzheimer’s Association reported that cost of care, dearth of insurance coverage, and lack of access to community healthcare facilities were significant barriers for Black caregivers seeking dementia resources and support. There has been an increase in the research on how community support services use among caregivers’ moderate stress and improve mental health. However, health disparities among Black family caregivers of people living with dementia have been understudied (Cothran et al., 2021), necessitating more research on community support services use among Black family caregivers.

Black older adults experience health disparities in dementia care/caregiving because they face disproportionately low rates of dementia diagnosis, treatment access, quality care, and involvement in clinical research and trials due to stigma, lack of diversity among healthcare workers, distrust in medical research, and the American healthcare system (Alzheimer's Association, 2022). The continued health disparities and inequities experienced by Black family caregivers illuminate the lack of focus on ethnic minority caregivers and how to best help them engage with community-based support services and remove barriers to receiving care (Hossain & Khan, 2020). It is important that we study racial and ethnic disparities as older Black adults and family caregivers are largely underrepresented in studies and clinical trials pertaining to the diagnosis and treatment of dementia (Alzheimer' Association, 2022). More research is needed to further cast light on health disparities experienced by Black family caregivers and provide information on related causative factors.

1.3 Inequity in Mental Health Coverage and Access to Community-Support Services

There are inequities in the availability and accessibility of mental health services at all levels and in most circumstances, for dementia family caregivers (Burns, 2009). Socioeconomic and underinsured status may hinder access to mental health care in high-income and low- and middle-income nations (Burns, 2009). Research has shown that low-income individuals identified financial hurdles to getting care (Burns, 2009). Black people, people of lower socioeconomic status, and people with cognitive and physical impairments are disproportionately exposed to conditions and environments that negatively affect health risks and outcomes, resulting in higher rates of health disparities **(**NCSL, 2021).

Health disparities refer to the unequal distribution of health outcomes among different population groups. They occur when certain groups of people experience a higher rate of disease, injury, chronic health conditions, or death than other groups (CDC, 2021). Though health disparities are frequently associated with unequal distribution of health outcomes, healthcare disparities refer to inequalities in health insurance coverage, access to and utilization of care, and treatment (CDC, 2021). Although Medicare is a government-run healthcare program for those over 65 in the United States (Kelley et al., 2015), it does not cover many health-related expenses most important to those with chronic diseases or life-limiting conditions, such as home care, equipment, and community-based support services. These unmet and uninsured demands are most prevalent among PLWD and their caregivers (Kelley et al., 2015). Insurance status affects not only the person living with dementia but also the caregiver, disparities in healthcare coverage are well-documented regarding their existence and the associated negative consequences for the PLWD and their caregivers (IOM, 2001; Johnson et al., 2004). Inadequate insurance coverage and difficulties navigating the healthcare system are factors that cause or contribute to inequities in access to care (NCSL, 2022).

Regarding dementia care, older Black adults encounter discrimination (CDC, 2021). According to the Alzheimer's Association's findings from two national surveys, Black Americans experienced the most prejudice in dementia health care, followed by Native Americans, Asian Americans, and Hispanic Americans (Alzheimer's Association; CDC, 2021). Black family caregivers' interactions with health care and community services providers diminish when they experience discrimination from the providers (Alzheimer's Association, 2021). Because the healthcare systems have historically underserved this population, they tend to rely less on professional care, have longer wait times for initial diagnoses, and have less access to dementia education, training, support services information, insurance, and healthcare services

(McCarthy et al., 2022). The costs and repercussions of uninsured and underinsured populations are unseen and difficult to quantify, particularly among family caregivers. IOM, 2001).

Uninsured family dementia caregivers are far more inclined to ignore medical needs. They also get fewer preventive services and are less likely to get regular treatment for chronic illnesses like hypertension, dementia, and diabetes (Schulz & Martire, 2004). Uncontrolled chronic diseases can lead to costly and disabling complications (IOM, 2001, Sorensen et al., 2006). When obtaining care and community-based support services (CSS), uninsured and underfunded family dementia caregivers frequently encounter stigma and bias (Johnson et al., 2004), impeding their efforts to get CSS (Johnson et al., 2004).

Additionally, caregivers with acute exacerbation of poorly managed chronic diseases may destabilize the PLWD if their caregiver cannot carry out their caring duties: burnout among caregivers can have disastrous consequences (Sanders, 2016). For instance, the PLWD’s access to medication and medical appointments can be affected leading to serious safety and medical complications. Most disparity research has focused on technical aspects of care, such as receiving specific tests, therapies, or procedures. (Johnson et al., 2004). However, to close the gaps in care, promote fairness, and begin to combat discrimination faced by Black family caregivers, it is crucial to validate the Black caregivers’ personal experience with racism and discrimination (Gardiner et al., 2021). Furthermore, health systems must address the historical prejudice and institutional inequities that inhibit Black caregivers’ access to mental health and community support services (Le & Boddie, 2020).

1.4 Importance of Perceived Adequacy of Coverage and Support

There are two ways to look at coverage and social support: how it is seen and how it is given. Perceived adequate coverage and social support are how a person feels about the amount and quality of support they get from their social network. Received social support, on the other hand, is the objective measurement of how much insurance, help, and to support a person gets from his or her social network. Research has shown that perceived adequacy of insurance social support is a better indicator of an individual’s happiness than received coverage and social support. It is also closely linked to personality traits like optimism and self-esteem (Ong et al., 2018; CDC, 2019). Support can take the shape of natural aid from others or perceived support, which measures people’s trust in the availability of enough help when they need it; the perceptions of the adequacy of the coverage and perceived support among Black caregivers of PLWD have received less attention (Roohafza et al., 2014).

Perceived support can also be explained as reflecting a person’s view of their circumstance instead of accurately indicating the degree of help (Eagle et al., 2019). Historically, access to care has been more difficult for Black and other minoritized and/ or low-income populations. One explanation is that they’re more likely to be uninsured than White people and people with high-income levels (AHRQ, 2021; Chin et al., 2011; Johnson et al., 2004). They are less likely than older White adults to receive routine medical care and have higher morbidity and mortality rates (AMA, 2022).

1.5 Stress

In a broad sense, stress represents a process in which an individual’s perceived demands or threats surpass his or her available resources (Cothran et al., 2021). Long-term caregiving may generate stressors that put caregivers at risk for worsening physical, emotional, and mental health (Ong et al., 2019; Owens & Chadiha, 2013). Older adults' care is well-documented in the extant literature (Ong, 2018). Long-term caregiving for the older adult can be a source of chronic stress that affects not just the everyday lives and health of the caregivers but also society (Ong et al., 2018). Research has shed light on the distinctions between dementia caregiving and providing care to an older adult with physical impairment alone, validating subjective accounts that dementia caring is the more stressful sort of family caregiving (Schulz & Martire, 2004). In formal and hypothetical terms, caregiver stress is described as the inequitable exchange of help between people in close relational proximity, resulting in psychological and physiological stress for the caregiver (Sanders, 2016). Family caregivers for older adults with chronic stress will experience worsening chronic conditions and are frequently at high risk for developing more health issues (Sanders, 2016; Schulz & Martire, 2004).

Being an older Black female or a spousal caregiver with lower socioeconomic status places the caregiver at higher risk for self-reported depressive symptoms, subjective burden, and poorer physical health (Owens & Chadiah, 2013). Universally, Black people experience daily pressures that negatively impact their health. The additional stressors associated with dementia caregiving may increase negative health consequences (Cothran et al., 2021). Stress has connected with sleep disturbances and depressive symptoms; additionally, it has been found that discrimination was an independent contributor to depressive symptoms (Cothran et al., 2021).

1.6 How Black family caregivers cope with stress-related adverse mental health outcomes

Community support services are essential and can play an essential role in addressing the issue of stress-related adverse mental health outcomes for Black family caregivers (Roohafza et al., 2014). While these services are valuable to all families affected by dementia, broadening them to respond to the needs of Black caregivers, who are already at risk of poor health and wellness due to their caregiving responsibilities, would be advantageous (Parker et al., 2020). This proposed study will examine the gap around the underutilization of community support services by Black dementia caregivers and the effects on their mental health, using a mixed-method approach to better understand this phenomenon; policy-level initiatives are in short supply to address these unmet needs and systemic drivers of inequality (Parker et al., 2020).

1.7 Background

Health status, lifestyle, and socioeconomic factors influence the racial difference in risk factors, dementia diagnosis, and disease severity (Zhang, 2016; Galvin et al., 2021; NIA-NIH, 2021). Indicators of situational pressures that may predispose caregivers to high levels of stress, decreased emotional health, and poor physical health is characteristic of the care recipient's behavior issues, such as care resistance, frequent waking at night, nighttime caregiving, and inability to fall back to sleep (Liu et al., 2022). Reduced preventative health behaviors and decreased socialization have been connected to the caregiving load, negatively affecting the care recipient. Behavioral issues such as verbal outbursts, inappropriate social behaviors, impulsivity, resistance to care, agitation, striking, wandering, and inappropriate acting out that sometimes accompany complex dementia can be highly stressful for caregivers (Mitchell et al., 2011; Sanders, 2016). Additionally, caregivers' overall impaired health may be due to persistent stress. Many therapies have proven beneficial in cognitive-behavioral coping (Gillman & Turner, 2013).

Dementia diagnosis, mourning over the loss of a personal connection, changes in family responsibilities, changes in job demands, positive and negative effects of family caregiving, and transition to the formal caregiver as the PLWD becomes increasingly dependent on the caregiver are some of the complications of dementia caregiving (Cabote et al., 2015; Reinhard et al., 2008); these illustrate how physically, and emotionally demanding dementia caregiving can be. This unique and complex problem is primarily described as stress, burden, and negative physical and mental health repercussions (FCA, 2006; Meyers, 2003). Although dementia is a condition involving cognitive decline, the non-cognitive aspects, often known as behavioral and psychological symptoms associated with dementia (BPSD), are more difficult for caregivers to manage and have the most significant influence on whether the individual is institutionalized (Ornstein et al., 2013). The combination of high prevalence, greater severity, and late diagnosis of dementia in older Black adults differentially impacts the Black family caregivers of those living with Alzheimer's Disease and Related Dementias (Chin et al., 2011).

1.8 Community Support Services (CSS)

The purpose of community support services is to assist community-dwelling caregivers and people living with dementia to remain safe in their homes and delay or avoid institutionalization. CSS provides and acts as a conduit to necessary resources for caregivers and the person living with dementia, such as wellness programs, nutritional support, health, and aging educational programs, individual caregiver counseling, housing assistance, and financial and general safety aid (Siegler et al., 2015; Ejem et al., 2014). These programs can help reduce the negative impacts of stressful caregiving relationships and their impact on mental health (Ejem et al., 2014). Community support services extend emotional support that improves self-confidence and belonging and instructional guidance for people living with ADRDs. Social support is necessary to reduce adverse mental health outcomes (Harandi et al., 2017).

Studies of ADRDs caregivers proved that support systems are crucial for distributing tasks and chores of caring, validating caregivers' desires for self-care, and mitigating the mental health impact (Au, 2010; Waligora, 2019). Community support services can help caregivers improve their health and potentially mitigate the negative impacts of life pressures (Ejem et al., 2014). Community support services include social support such as family and friends, support groups, meals on wheels, senior centers, respite care, adult day services centers, ADRD training, and spiritual support. CSS may be administered by federal, local, or state governments, charities, or religious organizations, though caregivers may have to pay a fee to use these services (Siegler et al., 2015).

Clinicians should learn about CSS and the organizations that provide them. Providers need to know about CSS and work with them to build more flexible and responsive care models (e.g., medical homes) for caregivers and those living with dementia. The services and assistance these organizations provide can be vital in assisting caregivers in keeping the person living with dementia in the community (Siegler et al., 2015). As healthcare shifts toward a more innovative and holistic treatment approach, CSS staff and primary care experts have the opportunity to work together to preserve patients' health and enable them to remain securely in the community (Siegler et al., 2015).

1.9 Neighborhood Cohesion

The trusting network of relationships and shared beliefs and customs among inhabitants in an area is known as neighborhood social cohesiveness (Brisson, 2015). Neighborhood cohesion arose concurrently with early conceptions of community spirit. However, community spirit has taken on a broader meaning, such as comprehending community relationships beyond individual interactions and habits (Gan et al., 2021; Brisson, 2015). Neighborhood cohesion goes beyond neighborhood friendliness; it defines how neighbors regularly care for and support one another; their social interdependence is a protective mechanism (Gan et al., 2021; Cagney et al., 2009; Dong & Bergren, 2017). Neighborhood cohesion is linked to positive health (Dong & Bergen, 2017). Caregivers residing in cohesive neighborhoods can experience less stress knowing that neighbors can assist with caring for their loved ones. Neighbors can offer to help with instrumental activities of daily living (iADLS), such as laundry, cooking, and running errands (Brisson, 2015). Millar (2020), in his work, noted that neighborhood cohesion might act as a safeguard for older adults' health by offering social support and empowering the adoption of positive health attitudes like increased physical activity. Health conditions such as high blood pressure and diabetes improved for residents in these cohesive neighborhoods (Robinettee et al., 2017).

Neighborhood settings may have varied effects on older adults from different ethnoracial groups. For example, policies linked with structural racism (redlining) have exacerbated racial disparities in exposure to disadvantaged areas, particularly among older persons (Millar, 2020). A neighborhood with inadequate social, physical, and financial resources is one of the ways that health disadvantages have been shown to accumulate over time, predominantly impacting older Black individuals who have historically been disadvantaged (Millar, 2020). Disparities related to neighborhood cohesion are not limited to low socioeconomic areas. Racial and ethnic minority older adults residing in high-income neighborhoods experience health disparities, indicating that the benefits generally associated with spending time in more affluent places deliver varied returns to health and well-being depending on race and ethnicity (Denneu et al., 2018).

1.10 Specific Aims

Disparities in the utilization of community support services among Black family caregivers of people living with dementia, as well as the impact of community-based support services on the mental health of Black family caregivers, will be investigated in this study. This proposed mixed-method strategy combines focus group data from a prospective Black family caregiver research project with analysis of data from the National Health & Aging Trends Study (NHATS and the National Study of Caregiving [NSOC]). Focus group interviews with six current and former caregivers from the planned research will make up the qualitative portion of the study, which will help researchers learn more about the barriers and facilitators of community support services and will amplify the challenges faced by Black caregivers and their lived experiences with the use of community resources. Using secondary data from the NHATS and NSOC, this mixed-methods study will examine the relationship between mental health and the utilization of community-based support services and the impact of neighborhood cohesiveness on such programs. The study aims are as follows:

Aim 1: Examine how community support services affect the mental health of Black caregivers of people living with dementia in the community by analyzing data from the NHATS 5 and NSOC II.

Aim 2: Investigate the effect of neighborhood cohesion on the Black caregiver's mental health by analyzing NHATS round 5 and NSOC data round II.

Aim 3: Examine the factors influencing the use of community support services, including facilitators and barriers, through focus groups with a small sample of Black family caregivers.

Each approach informs the understanding of the findings by iteratively analyzing the qualitative and quantitative data. Upcoming chapters of this study include a detailed review of the literature (chapter 2), and a comprehensive description of the methods for addressing and achieving aims 1-3 of this study.

Caregiving can significantly impact the caregiver's life in various ways, including their ability to work, participate in interpersonal interactions, and maintain excellent physical and mental health. Emotional, psychological, and social well-being are part of individual mental health. It impacts the way a person thinks, feels, and behaves. It also influences how a person deals with daily stress, interacts with people, and makes good decisions. Mental health is vital at all phases of life, including youth, puberty, and maturity (CDC, 2021; MentalHealth.gov, 2020).

The cornerstone for an individual’s well-being and good functioning is mental health. It’s more than just the lack of a mental illness; it’s the ability to think, learn, and comprehend one’s feelings and those of others. Internally and externally, mental health is a state of balance. This equilibrium combines physical, emotional, intellectual, social, economic, cultural, spiritual, and other linked variables (WHO, 2021).!

Chapter 2 Literature Review

This chapter synthesizes the literature related to the experiences of Black family caregivers of people living with dementia. Specifically, I consider how community-based support services and neighborhood cohesion may influence the relationships between stress, mental health, and caregiver burden. Chapter two also describes the disparities, and differentiation between Black caregiver stress and other ethnic groups, as well as the facilitators, and barriers to support use.

2.1 Defining Dementia

Dementia is a set of symptoms linked to a loss of memory, reasoning, or other cognitive abilities (Brodaty & Donkin, 2009). Some people live well into their nineties and beyond without showing any signs of dementia (NIH, 2021; Quinones et al., 2020). While the chance of getting dementia increases with age, dementia-related cognitive impairments should not be equated with the normal aging process (Olivari et al., 2020; Michigan.gov, 2022; NINDS.NIH. gov, 2022). Alzheimer's disease is thought to cause between 60 and 80 percent of dementia cases, even though dementia has various origins. (NIH, 2021; Olivari et al., 2020). Alzheimer’s disease, frontotemporal dementia, Lewy body dementia, vascular dementia, and mixed dementia are the five most common types of dementia (Alzheimer’s Association, 2021). The type of dementia determines the disease trajectory and may influence the level of care provided by the caregiver and the behavioral and psychological symptoms associated with dementia (BPSD), such as physical aggression, verbal outbursts, and resistance to care. (Ornstein et al., 2013; Schulz &

Sherwood, 2017). Since there is no treatment for dementia, early recognition of symptoms is critical for management (Alzheimer’s Association, 2021). Obtaining an early diagnosis, however, might aid in managing the illness and seeking support services information (NIH, 2021; Quinones et al., 2020).

2.2 The Scope and Significance of the Caregiving Role

The intricacies and duties of being a caregiver are substantial and can be summarized as follows: caregivers endure many of the same stresses as people living with dementia but receive less support (Sharpe, 2018). Love, gratitude, spiritual satisfaction, obligation, guilt, and societal constraints can motivate family members to care for others (Brodaty & Donkin, 2009). Family caregivers are significant since they act as the person's ears, eyes, advocates, and information gatherers and spend substantial time with the care recipient (Reinhard et al., 2008; Sharpe, 2018). Caregiving can impact the caregiver in various ways, including their capacity to work, engage in social activities and maintain excellent physical and mental health (APA, 2015; CDC, 2019; FCA, 2006). Caring for others has all the characteristics of a chronic stress experience: It causes physical and psychological strain over extended periods, is accompanied by high degrees of unpredictability, and uncontrollability can cause secondary stress in numerous life domains, including job and family relationships, which demand heightened attentiveness (Reinhard et al., 2008; Schulz & Sherwood, 2008).

Caring for a family member or friend living with dementia requires much attention, effort, and physical labor (Morton et al., 2010). Compared to family caregivers of persons with other chronic conditions, caregivers of people living with dementia are more likely to be vigilant of the care recipient's health and spend more hours providing care and support (Alzheimer Association, 2021).

In 2020, Alzheimer's and other dementias caregivers gave a projected 15.3 billion hours of informal, unpaid help, a contribution worth $256.7 billion to the nation (Alzheimer’s Association, 2022). These cost estimates may ignore or grossly underestimate the enormous hidden unpaid costs experienced by caregivers. Indirect expenses include loss of earnings by patients and family caregivers as they give up or reduce their employment, informal care hours, and mortality load (Brodaty & Donkin, 2009).

Caregiving for someone with dementia has been associated with feelings of helplessness and isolation, depression, physical health issues, and even premature death (Morton et al., 2010). Caregivers of persons living with dementia have been demonstrated to help more, make more compromises, and feel more stressed than those who care for physically dependent older adults (Gaugler, 2022; Newton et al., 2010). Chronic and frequent extreme stress brought on by caring for a loved one with dementia may put the caregivers at significant risk for developing dementia (Morton et al., 2010; Schulz & Sherwod, 2017). The increased prevalence of depressive symptoms and mental health issues among family caregivers with the physical strain of caring for someone who cannot perform activities of daily living (ADL) places many family caregivers at grave risk for poor physical health outcomes. Indeed, family caregiving can result in higher healthcare needs for the caregiver (FCA, 2006).

There is a psychological and financial cost to caregiving; 70% of the lifelong cost of care for a person with dementia is shouldered by family caregivers in the form of unpaid caregiving and out-of-pocket expenses for goods ranging from prescriptions to food (Alzheimer’s Association, 2022; APA, 2015; NAC, 2020). Caregiving can be financially devasting for Black caregivers since many face more financial hardships, including taking on more financial obligations, skipping or being late on bills and student loan payments, borrowing money from friends, depleting savings, and declaring bankruptcy (APA, 2015; NAC, 2020). Because of this potential financial strain, many caregivers continue to work in addition to providing informal care for older adults living with dementia (Wilson et al., 2007).

Caregiver stress is a significant problem disproportionately affecting Black family caregivers of persons living with dementia and bringing exceptionally high risks to the Black family caregivers' physical and mental health, which can lead to higher incidences of anxiety and depression (Schulz and Martire, 2004). In addition to the issue of care load and stress, more Black family caregivers than White think that discrimination would prevent them from getting the care they need for Alzheimer's, and 50 percent of Black Americans claim to have encountered healthcare discrimination (Alzheimer's Association, 2022). Black family caregivers have higher care burdens and spend more time on average caring for their loved ones than their white counterparts; 57 percent of Black caregivers met the criteria for "high burden" and spent an average of 30 hours a week caring for their persons living with dementia (Flynn, 2018).

Racial and ethnic minority caregivers with a lower socioeconomic position are more likely to face negative social determinants of health and prejudice, which increase stress and create barriers to healthcare access (Aranda et al., 2021). Furthermore, the Black community's mental health requirements are often aggravated and largely unfulfilled because of the convergence of classism, racism, and health inequality (Vance, 2019). Compared to non-White caregivers such as Asian, and American Indians, half or more Black caregivers report encountering discrimination while navigating medical settings for the person they are caring for, with Black caregivers' main worry being those staff members or physicians will not listen to them because of their race, color, or ethnicity (Alzheimer's Association, 2022).

Aranda et al. (2021) report that there are considerable racial and ethnic inequalities in the prevalence of ADRD. Specifically, inequalities exist in Black family caregivers’ health that may worsen upon assuming the role (Aranda et al., 2021). Concerning the relationship between stress and Black family caregivers, stress is a barrier to improving mental health in dementia family caregivers; their stress levels were correlated explicitly to race and ethnicity, with Black family caregivers experiencing much greater stress levels. (Zahed et al., 2020).

Improving caregiver mental health requires expanding the availability of mental health services, medical treatment, and community-based support services for family caregivers. The effects of caregiving on caregivers' health and well-being can be mitigated at least in part by an assessment of family caregiver needs leading to a care plan with support services, caregiver dementia education, and community support programs; respite to reduce caregiver burden; financial support to alleviate the economic hardship of caregiving; and primary care initiatives to improve caregiver needs (FCA, 2006). To enhance stress management and mental health in this population and enable optimal and meaningful care, social and community-based services emphasizing physical, mental, and social health are required, particularly for Black family caregivers (FCA, 2006; Zahed et al., 2020). Adopting coping activities by Black family caregivers amid stress may provide momentary comfort. Still, it may negatively impact chronic health issues or impair mental health outcomes over time, primarily when traded for mental well-being habits (Cothran et al., 2021).

Although caregiving research within the minoritized population is slowly increasing, the number of minority groups included in cross-sectional caregiving studies is still under-represented, which restricts our understanding of the influences of time and culture on caregivers' health outcomes (Dilworth-Anderson et al., 2004). Examining community-based support services and how Black caregivers engage with them is critical to improving mental health and the ability to maintain the caregiver role longer (FCA, 2006; Schulz & Sherwood, 2017). Additionally, we need a deeper understanding of the various caring experiences and their effects on health (Schulz & Sherwood, 2017); because the disadvantages and costs of failing to address the Black family caregiving gap include worsening disparities, health equity, unmet care needs, safety concerns, and poor health (Gaugler, 2022). The outcome will have costly, negative consequences for the PLWD, their caregivers, and their communities (Gaugler, 2022). Fully incorporating the family caregiver into health care planning and delivery to persons living with dementia will better support the persons and their caregivers (Gaugler, 2022; Schulz & Sherwood, 2017). Black caregivers of people living with dementia strongly desire more community resources to assist with their caregiving responsibilities (Abramsohn et al., 2019).

2.3 The Range of Caregiver Roles

The term caregiver describes persons who care for those who need continuous support with daily activities (CDC, 2019). Caregiving is attending to the health and well-being of another individual, physically, or emotionally (Alzheimer's Association, 2022). First used in the 1980s, family caregivers are those who provide care for older family members (Llanque et al., 2016); family caregiving generally involves providing exceptional care beyond what is expected or normal in family ties (Schulz & Martire, 2004). While arriving at a universal definition of caregiver has been challenging, the terminology has evolved (Hermanns & Mastel-Smith, 2012). Over the years, informal, primary, unpaid, and family caregivers have described persons providing care to relatives or close friends.

Caring for others is omnipresent in human history. Historically, family members were the primary and often only support for disabled, older adults before government-sponsored programs evolved (e.g., Social Security, Medicare) (Hermanns & Mastel-Smith, 2012; Schulz & Martire,2004; Vitaliano et al., 2003). The critical difference between historical and present caregiving is the number of family caregivers, the length of time they provide care, the complex care provided, and the stress level associated with the caregiver role (FCA, 2006; Schulz & Martire, 2004). It is estimated that in 2020, almost 11 million family caregivers will provide unpaid care for people living with dementia in the community, totaling 15.3 billion hours of care and a value of $257 billion (Alzheimer's Association, 2022).

Notwithstanding many comparable experiences, the roles of caregivers vary significantly across the caring process; individuals who provide care do it in conjunction with other tasks and obligations (Schulz & Eden, 2016). Assistance with one or more activities of daily living (bathing, dressing, feeding) and numerous instrumental activities of daily living (shopping, cleaning, driving) are among the most common caregiving tasks (CDC, 2019). Caregivers also provide emotional support and other services to people living with ADRD (CDC, 2019; Gaugler et al., 2002; Zahed et al., 2020; Vitaliano et al., 2003). Additionally, caregivers link the person and health care providers, coordinating care and ensuring safety is maintained (CDC, 2019; Zahed et al., 2020; Gaugler et al., 2002). Though trained, professional, and paid caregivers are available, family caregivers are the central forces that support people living with ADRD in the community (CDC, 2019; Castro et al., 2010).

2.4 Health and Healthcare Disparities Associated with ADRD

Examining disparities starts with noticing them and making more efforts to learn more about the structures that cause and encourage them. To reduce disparities, the structures that cause and encourage them must be broken down. (Aranda et al., 2021). Racism is the cause of significant and persistent health disparities in the United States (Weil, 2022). The body of literature demonstrates that despite underrepresentation underestimating disease probability and disparity, substantial evidence demonstrates that dementia disproportionately affects the same demographics underrepresented in dementia and family caregiving research and is almost absent in some cases (Aranda et al., 2021; Gilmore-Bykovskyi et al., 2019; Le & Boddie, 2020). There continues to be increasing socioeconomic and geographic disparity in healthcare (NIA, 2019). Studying diversity in aging requires statistically valid samples; collecting and maintaining research samples have become more challenging in recent years, and high participation rates in representative sample populations are critical to preserving their value (NIA, 2019). In terms of dementia diagnosis, prevalence, incidence, disease progression, treatment response, and disease affliction, there are well-documented health and healthcare disparities among different racial/ethnic minority populations (Gilmore-Bykovskyi et al., 2019).

Additionally, cultural influences and the normalization of dementia symptoms as part of the natural aging process may account for the later diagnosis of dementia in older Black adults compared to older White adults (Quinones et al., 2020). Underrepresented racial/ethnic groups also experience a more significant cognitive deterioration throughout their disease, which may be related to differences in socioeconomic resources such as educational quality, the formation of cognitive reserve, financial resources, and early and midlife stress (Quinones et al., 2020). There are still substantial gaps in dementia family caregiving research (Gaugler, 2022).

To improve the quality of life for those with dementia and their families and to reduce racial disparities in dementia care and outcomes, it is essential to gain an understanding of the diverse experiences of those with dementia and their care partners to personalize services and social supports to meet their specific needs (Quinones et al., 2020). It is critical for health equality and equity to ensure that dementia healthcare and CSS are easily accessible, reasonably priced, and efficient for all populations (Aranda et al., 2021).

Comparing Concepts of Health and Healthcare. It is vital to recognize and address health and healthcare disparities that might influence access and future care delivery (Aranda et al., 2021; Novak et al., 2020). The phrases health disparities and health care disparities are used interchangeably; however, there are significant differences between the two. A health disparity occurs when one group has a higher burden of sickness, injury, disability, or mortality than another. In contrast, healthcare disparity describes inequalities in health insurance coverage, access to and use of health care, and healthcare quality between groups (Alzheimer's Association, 2021; Aranda et al., 2021; Babulal et al., 2018). The term dementia care disparities describe the inequitable access to healthcare and long-term services and support for both persons with dementia and their caregivers, which ultimately has an adverse impact on their health outcomes (Balls-Berry & Babulal, 2022). It is critical to health equity to ensure that services and support are accessible and effective for all members of the dementia community (Aranda et al., 2021).

Health Disparities in Dementia Care. Frequently, Black older adults are often diagnosed at a later stage of the disease when treatments are less effective (Alzheimer's Association, 2021). The causes behind these racial disparities remain uncertain (Zuelsdorff, 2020). Health status, lifestyle, and socioeconomic factors may influence the racial difference in dementia prevalence Black older adults are unduly affected by comorbidities such as cardiovascular disease and diabetes, associated with a heightened risk of developing dementia (Alzheimer's Association, 2021; Cothran et al., 2021). While ADRD impacts all populations, it affects them at varying rates and outcomes (Quiñones et al., 2020; Zuelsdorff et al., 2020). A paucity of research evaluates

ADRD risk and progression in the context of comorbidities and, over time, considers changing dynamics of comorbidities as a contributor (Quiñones et al., 2020). Dementia causes increased mortality rates in the United States, especially among older Black adults, leading to an increasing number of poorer health and impairment cases (Alzheimer's Association, 2021).

Healthcare Disparities Among Persons with ADRD: Although they are twice as likely to develop dementia, older Black adults are more often diagnosed later in the disease process (end-stage) when they are more physically and cognitively impaired, resulting in higher care needs (AARP, 2020; Aranda et al., 2021; Quiñones et al., 2020; Santos et al., 2019). According to the Alzheimer's Association (2021), over 36% of Black Americans believe that discrimination would impede obtaining ADRD care. More than half of non-White people report experiencing discrimination when interacting with healthcare providers and settings for their care recipients (Perlin et al., 1999).

Older Black adults and other marginalized populations expect and experience more barriers to dementia care, have less faith in medical research, and feel less secure that access to health professionals who understand their ethnic and racial background and experiences is available (Alzheimer's Association, 2021). Social determinants of health (SDOH) also refer to the circumstances where individuals are born, live, play, study, and work (CDC, 2019). SDOH disparities also contribute to the severe and ongoing inequalities in chronic disease prevalence across racial, ethnic, and socioeconomic groups in the United States by systematically reducing the possibilities for certain groups to maintain optimum health (Aranda et al., 2021; CDC, 2019).

Caregiver Stress

Caregiver stress is the unequal distribution of responsibility for helping those close to one another, which creates adverse emotional and physical burdens and can manifest in fatigue, resentment, or guilt (Llanque et al., 2014). Caregivers frequently prioritize the needs of others over their own when caring for a loved one; caregivers frequently devote significant time, effort, and their own physical and emotional needs, which can result in anxiety, stress, worry, and/or depression (ADAA, 2022). Older adults with dementia develop physical dependence and behavioral signs such as persistent questioning, physical and verbal hostility, poor sleep patterns, and negative response to care. Dementia caregiving is more demanding and stressful than caring for older adults with other chronic conditions (Merrilees, 2016; Gitlin et al., 2012). Since the early 1980s, when family caregiving became a well-researched issue, most studies have focused on the burden of caring and the possible detrimental impacts of caregiving stress on physical and mental health (American Psychological Association, 2015).

Two-thirds of dementia caregivers are women, approximately 30% are over 65 years old, and over 60% are married, live with a partner, or are in a long-term relationship (ASPE.hhs.gov, 2014; Castro et al., 2010). While these family caregivers are crucial to the health care of older adults living with dementia, their own well-being may suffer due to their stresses (Riffin et al., 2017; Vitaliano et al., 2003). Family caregivers have experienced increased use of medications, worsening self-reported physical and mental health, more significant depression and anxiety, impaired immunological function, and an increased risk of premature mortality (CDC, 2019). Caregiving has a plethora of benefits (Brodaty & Donkin, 2009). For many caregivers, being available when a loved one needs assistance is a fundamental value and a service they desire to offer (Brodaty & Donkin, 2009). However, a transformation of roles and feelings is probably guaranteed. It is reasonable to experience frustration, exhaustion, loneliness, or sadness. Caregiver stress — the mental and physical strain associated with caring — is typical (Chen et al., 2020). Caregiving imposes physical, psychological, emotional, and financial hardships that can negatively impact the caregivers’ general health, immunological function, and lifespan (APA, 2015; Chen et al., 2020; Riffin et al., 2017; Vitaliano et al., 2003).

Pearlin, Menaghan, Lieberman, and Mullan (1981) were the first to articulate the concept of a caregiver’s stress process, while Pearlin, Mullin, Semple, and Skaff (1990) provided a conceptual framework for understanding it (Williams et al., 2019). The caregiver stress process, according to these authors, is made up of four interconnected domains: (1) the caregiver’s background and context, (2) stressors (such as pressures of caregiving and secondary strains), (3) mediators of stress (coping responses and social supports), and (4) outcomes or manifestations of stress– that might include depression, anxiety, and poor well-being for the caregiver (Williams et al., 2019; Pearlin et al., 1990).

Nearly half of all caregivers (48%) who help older adults do so for someone with dementia (AA, 2021). Older adults living with ADRD frequently have trouble communicating their needs, memory loss, poor judgment, and a deterioration in functioning ability. Older adults with complex cognitive, behavioral, and functional impairments increase the care load for the caregiver (Sorenson et al., 2006). The older adult may become bedridden and more reliant on the caregiver as the disease worsens. ADRD family caregivers provide more extensive and intensive care than caregivers of any other chronic condition; these caregivers are often more stressed (McAuliffe et al., 2021).

Elements such as dementia-related behaviors and uncontrolled outbursts that contribute to difficulties or problems in the caring process were among the stressors experienced by family caregivers (Cothran et al., 2020). Caregivers of family members living with dementia are significantly affected by emotional pressures and are more likely to develop depressive symptoms (Bourassa et al., 2021). Dementia caregiving can be detrimental to the caregiver’s mental and physical health (Hilgeman et al., 2009). Agitation, roaming, and hostility are all known to be significant sources of concern for caregivers (Givens et al., 2011). As a result, caregivers become increasingly more focused on the person's care needs, diminishing opportunities to participate in activities other than caregiving, which adds to their stress. The increased stress leads to anxiety, depression symptoms, and a lower sense of well-being (Sutter et al., 2014; Sorenson et al., 2006; Perlin et al., 1999). The Black family caregiving population has disparate unaddressed stress and despair (Vance, 2019).

Only recently has population-based research investigated racial differences in older adult caregiving (NAC, 2020). Notably, over the last five years, the number of caregivers identifying as African Americans has risen dramatically. Because of this, as well as African American caregivers' individualized experiences, more focused efforts are required to directly address caregiver stress and its impact on Black caregivers (AARP, 2021; NAC, 2020, Podgorski, 2018). Although Black family caregivers are more likely than White caregivers to give more than 40 hours of care each week (54.3 percent vs. 38.6%), they are often reluctant to utilize community-based support services for training, respite care, and other support services (Le & Boddie, 2020). This may be due to historical discrimination and systemic injustice from service providers and institutions (Le & Boddie, 2020).

Compared to White dementia caregivers, Black dementia caregivers are 69 percent less likely to seek respite services (Alzheimer's Association, 2021). Cultural norms may influence inequalities in caregivers' perceptions of support in various racial and ethnic contexts. (Alzheimer's Association, 2021; Dilworth-Anderson et al., 2004). In the caregiver stress model, Perlin et al. (1999) identify secondary stressors as those developed when the caregivers mistrust the healthcare system or have perceived racism. Secondary stress can impact mental health and well-being.

Stress, also referred to as emotional reactions, is a natural defense mechanism that enables individuals to deal with threats and difficulties, whether perceived or genuine. It is believed to be essential in task execution (Tsiamyrtzis et al., 2012). The extent to which a person views a situation as frightening or worrisome elicits stress as a physiological response to a problem that produces that fight or flight reaction. Therefore, stress can be experienced physiologically or physically (APA, 2017), leading to mental and physical illness.

2.5 Impact of Caregiving on Black Caregivers' Mental Health, Specifically Anxiety and Depression, and How Black Caregiver Stress Differs from Their White counterparts.

Caregiving is related to a multitude of physical and mental health problems. Stress negatively influences the body and the psyche, and it is widely recognized that caregiving is stressful (Rainne, 2021). Caregivers are more likely to report having anxiety and depression than the general population (Rainne, 2021). Some stress is a normal part of life; however, stress occurs for many Black people. Structural socioeconomic injustices, such as racism and discrimination, are well-known factors that increase their risk of chronic stress (Cothran et al., 2021).

Black family caregivers perform a valuable service to the PLWD in the absence of formal long-term care. They frequently suffer from chronic stress, which has detrimental repercussions on the caregiver's mental and physical health, such as heart disease and sleep disturbances (Le & Boddie, 2020; Ornstein et al., 2013; Rainne, 2021). Black family caregivers provide higher-intensity caregiving, report more unmet needs, and care for people with dementia with higher levels of dementia-related behavioral symptoms. Few studies have found variability in caregiver psychological well-being among race and ethnic subgroups (Aranda et al., 2021, Chen et al., 2020).

Black caregivers, on average, describe not having relatives, friends, or neighbors to help, thereby making them the sole caregiver for a care recipient, residing with their care recipient, making less money, and working more hours than non-Hispanic White caregivers (Dilworth-Anderson et al., 2002; Le & Boddie, 2020). Compared to non-Hispanic White caregivers, Black caregivers are less likely to obtain information from medical care providers regarding managing care for their older adults, meaning that Black caregivers experience more negative mental health outcomes (Rainne, 2021). The lack of information sharing could result from documented racial bias in provider-patient/caregiver interactions (Ferguson & Candib, 2002; Johnson et al., 2004). Black caregivers require even more opportunities for caregiver education and access to supportive services sensitive to their cultural contexts (Le & Boddie, 2020).

The cultural diversity of Black people, their history of racial discrimination in accessing healthcare, and their interactions with providers may impact their mental health at levels that require extensive empirical research (Le & Boddie, 2020; Worley, 2012). However, it’s critical to consider how these circumstances might affect Black caregivers' descriptions of their stress, mental health, and well-being (Worley, 2012). In the Black community, depression is commonly misdiagnosed, underdiagnosed, or not diagnosed because of the stigma associated with mental illness and the general distrust of mental health treatment systems (Bailey et al., 2011; Vance, 2019; WFU, 2020). Racism and discrimination are key factors influencing the worsening health disparities for Black people, especially in dementia care (Cothran et al., 2021; Johnson et al., 2004).

2.6 Components of Caregiver Stress

Early caregiver stress research typically used a single indicator, such as self-reported health, to determine the impact of caregiving stress on physical health. Fewer studies have sought to relate caregiving pressures to several health characteristics, including mental health (Son et al., 2007). Pearlin's caregiver stress model guides this study. Pearlin and team (1999) recognized that the caregiver's background (culture, socioeconomic status, family network, and personal history) impacts primary stressors (care-recipient behavior, care-recipient care needs, caregiver subjective stress); in turn, these stressors can lead to the development of secondary stressors (mistrust of health care system and perceived racism). If unmanaged, primary, and secondary stressors can lead to secondary role strains (conflicts with family roles, anxiety, and social isolation) (Ice et al., 2012). Community support services (support groups, help-seeking, neighborhood cohesion, respite, ADRD training) can mediate the effects of primary and secondary stressors and secondary role strains. Ultimately, mediators also contribute to mental health and well-being (Hill & Maimon, 2012) (**Figure 1**)

2.7 Significant Components of Caregiver Stress

The components of caregiver stress, such as financial burden, physical and emotional exhaustion, anxiety, stigma, and limited social support, have more impactful influence on Black caregivers due to the added stress of mistrust of the system, economic inequality, and other challenges that are unique to Black people.

2.7.1 Phases of Caregiving

According to Kokorelias et al. (2020), dementia family caregivers need assistance throughout the disease's trajectory. The team's unique study on caregiver support needs indicated that diseases like Alzheimer's rarely stay the same over time, meaning that the caregiving experience and the caregiver’s needs will change as the disease progresses. Thereby highlighting the dementia family caregiver duties and the need for support as they progress through the disease. The five most crucial care phases: are monitoring initial symptoms, navigating diagnosis, assisting with instrumental activities of daily living (iADLs), assisting with basic activities of daily living (ADLs), and planning for the future (Kokorelias et al., 2020).

2.7.2 Theoretical Foundations

To better understand specific features of the caring situation, researchers have expanded fundamental stress/coping models to family caregiving and used numerous additional theoretical explanations borrowed from social and clinical psychology, sociology, and the health and biological sciences (Schulz & Martire, 2004). The study of caregiving has enriched basic and applied social, behavioral science, and nursing research (Schulz & Martire, 2004).

Pearlin et al. (1990) created the Stress Process Model (SPM) to help understand how caregivers experience and appraise stress. The model quickly became the most important and comprehensive model of stress and was later expanded to include stressors related to dementia caregiving. This dementia caregiving stress theoretical framework guides this research that depicts the links between the caregiver’s background, appraisal of the stress, evaluation, emotion, and coping (Pearlin et al., 1990; Myer, 2003). This theoretical framework also emphasized individual differences in evaluation and coping and a psychological, process-oriented strategy to comprehend the stress transaction (Myer, 2003).

2.7.3 Description of the Model

The relationship between the burden of caregiving, community support services, and mental health is complex (FCA, 2006). No single explanation effectively describes the delicate relationships (Katerndahl and Parchman, 2002; Pearlin et al., 1990). Pearlin's stress model illustrates that this is not a linear relationship. It amplifies the complexity of the relational stress factors that can lead to poor mental health outcomes for the caregiver. It also indicates that support services moderate the relationship (Katerndahl & Parchman, 2002). Long-term caregiving, according to Pearlin, exhausts supportive social resources and lowers control views (Meyers, 2003).

The model recognizes the impact of the caregiver's background, such as socioeconomic status, on the stressors, mediators, mental health (outcome) (Lee et al., 2006). The work is influenced by the interplay between the caregiver's socioeconomic background, stresses (primary and secondary), and psychological strains, with coping and social support as mediating elements (Lee et al., 2006). The model further illustrates how community support services mediate stressors and mental health, influencing mental health (Fig 1). The stress model identifies two types of stress, objective, and subjective stress. Caregiving burden, emotional distress associated with meeting the care receiver's daily care needs, dementia-related behaviors, attentiveness, and the caregiver's perceived stress were all examples of subjective stress (Hilgeman et al., 2009). Objective stressors are the stimuli or actions associated with the care receiver that causes the caregiver to have an emotional reaction (Hilgeman et al., 2009).

This research is not just about stress-related conditions but, more importantly, how these conditions evolve and inter-relate with each other (Pearlin et al., 1990). **Figure 2**. Consistent with the stress process model, caregiving is a formidable stressor that causes pressure on numerous aspects of caregiving, ultimately increasing the likelihood of poor mental health outcomes (Ornstein et al., 2013).

2.8 Caregiver Background (Culture, Socioeconomic Status, Family Network, and Personal History).

The care of a person living with dementia, as well as the socioeconomic status of a caregiver, influences the possibility of physical, psychological, or emotional tension (Rainne, 2021). Limited caregiving research on minority populations contributes to inadequate knowledge of the impacts of time and culture on caregivers' health outcomes (Dilworth-Anderson et al., 2004). Poorer communities impair residents' mental health by subjecting them to stressful situations. History of living in neighborhoods with socioeconomic disadvantage, a high density of racial and ethnic minorities, residential instability, little to no social ties, low shared success, and visible signs of illness increases the likelihood of perceiving or experiencing environmental disadvantage and danger, leading to increased stress (Hill & Maimon, 2012, Rainne, 2021).

2.8.1 Primary Stressors (Care-Recipient Behavior, Care Needs, Caregiver Subjective Stress, Sleep Quality)

Care recipients' increased care needs, resistance to care, and verbal outbursts contribute to primary stressors (Schulz & Eden, 2016). Additionally, late-night awakening to provide care may lead to poor sleep quality for the caregiver and is linked to stress and poor mental health (Hill & Maimon, 2020). Stress may also affect the caregiver's interaction with the PLWD, and the quality of care provided; unaddressed stress leads to adverse health issues and isolation (Zebrak et al., 2019). This can hasten admission to skilled nursing facilities (van den Kiemboo et al., 2020).

Secondary Stress (mistrust of healthcare systems and perceived racism) according to Hill and Maimon (2012), Mirowksy and Ross defined mistrust as the mental habit of viewing others' motives and actions as unhelpful, self-serving, dishonest, and potentially harmful. In terms of perceived racism, it is a primary driver of stress and adverse mental health outcomes for Black caregivers and impacts racial/ethnic health disparities (Firestone, 2020).

Secondary Role Strains (conflicts with family roles, anxiety, and social isolation), the incapacity of family members to realize common ideals and to build and maintain informal social regulations are defined as social disorganization; which contributes to role strains, stress, and impaired mental health (Hill & Maimon, 2012; McLennon et al., 2011). Culturally, some caregivers believe they must provide all the care necessary for the older adult without support, resulting in feelings of failure if help is needed (NAC, 2021). Additionally, the country's mobility and changing demography have impacted dementia family caregiving because older adults live far from their immediate relatives, resulting in dementia family caregivers increasingly working alone (NAC, 2020).

Mediator of Stress (support groups, help-seeking, neighborhood cohesion, respite, and ADRD training) the use of support groups, respite, help-seeking, aging-friendly beliefs, and neighborhood cohesion can mediate the impression of feeling stuck as a lone caregiver (Bertrand et al., 2006; McLennon et al., 2011). Black caregivers have indicated a need for high-quality, easily accessible respite that would allow them to take a break from providing care, ease their daily stress, and engage in distractive activities; respite can serve as a facilitator to various supports that mitigate concerns related to caregiving stress (Bangerter et al, 2021). From the point of view of the healthcare system, providers are in an excellent position to support Black family caregivers in lowering the risk of negative mental health outcomes (Fortinsky, 2010).

They can do this by candidly and thoroughly explaining dementia development, recommending symptom management as they arise, and connecting Black family caregivers with the proper community-based support services (Fortinsky, 2010).

The best way to mediate stress is to make time for hobbies and interests, ask for help from other family members, have a positive aging belief, and join support groups where caregivers share their experiences, which have been shown to have a positive effect on caregivers (Parkinson et al., 2017). Frequent participation in enjoyable activities that make caregivers feel good has health benefits and has been linked to resilience in people (Parkinson et al, 2017).

2.9 Factors That Impact Caregiving Sustainability

Providing care for an older adult living with dementia can be pleasant and provide a sense of accomplishment, but it can also be arduous work that takes a toll on the caregiver's time, finances, emotions, and health (NAC, 2020). Due to spending so much time with their patients, caregivers often feel physically and emotionally isolated. Mental health issues like depression, fatigue, anxiety, and a constant sense of being overwhelmed (Solllitto, 2021). The caregiver's mental health and the level of care provided can both be at risk from the adverse effects of compassion fatigue. Guilt, self-flagellation, or denial that arises from caring for a loved one and questioning the decision to be a caregiver (Sollitto, 2021).

Caregivers may miss out on resources that can help them manage the fundamental difficulties of caregiving if they don't self-identify as caregivers (NAC, 2020). Even though there has been an overall increase in services to help family caregivers, services vary in how easy they are to get to, how good they are, and how often they are used; family caregivers often go through periods when these services are used or use them less (Cotton et al., 2021). Finding affordable and essential community-based resources can be difficult for individuals with dementia and their family caregivers (ASPE, 2017).

2.9.1 Employment (Income)

Caregivers have reported difficulties maintaining their employment while serving as a caregiver; they report having to go in late, leave early and take time off or leave of absence; some report decreasing work hours or taking fewer demanding positions (Zebrak et al., 2019). The influence of family caregiving on employment can affect both individuals and employers. Employers may suffer significant financial losses due to absenteeism, employee replacement, and decreases in employee productivity. Caregivers may face reduced or lost income, job insecurity, and limited upward mobility, and employers may face substantial financial losses due to absenteeism, employee replacement, and decreased productivity (APA, 2015; Reinhard et al., 2008; Zebrak et al., 2019).

2.9.2 Social Support

As with most new life-course disruptions, the experience of providing care is greatly facilitated by social connections with others (Roth, 2020). Among these exchanges, those between the caregiver and care recipient are the most evident. Prior research demonstrates that this relationship's features are crucial in defining the caregiver's physical and mental well-being (Roth, 2020).

Social support has varied meanings and usually comprises a few elements, such as social networks, support, and resources (Xian & Xu, 2020). One definition of social support is sharing emotional and practical support through interpersonal interactions (Donnella et al., 2017). Having a helpful social network, including family, friends, and experts, can make a huge difference in how manageable a caregiver's situation feels (Perlin et al., 1990; Roth, 2020). The main components of social support are received, professional, and perceived availability of support (Donnella et al., 2017; Gitlin et al., 2017; Xian & Xu, 2020).

The Stress Process Model proposes that social support buffers the adverse effects of stress on health (Liang et al., 2020). Individuals’ perceptions of social support include psychological, physical, and informational support from their social network. Social support can help family caregivers sleep better, leading to a more stable living environment (Liang et al., 2020). Perceived social support is a person's opinion of how much social support is available, while received social support is the tangible support a person gets from their family and friends (Leung et al., 2020; Xian & Xu, 2020).

Caregivers with bigger social networks might be healthier and more resilient than those who don't take care of anyone and have fewer social ties. This would explain how social capital could help reduce stress (Thiel, 2016). Thiel (2016) found that caregivers who feel more connected to their community and neighbors have fewer physical and mental health problems than caregivers who feel they are on their own.

Similarly, community-based supports and services (CBSS) are intended to support family caregivers so that persons who live with dementia in the community to stay safely in their homes and postpone or avoid institutionalization (Siegler et al., 2015). In addition to general assistance with housing, finances, and home safety, CBSS offer (and serve as a link to) specific resources for older people and their caregivers, such as wellness programs, nutritional support, support groups, respite, adult day programs/senior centers, health, and aging programs, and counseling services for caregivers (NAC, 2020; Siegler et al., 2015).

Respite, caregiving for a PLWD can be exhausting, but respite programs can help the caregivers take short or longer breaks to recharge. Planning for regular breaks from caregiving is not only good for the health of the caregiver and the person receiving care, but it can also make it easier to find temporary replacements for the family caregiver in an emergency (Sollitto, 2021). Theil (2016) in his work noted that public programs such as community support services could encourage caregivers to get involved socially and with the community, thereby reducing the isolation of caregiving.

Adult Day Programs, when family caregivers need to go to work, run errands, or take a break, they can drop their PLWD off at an adult day care center. Adult daycare centers are places where PLWD can spend the day or part of the day in an atmosphere that is both safe and stimulating socially.

Senior Centers in a Senior Center, seniors can engage in various activities under the supervision of qualified staff in a secure setting. Respite care, "visits" via telephone, in-home visitors, nursing home visitors, home health aides, support groups, adult day care, and information and referrals to other community services are provided by some of these organizations (Sollitto, 2021).

Family and Friends, the caregiver can receive the support they require from friends and relatives. The PLWD's neighbors may offer to deliver food, run errands (such as picking up medicines), or drop by for a chat and a cup of coffee. It's just as crucial to take a break from being a caregiver emotionally as it is physically.

Support Groups, support groups for caregivers, are an additional alternative for locating friends and other caregivers who comprehend the difficulties and who may also offer novel ideas for solutions or workarounds. The accessibility and mobility of online caregiver support groups make them an attractive choice for today's time-pressed caregivers (Morris, 2021). These support groups can be formal (offered by an organization such as the Alzheimer's Association) or they can be informal, where people who know one another gather to share experiences.

Most family caregivers are eager to get information about CBSS; nevertheless, they are frequently unaware of the breadth of services offered or how to access them (Siegler et al., 2015). Despite the lack of in-home caregiver skills training, Davis and colleagues report a significant decrease in burden and anxiety for caregivers who receive friendly, socially supportive phone calls that provide some break from caregiving (Rheindart et al., 2008). A caregiver's stress and depression can be alleviated by receiving indirect contact from CBSS providers and increased social support.

2.10 Facilitators and Barriers to Community-Based Support Services Utilization

Even though caregivers often benefit from getting help as soon as possible, Black family caregivers underutilize CBSS for several reasons, including a lack of awareness, hesitancy, inaccessibility, and expense (Cotton et al., 2021; Siegler et al., 2015). These barriers often keep them from getting help until the disease is in a more advanced stage or there is a crisis (Cotton et al., 2021; Siegler et al., 2015). Community-based support resources such as respite, culturally relevant ADRD training, adult day program, and support groups can help reduce caregiving stress (NAC, 2020; Van’t Leven, 2013). The complexity of finding care, services, or support, the long-term services, and support systems are typically dispersed or fragmented, which may be stressful, aggravating, unpleasant, and expensive are all factors that create barriers to community-based support use (NAC, 2020).

Even with the various forms of conventional support services available in the community, it is typical for Black family caregivers not to take advantage of them because of inflexibility, poor quality, distrust, and disparities (Cotton et al., 2021; Macleod et al., 2017). They may be unfamiliar with obtaining assistance or have difficulties acknowledging that they require them (Siegler et al., 2015). According to the National Alliance for Caregiving (NAC) 2020, when compared to non-Hispanic White caregivers, Black caregivers were less likely to get respite services and information from medical care providers. Black caregivers are still not appropriately directed to appropriate community support service information (Macleod et al., 2017). To develop pragmatic and culturally appropriate interventions, scientists must first recognize this gap and explore the barriers and facilitators to community support utilization (Young et al., 2020).

2.10.1 Barriers

The *inflexibility* of services created a key impediment to their demands being satisfied. Some support service offerings might be too limited regarding service alternatives and ways to use the available services for family caregivers (Cotton et al., 2021; Macleod et al., 2017).

Care Recipient Resistance to respite, organized activity groups, and in-home housekeeping and care services may have been a significant factor in why caregivers did not use these services. Interestingly, care recipients resisted these services because they did not want strangers in the house, did not want to leave the house, reacted negatively to routine changes, and did not want to be away from the caregiver (Cotton et al., 20121; Macleod et al., 2017).

Poor Quality of services: research by Macleod and the team (2017) revealed that the low quality of the service offered was a common obstacle to in-home care. Family caregivers' concerns with paid caregivers who come to their home being inconsistent and constantly changing care workers may be stressful or disruptive to those living with dementia. This was a deterrent for some people to use the service again.

Distrust: Black family caregivers with previous negative experiences may be reluctant to use support services, including respite, in-home care, and long-term care. Caregivers' negative experiences could make them reluctant to use respite or in-home care in the future (Macleod et al., 2017).

Disparities: (providers' lack of knowledge of available resources) within the healthcare system and lack of knowledge about available support services left Black family caregivers with no idea where to turn for answers to their service-related queries or get relevant information to their circumstances (Macleod et al., 2017).

*Sleep Interruptions: o*bjective stresses such as the person living with dementia's need for assistance with activities of daily living and medication administration have been incorporated in studies exploring the impact of caregiver burden on sleep quality (Liang et al., 2020). Night awakening to provide care is most impactful on the caregivers' sleep because they might find it challenging to return to sleep (Liang et al., 2020).

Factors influencing service utilization among Black caregivers: poor service fit, restricted service availability, physical health restrictions, past experiences with illness and service use, social history, and tensions within the caring network have been linked to caregivers delayed and low service utilization (Cotton et al., 2021).

2.10.2 Facilitators

Community support services can offer a range of benefits, such as providing information and education, facilitating social interaction and peer support, and reducing stress and isolation. Below are factors that facilitate the use of community support services.

*Caregiver Beliefs: B*lack family caregivers acknowledging it is ok to take regular breaks from their caregiving responsibilities to offer the best care possible for the person living with dementia can be a facilitator of community service use (Macleod et al., 2017).

*Care Recipients Buy-In: g*etting buy-in from the person living with dementia through effective communication and a calm approach fostered the family caregiver to seek community support (Cotton et al., 2021; Macleod et al., 2017).

*Previous experience or recommendations: f*amily caregivers' personal and more extensive networks significantly influenced their perspectives about dementia caregiving and community support services, particularly when seeking such assistance. However, earlier personal experiences typically also included experiences shared through informal networks (Cotton et al., 2021).

CSS navigation might be complicated; the eligibility for CSS benefits depends on various personal and provider/service-related characteristics (Siegler et al., 2015). Because family caregivers have unique perspectives on their responsibilities, social factors that lead to community-based support service utilization must be modified to provide the best appropriate and easily accessible assistance given caregiver diversity and circumstances (Young et al., 2020). A more precise knowledge of the influence on family caregivers' community service use could result from a stronger focus on the intersection between neighborhood cohesion, disparities, and mental health (Cotton et al., 2021).

2.11 Neighborhood Cohesion

Focusing more on how health and social factors in a neighborhood affect each other has led to a better understanding of how health disparities, social determinants of health, and exposure to environmental and social disadvantages all affect each other (Cotton et al., 2021).

Within cities and towns, neighborhoods are discrete geographical zones where groups of people live and interact; the boundaries and conditions that constitute a neighborhood are unique. History and developments and the beliefs and actions of residents and nonresidents help define boundaries, as can governmental categorizations like ZIP codes and census regions (Hill & Miamon, 2020).

In examining the detrimental effects of prejudice on disease risk and aging, neighborhood surroundings, particularly neighborhood cohesion, are vital to evaluate (Hailu et al., 2020). Positive neighborhood cohesion, generally marked by solid social connectivity and collective efficacy, may guard against chronic psychosocial stresses like prejudice and adverse mental health (Hailu et al., 2022). The impact of the environment and local setting on physical and mental health is becoming more well-documented. The environment may influence the health of older adults and the neighborhood they live in (Zaheed et al., 2019).

According to the literature, neighborhood characteristics which can act as both protective and risk variables, appear to be significant contributors to older persons' physical, psychological, and mental health outcomes (Dong & Bergren, 2016). According to research on neighborhood influences on health, neighborhood disorder moderates the positive influence of neighborhood cohesion on health. Cohesion and disorder interact with health outcomes separately, but they also interact with one another, perhaps affecting the scale of some health outcomes (Dong & Bergren, 2016; Hill & Maimon, 2020).

Neighborhood cohesion is characterized by deep social connectedness, available local organizations, and voluntary associations, and informal social control is commonly used. The degree to which neighborhood members live peacefully together, trust and aid one another, willingness to intervene in various crises, and share common values is an indicator of neighborhood cohesion (Hill & Maimon, 2020).

Neighborhood cohesion may improve mental health by enhancing individual residents' knowledge that their neighbors get along, trust, assist, and support one another, have shared values, and are willing to intervene in the community's best interests (Hill & Maimon, 2020).

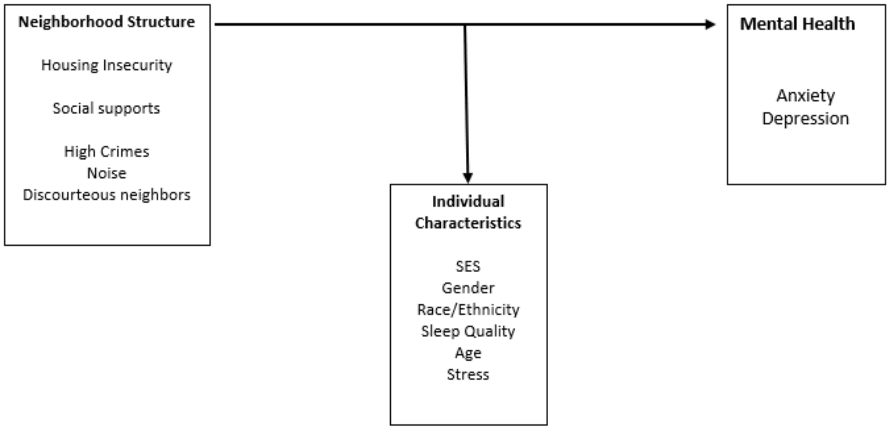

Figure 1 Moderators of the link between neighborhood context and mental health adapted from Hill & Maimon, 2020

To summarize, this literature review defined dementia as a cognitive impairment that is more than just forgetfulness. Alzheimer's disease is the most common cause of dementia. Alzheimer's disease and other dementias disproportionately affect racial and ethnic minorities and those from low socioeconomic backgrounds. Despite this, these underrepresented groups are elusive in studies (Gilmore-Bykovskyi et al., 2019). To truly understand ADRD and its impact on caregivers, minority groups need to be included in all levels of research (Gilmore-Bykovskyi et al., 2019; Aranda et al., 2021).

Black family caregivers tend to be solo caregivers with minimal support from friends and family, unlike their White counterparts. Caregivers of patients with dementia who are black have assistance requirements. Their existing social networks may become less accessible as the disease progresses, making it more difficult for them to receive informal assistance as the condition progresses (Xian & Xu, 2020). Black caregiver resilience should not be misinterpreted to mean that they don't experience stress or that stress impacts their caregiving responsibilities any less (Gaugler et al., 2007; Lavretsky et al., 2010).

Acknowledging Black caregiver research as a public health issue means that society recognizes that communities, healthcare institutions, providers, government, society, and especially families bear significant and unmanageable stressful responsibilities resulting from ADRD (Aranda et al., 2021). Stress is a normal part of life; however, stress occurrence for Black people and structural socioeconomic injustices, such as racism and discrimination, housing discrimination, and housing insecurities, are well-known factors that add to their risk of chronic stress that impacts their mental health (Cothran et al., 2021; Hill & Maimon, 2012). Unlike their White counterparts, black caregivers of people living with dementia face more challenging situations and events throughout their caregiving journey (McLennon et al., 2011).

Hill & Maimon (2012) found that socioeconomic disadvantage at the neighborhood level may jeopardize mental health by limiting prospects for individual-level socioeconomic status. According to their research, impoverished communities have limited access to community resources, programs, support services, and opportunities, such as high-quality health care and ADRD training (Majoka & Schimming, 2021; Van't Leven et al., 2013). Black family caregivers still carry the generational trauma and scars that led to the mistrust of health care and providers. Additionally, cultural and language barriers and low SES can impact access and affordability of support services for Black and low-income caregivers.

Further literature review reveals that interventions don't always encourage active caregiver participation. They are not tailored to the caregiver's needs, are usually sparse or in small chunks of time, are inflexible to the caregiver's needs or risks, are insensitive to the person's stage of dementia, are culturally insensitive, and are not customized to the type of dementia the person is living with (Merrilees, 2016). In addition to a lack of awareness of available resources, time restrictions, the need for constant supervision of the PLWD, financial limitations, guilt, access, and proximity to resources are just a few barriers that impede caregivers from receiving the assistance they require. (Merrilees, 2016). PLWD's resistance to support services, caregivers' feeling that they must do it all or not considering themselves as caregivers (labor of love), and cultural background are other issues that hamper access, and use/ family caregivers have to seek out the support services independently, relying on word of mouth and the experiences of friends and other family members. According to polls, half of the non-White caregivers reported experiencing discrimination when navigating healthcare settings and seeking support services. Their main concern is that providers or staff will not listen to their support services concerns due to their race, color, or ethnicity (CDC, 2020).

Primary data collecting that is more inclusive of underrepresented populations, transparent, and representative is a critical next step in eliminating current gaps and enabling more equitable delivery of programs, resources, and services for caregivers and their care recipients. (NAC, 2020). According to Abramsohn et al. (2019), their research findings showed that Black caregivers require additional and improved access to federally funded CSS. Additionally, Abramsohn et al. found this consistent with a previous qualitative study that indicated that Black caregivers of people living with dementia wished for more easily accessible community support services to help them with their caregiving commitments.

Cultural sensitivity is an important skill for developing and delivering community support services that meet the needs and preferences of caregivers from diverse racial and ethnic backgrounds (NAC, 2020). Improved cultural competency training for scientists and healthcare providers to promote the involvement of Black and other color caregivers as significant partners in caregiving research and care of the person living with dementia has an enormous potential to improve mental health outcomes for the caregiver (NAC, 2020). Furthermore, service providers must understand that Black caregivers are heterogeneous and not all the same (Le & Boddie, 2020). Each family caregiver and care recipient have unique needs and preferences. Caregivers will benefit from providers who pause and inquire about their needs (Le & Boddie, 2020).

2.12 Future Implications

Caregivers' assessments of the weight of their situations and stress can impact their physical and mental health, especially for older adult caregivers who may already have chronic diseases, comorbid conditions, and frailties (McLennon et al., 2011). This research study may explain why family caregivers of persons living with dementia do not access or use community support services, spotlighting Black family caregivers who tend to access and use these services less than their White counterparts. **Aim 1** examines the relationship between Black family caregivers' mental health (depressive symptoms and anxiety) and community support services use. And may identify the gaps and make recommendations for future study and practice to be more personalized and holistic. **Aim 2** investigates the effects of neighborhood cohesion on the Black caregiver's mental health. Simultaneously, identifying gaps and recommendations can better understand how the social determinants of health (education, health disparities, transportation) contribute to neighborhood cohesion and community service use. **Aim 3,** using survey questions embedded in an upcoming Black caregiver study, examines the facilitators and barriers to community support services use. By understanding the caregivers' lived experiences, this research may guide future studies that address healthcare disparities that impact how Black caregivers of people living with ADRD can access and use community support services.

Community-based support services can be instrumental in making caregiving more positive in many ways, such as building and expanding social networks, increasing trust and reciprocity between neighbors, seeking shared interests, sharing health-related knowledge and information, and making it easier for caregivers to get to services and amenities to reduce stress and improve mental health (Lu et al., 2020 and Thiel, 2016). Although family caregiving stress and its impact on mental health is considered a public health issue, nursing has a significant role in intervention and policy development. Nursing, nursing research, and clinical practice benefit from understanding caregiver stress. Nurses are at the forefront of engaging with care recipients and their caregivers and are instrumental in developing interventions to help the dyad maintain their mental and physical health (Llanque et al., 2016). Nurses have a unique perspective, given our role in the hands-on care of our patients and intimate interactions with family caregivers that other disciplines do not have. In clinical settings, working with caregivers of PLWD presenting with behavioral symptoms is an ideal opportunity to develop customized education, individualized behavioral management programs, and strategies tailored to the care recipient's and caregiver's traits and abilities (Merrilees, 2016).

Nurses, especially home care nurses, are in a prime position to raise awareness of the injustices they observe and experience in dementia caregiving and the hidden financial and emotional costs of family caregiving. They can assist in amplifying the caregiver's voice (Ward-Griffin, 2012). Nurses can help caregivers by evaluating their concerns, reviewing practical recommendations, connecting them to essential resources and services, and providing counseling and emotional support. Nurses can address social determinants of health in an individual by providing dementia training that helps the Black family caregivers to understand and manage the symptoms and behaviors presented by the person living with dementia and education on available community support services at a structural level working with community service providers and medical providers to determine the best process for improving caregiver access.

Nursing can drive policy changes, creating interdisciplinary care teams to address the issues associated with lack of support services use and adverse mental health. They can also support the integration of caregivers into the healthcare team. Leadership can establish a culturally competent workforce, including cultural competence training for providers who can help people recognize and overcome unconscious bias (CDC, 2021): Increasing diversity in the workforce is important because representation matters to the caregivers. Nurses have the best understanding of CG’s hands-on role. Nursing can be instrumental in decreasing the barriers to support services while increasing dementia care education/training.

Before meeting the needs of Black family caregivers, the healthcare system and providers must recognize and hear them (Le & Boddie, 2020). Years of institutional injustice, racism, and historical prejudice have dissuaded many African American caregivers from optimally using community-based support services. By understanding the goals of this study, we can create interventions to address the issues identified, such as lack of access to support services, inadequate respite care, and the need for culturally appropriate care. This will provide a better understanding of Black family caregivers' care needs and help improve service delivery. In addition, it will provide insight into how to create a more equitable and accessible care system for those caring for people living with dementia. The chapter that follows will discuss the methodological approach used to complete the aims of this mixed-methods research

Chapter 3 Methods

This study uses the Perlin Stress Model (SPM) to examine how community support services such as support groups, help from family and friends, and having time away from the PLWD affect the Black caregiver's mental health. This study analyzed publicly available datasets from the National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC). We also examined data from a focus group of caregivers to explore their experiences with community support services.

3.1 Study Design

I used a mixed-methods exploratory design to answer the research questions:

(1) how do community support services (CSS) affect the mental health of Black family caregivers of people living with dementia in the community?

(2) how does neighborhood cohesion affect the mental health of Black family caregivers of people living with dementia in the community?

(3) what are the barriers and facilitators to CSS use?

Finally, I investigated the effects of neighborhood cohesion on community support services using an existing cross-sectional nationally representative survey database (NHATS/NSOC). Next, I used the caregiver focus group to better understand their experiences with support services. This approach facilitates collecting, analyzing, and blending quantitative and qualitative data within a single study (Watkins, 2021). Using a mixed methods approach, I began with a secondary analysis of Black family caregivers who participated in NHATS/NSOC.

3.2 Quantitative Data—NHATS/ NSOC

Participants

The National Health and Aging Trends Study (NHATS) is a nationally representative cross-sectional study of Medicare participants aged 65 and older. The National Study of Caregiving (NSOC) studies the matched caregivers of NHATS participants who have challenges doing everyday tasks. NSOC conducts periodic telephone interviews with family members and unpaid caregivers of NHATS participants to gather information about their self-care, mobility, or housekeeping assistance. During the 30-minute interview, NSOC asks questions about the tasks, duration, and intensity of assistance, effects on the helpers, support services used, and demographic data.

Researchers recruited participants for the NHATS and NSOC research through multiple methods, including random digit dialing, household lists, local newspapers, radio, television advertising, referrals from community organizations, and mail (Freedman et al., 2019). Researchers purposefully chose NHATS cases utilizing a stratified three-stage approach that included counties or groupings of counties in the continental United States, ZIP codes, or ZIP code sections within the selected counties. Single counties or groups of counties make up primary sampling units (PSU). Primary sampling units (PSUs) contained secondary sampling units (SSUs), which were zip codes or portions of zip codes (PSUs). Percentage of older adults (65+), non-Hispanic black people (70-74), 75-90% of the total population (80-84), 85% of the whole population (85-89), and those who are 90 years old or older (90+). Oversampling enlarges the sample size according to age and race (NHATS 2020). NHATS identified 2011 and 2015 as the initial rounds and labeled previous sample members as returning and new sample members added in 2015 as first-time participants (Kasper, Freedman, & Spillman, 2013).

Researchers conducted NHATS in two waves, with interviews of care recipients and their caregivers conducted in separate waves. Both studies use questionnaires and telephone interviews to collect information about health, care, and well-being (Freedman et al., 2019). Both NHATS and NSOC use a two-stage, stratified design with oversampling of specific subpopulations.

Participants in the NHATS study were sorted into three categories based on their cognitive status: probable dementia, possible dementia, and no dementia. If a person reported that a doctor had told them they had dementia or Alzheimer's disease, the researchers considered them to have a high probability of having dementia. However, to address the potential inaccuracies of dementia diagnoses within a large-scale sample, a positive dementia diagnosis was evidenced by cognitive impairment over time (Kasper et al., 2013).

NHATS participants who needed assistance with activities of daily living and had completed the interview for NSOC eligibility were included. Eligible care recipients received help in the previous month with bathing, dressing, eating, or instrumental activities of daily living such as laundry, shopping, bill paying, or medicine tracking (NHATS/NSOC, 2020). NHATS also recorded races and primary races if more than one race was recorded for Sample Persons at baseline interviews (Kasper et al., 2013). In combination with the NHATS, NSOC conducted these data collections in 2011, 2015, and 2017 (Kasper et al., 2013).

Caregivers of People with Dementia in the NHATS/NSOC

To ensure a more accurate sample size of participants with dementia, the researchers at NHATS screened participants further to determine dementia classification.

Dementia Classification there are approximately 4.3 million people aged 65 and more with dementia, with another 4.0 million showing signs of cognitive impairment consistent with dementia; among those aged 71 and older, an estimated 3.6 million cases of probable dementia and 3.1 million cases of potential dementia (Kasper et al., 2013). NHATS participants were determined to have dementia based on scores on a dementia screening interview indicative of probable dementia, questions asked of proxy respondents (caregivers) who responded to the NHATS interview on behalf of the sample person (care recipient), and reports by the care recipient or caregiver that the care recipient has been diagnosed with dementia or other cognitive impairment. The eight-item dementia screening interview evaluates the test subject’s cognitive abilities, including their memory (immediate and delayed ten-word recall), orientation (identifying the President and Vice President), judgment (clock drawing task), and functional abilities (executive function) (Kasper et al., 2015).

The NHATS and the NSOC are national studies that include the viewpoints of both care recipients and caregivers. Instead of picking only one primary caretaker to interview, the team tried to talk to everyone who could be a caregiver to the care receiver. This method produces a statistically representative sample of all potential caregivers, allowing us to gain insights into the distribution of caring tasks (NSOC, 2020). NHATS collects the month and year of birth and age of spouse/partners, children, and household members of caregivers in the Other Person—Sensitive Demographic files (Kasper et al., 2015). The dataset obtained from NHATS/NSOC was in the form of a de-identified file. The research team could not connect the data to the participants. The National Study of Caregiving (NSOC) periodically gathers information on family and unpaid caregivers for National Health and Aging Trends Study participants. This project integrated and analyzed survey data from both large national representative sample data sources of Medicare beneficiaries (NHATS).

Measures and Protocols for Data Collection

The researchers completed data collection from the **NHATS/NSOC** database using standardized protocols from the NSOC user guide (Kasper et al., 2015) and the instruments pertinent to the proposed study. The researchers asked the helpers if they had been diagnosed with common chronic conditions and had experienced impairments and symptoms (e.g., pain, breathing problems, low energy, upper and lower body impairments, and sleep quality) in the last month. The researchers assessed the severity of impairments reported, measuring how they interfered with daily activities in the last month. Subjective well-being included brief depression and anxiety screening instruments (PHQ2 and GAD2). PHQ2 and GAD2 are two validated and reliable tools that are derived from the longer versions of the PHQ-9 and the GAD-7. The PHQ-2 asks: “Over the last two weeks, how often have you been bothered by the following problem: Little interest or pleasure in doing things?” GAD-2 asks, “Over the last two weeks, how often have you been feeling nervous, anxious, or on edge?” The PHQ-2 and GAD-2 are self-report questionnaires used by mental health professionals to assess the severity of depression and anxiety, respectively (Spitzer et al., 2001).

Anxiety was measured using the Generalized Anxiety Disorder 2-item instrument **(GAD-2)**. The GAD-2 is a scale for detecting Generalized Anxiety Disorders. It is psychometrically sound and straightforward to administer. Researchers can use the GAD-2 to conduct remote health surveys, epidemiologic studies, and primary care. The GAD-2 consists of two questions with scores ranging from 0 to 3 that measure how often anxiety symptoms afflict the patient over the last two weeks. The researchers proposed condensing the questionnaire and using only the first two questions related to the two core difficulties of GAD to create GAD-2 (**Tables 3-4**).

GAD-2 asks, “Over the last two weeks, how often have you been feeling nervous, anxious, or on edge?” It highlights crucial components present regardless of underlying illness. Due to its discriminating ability, it is a critical first step for screening GAD (Sapra et al., 2020).

Depression The Patient Health Questionnaire 2-item instrument, PHQ-2, derived from PHQ-9, was used to measure depression. This reliable and validated tool targets the core symptoms of depression. The 9-item Patient Health Questionnaire (PHQ-2) has proven efficient for screening major depression and validly indicating the severity of depressive symptoms in a clinical environment (Na et al., 2018). The researchers administered the PHQ-2 over the phone and asked participants two weeks beforehand how often they experienced a sad mood or a loss of pleasure in normal activities. The PHQ-2 asks: “Over the last two weeks, how often have you been bothered by the following problem: Little interest or pleasure in doing things?” Likert scale from 0 (not at all) to 3 (almost every day), the frequency is weighted equally, yielding a total score between 0 and 6 (BMJ, 2010).

We used these two interconnected data sources matching caregivers that provide information in the National Study of Caregiving (NSOC) with their corresponding care recipients (SP) from the National Health and Aging Trends Study (Kasper et al., 2015 & Freedman et al., 2019). This data provides extensive information on both the caregiver and care recipient. I used the 2015 round II of NSOC and information from the corresponding NHATS round 5, limiting the sample to caregivers providing care to their PLWD in the community and limited the sample to care receiver who has probable or possible dementia (those told by a physician that they have dementia). We used the 2015 cross-sectional NHATS round 5 dementia classification data for our analysis. This data set is valuable because it has a large and representative sample of older adults who have a high probability/possibility of having dementia and live in the community, as well as their unpaid caregivers who are over 55 years old.

3.3 Primary Measures – Overview of primary measures for Caregivers from NSOC dataset

Stress measures (primary outcome) derived from questions on aspects of caregiving related to the relationship with the care recipient (SP). It is self-reported, (a) how much do you enjoy being with the care receiver, (b) how much does the care receiver argue with you, (c) how much does the care receiver appreciate what you do, (d) how often does care receiver get on your nerves, (e) helping care receiver made you more confident about your abilities, (f) helping care receiver has taught you how to deal with difficult situations, (g) helping care receiver brought you closer to care receiver. These self-reported responses were re-coded as binary variables.

Depression (primary outcome) the NSOC survey asked caregivers if over the last month (a) how often they had little interest or pleasure in doing things, (b) felt down, depressed, or helpless, (c) felt nervous, anxious, or on edge, (d) been unable to stop or control worrying. The caregiver can respond with (a) not all, (b) several days, (c) more than half the days, (d) nearly every day, (e) refuse to answer, (f) do not know. These self-reported responses were re-coded as binary variables.

Community Support Use (dependent measure) the NHATS/NSOC searchers asked caregivers seven dichotomous items related to support use (a) whether caregivers had friends or family to talk about important things in life, (b) helped with their daily activities, such as running errands or helping with things around the house, (c) helped care for care receiver; and in the last year, (d) had gone to a support group for people who gave care; (e) used any service that took care of the patient so that they could take some time away from helping; (f) received any training to help take care of the patient; (g) found financial help for the patient, including helping patient apply for Medicaid. Caregivers can respond with (a) yes, (b) no, (c) refuse, and (d) do not know. These responses were re-coded as binary measures for the analysis.

To further understand how the caregiver found out about the support group, the service you used to take time away, the training, and financial help for the care receiver; they asked each one did you find out about this service/these services, (a) from a government or community agency; such as an area agency on aging, an aging and disability resource center, a senior center, a county or state social service agency, the VA, or any other federal, state, or county government agency; (b) by talking to a medical care provider or social worker; (c) from a church or synagogue; (d) from your employer; (e) on your own, from a friend, online, or at the library; (f) from any other source.

Neighborhood Cohesion (dependent variable) three items evaluating the care receiver's neighborhoods were asked (a) people in this/ care receiver's community know each other very well, (b) people in this/ care receiver's community are willing to help each other, (c) people in this/ care receiver's community can be trusted. The response choices were (a) agree a lot, (b) a little, or (c) do not agree. This was coded as a dichotomous question, yes or no for analysis.

Control Variables Five control variables helped identify participant demographics:

Race (self-reported) questions on race and primary race if more than one for both care receiver and caregivers. Response options: 1 = White, non-Hispanic; 2 = Black, non-Hispanic; 3 = Other (Am Indian/Asian/Native Hawaiian/Pacific Islander/other specify), non-Hispanic; 4 = Hispanic; 5 = DKRF; 6 = Missing. Although the primary focus of my research study is on Black family caregivers, I completed the comparative analysis using non-Hispanic White participants as the reference group.

Gender (self-reported) interviews confirmed the gender of the participants. If not obvious, ask the caregivers. The caregivers can correct the gender reported by the care receiver. Response options: 1 = Male, 2 = Female. This variable was not re-coded since it originated as a dichotomous variable in NHATS and NSOC datasets.

The researchers measured *age* (self-reported) by asking participants the month and year of their birth date at the time of the survey. I re-coded age into two weighted categories, 55-64 years old and 65 and over, to reflect the research focus on the older adult population.

Education (self-reported) the participants were asked highest degree or grade level for care receivers and caregivers. Response options: 1=no schooling; 2=1-8th grade; 3=9-12th grade; 4=HS graduate; 5=Vocational/Technical/Business/or Trade school certificate; 6=Some college but no degree; 7=associate degree; 8=Bachelor's degree; 9=Master's/professional/or doctoral degree; refused to answer; do not know. This variable was re-coded into three dichotomous categories: high school or less, some college or associate degree, and graduate or advanced degree.

Income (self-reported) elicits financial information, including whether the caregiver has checking/savings accounts, retirement accounts, and other stocks or mutual funds; home ownership; and total income for individuals (or couples). Respondents entered total income for the last year ranging from 1 to 99999999 when asked. This variable was re-coded into two categories: below 50,000 and over 50,000 and we accounted for missingness.

Health conditions (self-reported) This section contains self-reported chronic diseases and conditions. A person's general health status is inquired about first, followed by whether a doctor has ever diagnosed them with a chronic condition. The patient reported a diagnosis of cancer, dementia, Alzheimer’s, and fractured or broken bones since age 50. An open-ended question asks if a doctor has told the person they have another severe disease or illness. Care receivers provided information on the history of chronic conditions: cancer, diabetes, stroke, dementia/disease, Alzheimer’s high blood pressure, arthritis, osteoporosis, arthritis, and diabetes (Freedman et al., 2022). I re-coded these responses to dichotomous variables. A categorical variable created reflects having one condition, two conditions, and three or more conditions.

3.4 Data Preparation and Statistical analyses

The quantitative analysis was carried out using Stata (version 17.0). We ensured that estimates based on the sample data represented the general U.S. population. We used NHATS round 5 and round NSOC II cross-sectional datasets because they gave us the largest sample size of older adults in the subsample population we intend to examine. Using the data from the dementia classification, in which the care receiver reports that a doctor told them that they had dementia, gave me a larger sample size of care receivers who qualify as having a dementia diagnosis. To facilitate the analyses, I first conducted preprocessing to clean the data (e.g., item missingness) and descriptive analyses to assess the characteristics of the data elements (i.e., explore the patterns of the key variables). I treated all the outcomes as binary measures. I used regression-based modeling (e.g., Ordinary Least Squares Regression, binary logistic regression) to assess the effect of community support on mental health (depression and anxiety). The secondary data analysis informed the qualitative question development, approaches to coding, and thematic reduction; this was an iterative process.

***Aim 1*:** The *<u>objective</u>* is to determine the degree to which mental health status (e.g., depressive symptoms) is associated with using supportive services among Black family caregivers of people living with dementia in the community. To achieve this objective, I tested the hypothesis that decreased anxiety, depression, and improved mental health will be associated with community support services use. The secondary data analysis of the cross-sectional data was collected from participants in the NHATS rounds 5. NSOC II (2015) yielded 2,204 family caregivers or other unpaid caregivers who were eligible, and 672 were caregivers of PLWD in the community using multivariable regression models.

Aim 2: The *<u>objective</u>* is to investigate the effect of neighborhood cohesion on the Black caregiver's mental health. To achieve this objective, I hypothesized that caregivers who live in more cohesive neighborhoods are less likely to rely on community support services to cope with stress and improve their mental health. This portion of the study is completed by conducting secondary data analysis of the NHATS 5 and NSOC II (same sample size as in Aim 1). Similar to Aim 1, this analysis used multivariable regression models to assess the association between neighborhood cohesiveness and the use of community-based support services.

Aim 3: The *<u>objective</u>* is to examine the factors influencing the use of community support services, including facilitators and barriers. Current Black caregivers (n=6) were recruited nationally as part of a larger family caregiver research.

Qualitative Data (Focus Group)

Focus group discussions can uncover barriers and facilitators that other research methods may not reveal (Gundumogula, 2020). In the qualitative part of this research, we conducted a focus group to gain an in-depth understanding of the Black caregiver's life experiences with caring for someone living with dementia in the community and their use of CSS. (Kinalski et al., 2017; Nyumba et al., 2018). Focus groups are an excellent way to answer research questions about facilitators and barriers to community support service use because they allowed us to collect qualitative data from multiple caregivers at once who could provide valuable insights about their lived experiences. The objective of the focus group was to gather information about caregivers' experiences with community support services from a self-selected random group (Nyumba et al., 2018) so that we may better understand their individual needs and develop more effective interventions. The focus groups can also identify social and cultural influences that might not be revealed through surveys or other research methods.

The project manager and I screened interested participants via telephone calls. We provided an opportunity for questions about the research, reviewed the consent form, ensured that the participant had a computer with access to Zoom, and scheduled focus group interviews. Within 24-48 hours after the call, consent was mailed electronically or in hardcopy (participant’s choice) for signature, email Zoom calendar appointments. Hardcopy documents had a self-addressed stamped return envelope enclosed. Participants who had not returned signed papers within a week received a reminder call. We made calls two days before the focus group interview to remind the participants of the interview and encouraged them to test their Zoom with the link provided.

The facilitator reminded the participants of the aim of the focus group and the importance of their participation. We instructed participants that they may withdraw from the study at any time and for any reason. We ensured they knew joining this group would not put them at risk or in danger. We explained the potential risks and benefits (See Potential Risks, Protections Against Risks, and Potential Benefits section), especially noting that there were very few risks. We explained that each person’s comments would be recorded for transcription. We emphasized that their privacy would be respected and that the final transcriptions would be deidentified. (See appendix: A).

The focus group interviews were guided using a semi-structured format (**See appendix A**).

We used multiple research team members to promote division of labor. This allowed the assignment of specific tasks, such as having one individual responsible for verifying the presence of all participants and offering technical assistance, another to facilitate interviews, and a third to observe and take note of group dynamics. In this way, the research team can more efficiently and effectively complete the task at hand. The research assistant ensured that all participants signed in to Zoom without difficulties. The assistant did not participate in the discussion or respond to the participants' words with nonverbal cues. The research team and I debriefed about the session and any important nonverbal cues we noticed after all participants had left the zoom meeting.

Storage and Future Use of Data

The audio recordings of the interviews were electronically transcribed in Zoom. The transcription was cleaned and de-identified by the research team. The recording is securely stored for future use.

Training for Research Team Members

Research facilitator (SRL) is an expert qualitive methodologist, who also provided training to the team on transcribing and coding. A checklist of her duties was provided and reviewed before the focus group started. We discussed the process of the Zoom meeting and the importance of meeting briefly for a post-focus group debriefing and discussed what went well and what we could do better, for future focus group meetings.

Inclusion Criteria:

We conducted a focus group with participants who met the criteria to identify the key barriers and facilitators of community support services use, and explored the participants' experiences with such services. The participants must:

- self-identify as Black or African American,
- be 18 and over,
- speak and understand the English language,
- be related to or have a close personal relationship with a person over the age of 55 that has a dementia diagnosis or evidence of cognitive impairment,
- be responsible for, monitor, and/or provide assistance in activities of daily living for the care recipient, score 14 or higher on the Animal Naming Test, and
- have access to a computer/Zoom.

The study and protocol were reviewed and received exempt approval from the University of Michigan Institutional Review Board (IRB), HUM00218293.

Recruitment

Participants were recruited through flyers, social media (e.g., Facebook, LinkedIn), community engagement activities, snowball referrals and a contact list of former caregiver study participants who consented to be contacted regarding future studies for which they may qualify. Each participant completed a demographic survey that took approximately 25 minutes and then participated in the focus group, which lasted about an hour and a half. Participants were compensated for their time with a $75 Mastercard gift card ($25 after the survey completion and $50 following the focus group meeting). Participants were also provided with the option to receive checks of the same amount rather than gift cards (See Appendix A).

Sample

Focus groups typically have six to ten individuals to facilitate group conversations best. Larger groups make it harder for the group to communicate effectively with one another and may increase the possibility of participant disengagement (Klagge, J., 2018).

Analysis

Two researchers completed content analyses independently, using the rigorous and accelerated data reduction (RADaR) technique, which facilitated quick and succinct thematic data analysis (Watkins, 2017). Watkins (2017) outlines a five-step process for organizing, reducing, and analyzing qualitative data. Step one of this process ensures that all data transcripts are formatted similarly. It was vital to ensure that all data transcripts from qualitative research were formatted similarly to make the data easier to work with and analyze. By using predetermined coding, researchers can compare data across multiple transcripts more easily. Additionally, using the same format for the transcripts helps to ensure accuracy and consistency in the coding process. Finally, by creating a consistent format for all qualitative transcripts, researchers can save time and resources when creating the RADaR Phase 1 data reduction (Watkins, 2017).

Step two then involves placing the formatted transcripts into an all-inclusive data table. The RADaR Process begins by copying and pasting the text from data reports into a table with multiple rows and columns. This all-inclusive data table is the first in a series of data reduction tables, the cornerstone of the RADaR technique. We created data reduction tables in Microsoft Word and contained all the information from the transcripts or other data reports (Watkins, 2017). The data reduction process involves the creation of a data table, which serves as the foundation for subsequent phases that progressively narrow the data to reveal a condensed and streamlined list of qualitative results. (Watkins, 2017).

Step three involves reducing the data in the all-inclusive data table to produce a more concise data table. We removed all but the primary interest content from the Phase 1 data database to generate a Phase 2 data table. We only included rows that could help us answer the study question and excluded those that could not. To help us focus on the facts and create more precise pointed codes, we carefully removed portions of text or data from the Phase 1 table (Watkins, 2017).

Step four requires further reduction of the data to produce more data tables. We used the RADaR technique to reduce the text table and create a shorter, more condensed presentation of the data. We alternated between individual and team-based work over a short period to iteratively review each data phase and decide which text chunks to keep or remove.

Finally, step five involves drafting the project deliverables using the final phase of the data table. In the last phase of the RADaR method, we used the condensed data to craft language for the final analysis of results. We selected pertinent quotations to support the final themes for this dissertation.

The RADaR approach permitted us to create comprehensive data maps using spreadsheets. These adjustments aid in creating shorter, more terse data (Watkins, 2017). Using the RADaR technique, a research team member and I completed thematic coding to draw out primary and sub-themes. Each team member (F.U.J and S.R.) coded the data independently and then jointly until consensus was reached to reduce bias. After identifying themes from the focus group interview, we structured the data to produce a cohesive, reliable picture of the caregivers' lived experiences with community support service use (Sheppard, V., April 6, 2020).

Analyzing focus group transcripts allowed us to gain deeper insights into caregiver group dynamics and better understand CSS use, barriers to use and facilitators. It also helped us to uncover the underlying meanings within the focus group conversations and to identify consensus among participants. Thematic analysis was a valuable tool for understanding the caregivers' perspectives, opinions, and experiences and allowed us to draw meaningful conclusions from the data collected (Moore, 2021). Iteratively completing the analysis ensured that the themes developed reflected each participant's experience with CSS.

The next chapter will provide an overview of the analyzed quantitative and qualitative data. This chapter will summarize the most important findings and results from the quantitative and qualitative analysis. Additionally, this chapter will provide key themes that were identified through the focus group interviews.

Chapter 4 Results

This chapter presents the results of the mixed method data analysis. The study used a sequential explanatory design, which involved collecting and analyzing quantitative data first, followed by qualitative data. The purpose of this design was to use the qualitative data to explain and enrich the quantitative findings. The quantitative data were obtained from a survey of 1027 family dementia caregivers and their use of community support services to address depression and anxiety. Of the 1027 dementia caregivers, 337 were Black family dementia caregivers. The qualitative data were collected from semi-structured interviews with six Black current and former caregivers who participated in the focus group. The data analysis consisted of three phases: (a) descriptive and logistic statistics for the quantitative data, (b) thematic analysis for the qualitative data, and (c) integration of the quantitative and qualitative results. The following sections describe each phase in detail and report the main findings as they relate to the three research questions under study regarding (a) community support services and mental health, (b) neighborhood cohesion and mental health, (c) barriers and facilitators of community support services.

Our first question (Aim 1) was how does the use of community support services affect the mental health (depressive symptoms and anxiety) of Black family caregivers?

To answer this question, the data analysis examined the relationships between Black caregiver depression, anxiety, community support services and neighborhood cohesion. The data were summarized using descriptive statistics and the associations between race and the other variables were tested using logistic regression and bivariate analysis. The data were weighted to reflect the U.S. population and the significance level was set at .05. The analysis also considered how dementia classification influenced the results by stratifying the data into possible (n = 303) and probable (n = 724) dementia groups. The sample sizes for each group were 116 Black and 143 White caregivers for possible dementia, and 221 Black and 390 White caregivers for probable dementia. The findings of these analyses are reported below.

Description of the sample

Based on the CR's dementia classification, the characteristics of caregivers, care recipients, and their environment indicate that the sample had a varied income and education level, with women comprising 65% of the population. More than half of the caregivers in both categories (51%) were adult children of the care recipients, 97% enjoyed spending time with the CR, 71% reported that the CR did not argue, 97% appreciated the caregiver's efforts, and 70% did not irritate the caregiver. Regarding neighborhood cohesion, most individuals trust one another (83%) and help one another (83%) and know one another well (75%) **(Table 1).**

In the secondary dataset, black caregivers were found to have a high school degree or less (54%), an income of $49,000 or less (75%), and were less likely to report feeling anxious or depressed. They also reported not feeling alone, not having family help with the CR, not attending support group meetings (96%), not taking time away from caregiving (87%), and not receiving dementia training. In relation to the stress measures, participants were more likely to report that they enjoyed spending time with the CR (77%), felt appreciated by the CR for what they do (96%), were not bothered by the CR (24%), gained confidence in their abilities by helping the CR (91%), felt closer to the CR by helping them (96%), and rarely argued with the CR. (**Table 3**).

The focus group participants shared their lived experiences and opinions in depth about community support services use. Participant characteristics (n = 6): Five females and one male Black caregiver. Five currently work and one is retired. Two participants were former caregivers, and four are current caregivers. They all worked while caregiving. Each participant had been a caregiver to several care receivers at a time or consecutively; they provided care to mom (6), dad (2), uncle (3), stepmom (1), aunt (2), mother-in-law (1), husband (1), and grandmother (1). From this 90-minute group discussion, we identified key themes related to barriers and facilitators of community support services use: financial constraints of accessing services, lack of dementia training & social support, difficulties with attending support groups.

As it relates to the stress measures, significant results for anxiety were feeling alone (OR = 6.52 [2.45, 17.30]), CR arguing with caregiver (OR = 2.70 [1.30, 5.62]), CR got on nerves of caregiver (OR = 3.32 [1.46, 7.56]) and for depression were feeling alone (OR = 7.6 [3.26, 17.80]), CR arguing with caregiver (OR = 2.38 [1.22, 4.66]) for CR's with probable dementia. CR got on nerves of caregivers was significant for anxiety (OR = 4.75 [1.23, 1.83]) and so was feeling alone (OR = 5.9 [1.43, 2.46]) of those with possible dementia (see **Table 4**). There is an association between depression and community support services, with an odds ratio of 0.56 [.15, 2.13], (OR = 1.45 [.48, 5.55]), (OR = 1.45 [.23, 1.88]), (OR = 10.55 [.63, 1.77]), and (OR = 2.70 [.47, 1.57]), respectively. The stress measures were not significantly associated with CSS use, according to the bivariate logistic regression analyses presented in **Tables 6 and 7**. The latter analysis also stratified dementia classification and race. However, the confidence intervals for the association between supportive services and mental health were wide, indicating uncertain or weak association (**see Table 9**).

Our second question (Aim 2) asked how does neighborhood cohesion affect Black caregivers' mental health?

The neighborhood cohesion variable within NHATS means that the people living in care receiver's neighborhood know each other well, trust each other, and help each other. Bivariate analyses were conducted to examine how neighborhood cohesion predicted depression and anxiety based on dementia classifications, stress measures associated with community support services use, and neighborhood cohesion stratified by dementia classifications and race. The results of the stratification by dementia classification and race indicated that there were greater odds of Black dementia family caregivers living in less cohesive neighborhoods, where people did not know each other well, did not trust each other, and did not help each other. The odds of Black caregivers of people with possible dementia having anxiety were higher than those with probable dementia (see **Table 9**).

The table presents the results of the bivariate analysis of the association between neighborhood cohesion and depression/anxiety symptoms across different dementia classifications. The odds ratios and 95% confidence intervals indicate the effect of neighborhood cohesion on depression/anxiety symptoms by dementia classification. The results illustrated that community support services are associated with lower odds of depression and anxiety in caregivers of people living with dementia (see **Table 9**). To further clarify, in the multivariate analysis that adjusted for race and dementia classification, the most significant result indicated that living in a trusted neighborhood was associated with lower odds of depression .24 [.10, .54] in Black caregivers (see **Table 12**).

Supporting each other significantly reduced anxiety but did not affect depression. Both anxiety and despair were significantly reduced by a high degree of familiarity. In contrast to sadness, the CSS and neighborhood cohesion had a significant favorable influence on anxiety. The stress measure had a considerable beneficial effect on both anxiety and depression. The results also depict the probability of dementia for various independent variables, including support group, family help act, family talk, trust, help each other, know each other well, composite score for CSS, the composite score for neighborhood cohesion, the composite score for stress measures, and covariates, including CG age, gender, income, education, CG-CR relationship, and CR age. Finally, **Table 12** illustrates that anxiety measures are associated with CR with a higher probability of dementia than depression measures across all covariates that were used to account for bias.

Our third question (Aim 3) was: What are the factors that hinder or enable the use of community support services?

The participants shared common experiences/background with caregiving with most having provided care to multiple family members. They developed a rapport almost immediately, and they spoke freely about how they learned of and used community support services, focusing on the barriers and facilitators.

Facilitators of community support services use

The facilitators that were identified by the participants were government programs such as Area Agency on Aging (AAA) and The Healthier Black Elder Program (HBE). In response to how they learned of available community support services, some mentioned having to conduct their own research and word of mouth. Specifically, several participants mentioned their local (AAA). This government-funded organization provides services to seniors and their caregivers, such as home care, life skills education, case management, and other support services. Participants expressed gratitude for the agency's help in navigating the complicated web of support services, noting that the agency "helped me out a lot." This demonstrates just how important and helpful the AAA can be for older adults in need of community support.

The AAA offers nutrition programs like Meals on Wheels and nutritional counseling. It provides resources for caregivers such as support groups, caregiver education, and respite care. Finally, the local AAA also provides access to long-term care options and can help individuals and families access community-based services for seniors. AAAs enable older adults to select the services and living arrangements that better suit them, while supporting their caregivers. "The home care they provided helped keep him home; he stayed in his home for years" (Robinson-Lane & Johnson, 2023) and "They provided us with a lift chair and transportation to dialysis" (Robinson-Lane & Johnson, 2023).

Members of the group also found The Healthier Black Elder Program (HBE) to be a great resource for learning about community support programs. The Healthier Black Elder Program (HBE) is a community-based initiative designed to reduce health disparities among elderly African Americans in the Detroit community. The program concentrates on providing African American seniors with culturally relevant health education and resources in order to improve and maintain their health. Additionally, HBE seeks to expand access to preventive health and wellness services, such as examinations, health assessments, and referrals to specialized care. Participants noted that the program was beneficial in its focus on increasing physical activity, improving nutrition, and providing social support to help seniors manage chronic conditions, adopt healthy behaviors, and build positive relationships. The program's educational resources also help seniors better understand their health and the healthcare system (IOG, 2023).

"Healthier Black Elder was very helpful" (Robinson-Lane & Johnson, 2023).

"They have tons of programs" (Robinson-Lane & Johnson, 2023).

The program also provides access to a network of health professionals, such as nurses, health educators, and social workers, who are dedicated to helping older African Americans improve their health. Finally, the program encourages active community involvement and engagement by offering a variety of volunteer opportunities. Overall, members of the group found the Healthier Black Elder Program to be a valuable resource for learning about community support programs and accessing the health and wellness services needed to help elderly African Americans in the Detroit community.

Barriers of community support services use

To answer the question about barriers to community support services use, the themes that arose were lack of family support, inability to take time away from their caregiving responsibilities, and the expense of respite care. The social stigma associated with seeking assistance from community support services and social networks was seen as a barrier to using these services. "I have no family to help; I have had to pay them to come help" (Robinson-Lane & Johnson, 2023). Participants may feel judged for seeking assistance, and they may also believe they are a burden to their family and friends.

Time away

Caregivers often struggle to get time away because they are the primary source of care for their loved ones. They may be the only person capable of providing the necessary care, and they may feel a sense of responsibility to always be available. Additionally, the cost of finding alternate care and childcare may be too high for them to be able to get away. Finally, caregivers may feel guilty taking time away from their duties, as they may fear that the person, they are caring for will suffer in their absence. Our participants acknowledged the difficulties of planning time away from caregiving to care for themselves.

> *"I don't go on vacation. I would be paying for two vacations"* (Robinson-lane & Johnson, 2023), *"Last time I went on vacation with my mom and aunt, we lost my aunt in the hotel. That was the last vacation for me"* (Robinson-lane & Johnson, 2023).

Respite

Respite care can temporarily relieve caregiving responsibilities and allow caregivers to rest and recharge. Respite can be provided in the home or at an outside facility. Assisted living facilities could be used for short periods of respite. However, the cost of these community support services is often prohibitive for many families as these services are not covered by insurance. "*Respite in my state is $500 per day. I am paying for two vacations at that rate*" (Robinson-lane & Johnson, 2023) and *"Assisted living costs $11,000 a month"* (Robinson-lane & Johnson, 2023).

Overall barriers to accessing/using community support services.

> *"We do not qualify for assistance."*
>
> *"There is no family to help."*
>
> *"In-home nursing costs are killing me at $5,500 per month."*
>
> *"Caregivers are really busy people."*

Overall, the foremost barriers to using community support services for Black caregivers were financial constraints, lack of time, and feeling overwhelmed. Caregivers often feel isolated from family and friends due to the demands of caregiving and the lack of supportive resources. This can lead to feelings of loneliness and depression, harming physical and mental health. Many are unable to take a vacation or use respite care due to the financial cost and lack of assistance available. Additionally, caregivers are often too busy to seek help from outside resources.

This study aimed to examine the mental health and community support services use of Black caregivers of people with dementia. The study used a mixed method approach, combining secondary data analysis and focus group interviews. The secondary data analysis revealed that some aspects of caregiver stress, such as feeling alone and arguing with caregivers, were significantly associated with depression and anxiety. However, there was no significant relationship between community support services and mental health. This suggested a need for further research to understand how supportive services can benefit caregivers' well-being. The focus group interviews explored the factors that influenced the use of community support services among Black caregivers. The results showed that many caregivers used these services, but they also faced some facilitators and barriers to accessing them. The facilitators included availability, awareness, and programs like the Healthier Black Elder Program and local Area Agencies on Aging. The barriers included lack of family/social support, time constraints, and cost of respite care. These barriers can affect caregivers' mental health negatively and increase their feelings of loneliness and depression. Discussion

This study aimed to examine how community support services and neighborhood cohesion affected the mental health of Black family caregivers of people living with dementia in the community; specifically, I sought to understand the lived experiences of Black dementia family caregivers with community support services.

4.1 Aim 1 Black Dementia Family Caregivers' Mental Health and Use of Community Support Services

Caregivers of people with probable and possible dementia in the Black community faced similar challenges in terms of accessing community support services. Awareness of services was low, with only 14% of caregivers of those with probable dementia and 10% of caregivers of those with possible dementia receiving dementia training. Additionally, most caregivers (69% of those with probable dementia and 81% of those with possible dementia) earned an annual income of $49,000 or less, making it difficult to afford services. Lastly, only 5% of caregivers of those with probable dementia and 1% of caregivers of those with possible dementia attended support groups according to the secondary data analysis of the NSOC.

The secondary data analysis of the NHATS-NSOC dataset revealed that Black caregivers were less likely to report depression and anxiety compared to their White counterparts. The experience of depression and anxiety among the group is unsurprising as Black dementia family caregivers often care for a family member or loved one who are diagnosed with dementia late in the disease process--thus they often experience higher levels of caregiver burden. A Previous study has shown that Black caregivers carry a heavier care burden than other racial or ethnic groups (Fields et al., 2021). However, the underreporting of these symptoms may be related to the comfort they find in their faith and spirituality, as well as their extended family, friends, and community (Fields et al., 2021). Additionally, Black caregivers may be less likely to seek professional help for mental health issues and instead rely on family and friends for support (Fields et al., 2021). They may also have more positive attitudes and beliefs about their roles as caregivers and the ability to cope with the stress and demands of caregiving. Focus group participants acknowledged feeling honored to serve as caregivers to their loved ones *“my mom took care of me, so it was an honor to take care of her”* (Robinson-Lane & Johnson, 2023). This study also revealed that the prevalence of community support service use differs based on age, gender, race, ethnicity, and socioeconomic background. Members of the focus group explained that the availability and affordability of dementia support services depended on the socioeconomic status of the PLWD and the family. “The more money you had, the better the quality of services but less money meant you could get more services” (Robinson-Lane & Johnson, 2023). Home health aides who assist with activities of daily living and respite care are provided less often to older Black adults (Alzheimer’s Association, 2023).

Furthermore, focus group participants observed that those with lower incomes receive substandard care and have limited access to support services compared to those with higher incomes. The Alzheimer's Association (2023) has reported that dementia caregivers experience a higher level of financial strain than non-dementia caregivers, with 87% of dementia caregivers indicating at least some financial strain, compared to 61% of non-dementia caregivers. This financial burden can have a significant impact on the caregiver's physical and mental wellbeing.

Additionally, the study revealed that women are provided with more support services than men. Given the traditional gender roles that exist in family caregiving, it is unsurprising that most participants in the secondary data analysis (65%) and in the focus group (83%) were female. The NHATS/NSOC datasets included both primary and non-primary caregivers, and analysis of the data showed that women were more likely to identify as the primary caregivers in their families, and thus were more likely to receive support services than men.

The findings of the secondary data analysis are perplexing, as it appears to contradict the Perlin stress response model. Black caregivers are often faced with a heavier burden of care, which should logically lead to an increase in the utilization of community support services to alleviate stress levels and improve mental health. Nevertheless, the data suggests otherwise, which could be indicative of a greater systemic issue that could be preventing Black caregivers from seeking out such services (Fabius & Parker, 2022). It may be that healthcare stigma and mistrust may discourage Black family caregivers from seeking support (Molnar & Charles, 2019).

Unpaid caregiving is emotionally, physically, and financially exhausting. Black family caregivers face unique challenges due to a lack of access to resources, support, and information about dementia. This often leads to feelings of isolation and stigmatization. Due to these hardships, dementia family caregivers are typically stigmatized and isolated (Molnar & Charles, 2019). One focus group participant revealed that she felt guilty of "*being tired and bitter*" for having been a caregiver as early as 20-ish (Robinson-Lane & Johnson, 2023).

Another participant talked about feeling as if family and friends don't understand the amount of work it takes to be a caregiver. This participant mentioned rarely having the opportunity to relax or engage in self-care (Waligora et al., 2019). Waligora and team (2019) also noted that dementia caregivers reported difficulties sustaining familial and social relationships, feelings of isolation, a deficiency of familial and community support, and a desire for social encouragement. Dementia family caregivers need exceptional support and resources to offer practical and compassionate care (NAC & AARP, 2015; NIA, 2016; Alzheimer's Association, 2022). This suggests that Black caregivers may experience social isolation and that their support networks may be less accessible to them.

Additionally, Black caregivers maybe more likely to report feeling overwhelmed by their caregiving responsibilities, suggesting that they may be at higher risk for developing physical and mental health issues such as depression, anxiety, and chronic stress. This can lead to further health problems including higher blood pressure, weakened immune system, and an increased risk of heart disease (Cothran et al., 2021; McLennon et al., 2011 & Quiñones et al., 2020). One focus group participant talked about not receiving help from family "no family to help me" (Robinson-lane & Johnson, 2023), noting that help was forthcoming when payment was offered to family members. The participant stated, "I just go with the flow, it is what it is" (Robinson-Lane & Johnson, 2023). To decrease the potential for adverse health complications and comorbid conditions, these caregivers need to be cognizant of their physical and mental health, including adequate sleep and rest, engaging in physical activity, and eating a balanced diet.

Black family caregivers may also believe that services are not culturally competent or adapted to their community. Language, money, and transportation are further obstacles. Our focus group participants discussed the financial hardship of caregiving. Only two out of six participants reported on the importance of consulting an elder finance attorney to ensure their care receiver's money was handled in accordance with the law, which they felt facilitated access to obtaining support services. One of them shared attending an elder care presentation and meeting an attorney at the presentation by happenstance "I did not know I would need it" (Robinson-Lane & Johnson, 2023).

The secondary data analysis results showed that Black family caregivers taking care of a person with probable dementia were more likely to earn $49,000 annually, while 81% of those taking care of someone with possible dementia indicated making $49,000 or less (see **Table 3**). Caregivers require a social support network to manage caregiving responsibilities and stress. Locating credible doctors, dementia training and community support services education, and building family relationships, especially with old friends who remained after the diagnosis, have all been found to reduce stress and enhance mental health in previous work (Lindeza et al., 2020).

4.1.1 Aim 2 The objective is to investigate the effect of neighborhood cohesion on Black family caregiver's mental health.

The objective of aim two is to investigate the effect of neighborhood cohesion on Black family caregivers' mental health. We explored how levels of connectedness among neighbors in each community affect the likelihood of Black family caregivers using available resources and how this, in turn, impacts their mental health. Neighborhood cohesion can have an important influence on the use of community support services thereby impacting mental health. For example, our study found that community support services were moderately associated with lower levels of depression and anxiety among Black caregivers. The odds ratio was 0.43 [95% CI: 0.24, 0.77], indicating that higher neighborhood cohesion was linked to lower anxiety within a 95% confidence interval. Additionally, we found that higher neighborhood cohesion was strongly associated with lower anxiety, with an odds ratio of 0.67 [95% CI: 0.33, 1.35]. This means that caregivers who reported higher neighborhood cohesion were 33% less likely to have anxiety than those who reported lower neighborhood cohesion within a 95% confidence interval.

Lastly, we found a very strong association between higher neighborhood cohesion and lower anxiety, with an odds ratio of 0.76 [95% CI: 0.49, 1.19]. This means that caregivers who reported higher neighborhood cohesion were 24% less likely to have anxiety than those who reported lower neighborhood cohesion within a 95% confidence interval (See Table 8). When neighbors are connected, they are more likely to know about and utilize the services available. People in a socially connected neighborhood are more likely to look out for one another and help when needed. This could include things like providing transportation to services, giving moral support, or even helping with basic needs. Having a supportive and connected neighborhood can go a long way in helping people access the services they need when they need them.

4.1.2 Aim 3 The factors influencing the use of community support services, including facilitators and barriers.

The focus group provided insight into the underlying motivations and behaviors of the respondents' engagement with community support services. Common themes that emerged from the facilitators of community support service use discussion were, social support, respite, support groups, and dementia training. For clarification purposes, social support is a type of assistance or comfort provided by people in a person's social network, such as friends, family, coworkers, or peers. This type of support can be in the form of emotional support, tangible help, or informational support. Support groups, on the other hand, are organized groups of people with a common need, goal, or experience and who share their experiences and support each other. Members of support groups are typically strangers to each other, and the focus of the group is on providing support to members to help them cope with a particular issue (Barlett & Koehn, 2018).

Social Support

Various factors could impact why Black caregivers have limited access to their social networks. Some of these may include not feeling that they should impose on other family members, being laser-focused on caregiving, and lack of education on managing caregiving responsibilities best. Additionally, the generational trauma and financial hardships of Black families may contribute to a lack of support (Robinson et al., 2013). Isolation and depression can result from a lack of or limited social support. The participants discussed the lack of family support despite their families being aware of their caregiving duties. The findings from studies suggest that the social isolation resulting from the loss of old friendships and lack of family support, which are consequences of solo caregiving, have a significant negative influence on the personal and social lives of Black family caregivers (Ornstein et al., 2019).

Respite

A lack of awareness and financial resources for respite services is evidenced by the findings of NHATS/NSOC, where only 15% and 11% of Black caregivers of those with probable and possible dementia, respectively, reported having time away. Black family caregivers underutilize respite care significantly. (Parker & Fabius, 2020). Our focus group findings indicate that Black family caregivers of PLWD are less likely to use respite services than White family caregivers because it is cost prohibitive. Our findings do not explicitly address the question of the income level of White family caregivers, but it could be an important factor to consider in future research.

Respite care for people living with dementia in the community is not typically covered by insurance plans and must be paid for out of pocket or by other sources of funding (NIA, 2020). This is supported by one focus group member who stated, *"Respite care is very expensive. In my state is $500 per day. I cannot afford that"* (Robinson-Lane & Johnson, 2023). This is consistent with the literature suggesting that Black family caregivers are less likely to use community support services involving non-family members entering the home (Chin et al., 2011 & Parker & Fabius, 2020). The reluctance of Black caregivers may be because they might be less trusting of outsiders with their PLWD. Cultural values and stigma of sending a family member to a respite facility, lack of transportation options or difficulty getting to the respite facility, fear of negative attitudes of respite staff towards people of color, lack of culturally appropriate services, fear of the person with dementia being mistreated or neglected in a respite facility, and fear of the person with dementia not being able to communicate in a respite facility, are all barriers to accessing respite care (Roth, 2013).

Support groups

Caregivers may encounter a variety of barriers to participating in support groups, including lack of reliable transportation, cost-membership due or donation requirements that may add to the caregivers' financial burden, fear of being judged or having their struggles invalidated, feeling overwhelmed both physically and emotionally taxing, and time constraints (Cox, C, 2022). The caregiver might feel uncomfortable leaving the PLWD to attend a support group and feel the time should be spent providing care (Evertson et al., 2020).

The following quote speaks to the difficult situation many caregivers face when caring for a loved one. Caring for someone can be a time-consuming and emotionally taxing task, and often caregivers don't have the time or energy to devote to attending support groups (APA, 2021). This leaves them feeling isolated and overwhelmed as they try to navigate the challenges of caring for their loved ones (APA, 2021). *“I do not have time to attend support groups; who will care for my loved one?”* (Robinson-Lane & Johnson, 2023).

Dementia training

Several factors may contribute to the fact that some Black family dementia caregivers do not receive training. It is essential to consider these factors to increase access to dementia training for Black family caregivers. Healthcare providers should consider limited resources, cultural stigma, and financial concerns when developing dementia training programs. Furthermore, healthcare providers should strive to create a safe and non-judgmental environment for Black family caregivers to discuss dementia-related concerns openly. By addressing these issues, healthcare providers can better ensure that Black family caregivers have the resources and support to care for their loved ones safely and effectively with dementia (Goh, et al., 2022).

"I learned as I went along" (Robinson-Lane & Johnson, 2023).

The participants identified cost, lack of awareness, and social network as barriers to using community support services. These factors prevented them from taking time for self-care or engaging in available opportunities. Wealth determines the level and degree of support available.

> *"More help is available if you are low income, but you get better quality help if you have more money"* (Robinson-Lane & Johnson, 2023).

In summary, the group talked about resources such as: dementia training with focus on the stages, the different types, respite care, dealing with guilt, that might have helped their caregiving responsibilities be more manageable. Caregiving interventions need to be tailored to the specific needs of caregivers and provide a combination of strategies such as problem-solving, skills training, and community support services. Public health nurses can be instrumental in connecting caregivers with the necessary resources. Additionally, behavioral skills training can be effective in reducing caregiver depression (Robinson et al., 2013). CSS—support groups, help-seeking, respite, and dementia training—can reduce caregiver stress and promote mental health.

4.2 Implications

Dementia caregiving is becoming a significant public health issue due to the increasing number of individuals living with dementia. As the population of older adults grows, so does the number of people living with dementia. This strains caregivers, who often need physical and emotional support for their loved ones. Additionally, dementia can significantly impact the quality of life of those living with it and their caregivers. As a result, dementia caregiving has become a public health issue associated with increased depression, anxiety, and other mental health issues among caregivers.

This study revealed that Black family dementia caregivers face unique health challenges. For example, Black caregivers provide more care than their White counterparts and report worse physical health and more comorbid conditions than White caregivers (APA, 2011). However, unlike other minority groups such as Hispanic and Asian American caregivers who exhibit more depression than White caregivers, Black caregivers are less likely to express depression or other mental health symptoms (APA, 2011). The implications for future study could include further research into the specific challenges faced by Black caregivers such as lack of community support and barriers to accessing culturally competent services. Additionally, the development of culturally tailored interventions such as providing dementia training, addressing systemic barriers to healthcare, lack of access to mental health care, and support systems to address these challenges could be explored. By understanding the unique experiences of different minority groups, researchers and policymakers can better advocate for action to address the challenges faced by these groups and improve their lives.

Although our secondary data analysis was not clinically significant for stress, anxiety, or depression this does not mean that we should be satisfied that Black caregivers don’t experience these outcomes; instead, we should investigate further. Could this be a result of using the short form measure (PHQ-2 and GAD-2), we should consider if the two questions dug deep enough? Especially since Huang et al. (2022) found that Black caregivers had higher rates of depression and anxiety than White caregivers. Nurses might consider more open-ended questions related to stress, anxiety, and depression such as:

- How do you feel about your caregiving role and responsibilities?

- What are the main sources of stress or difficulty for you as a caregiver?
- How do you cope with the challenges and emotions that arise from caregiving?
- Do you have any symptoms of depression or anxiety, such as feeling sad, hopeless, worried, nervous, or irritable?
- Do you have any concerns or questions about the quality or availability of mental health care or support for Black caregivers?
- How can I help you to address your stress, anxiety, and depression as a caregiver?

Standardized testing, such used in the NSOC survey has historically been biased against Black people; therefore, it is essential that culturally responsive tools and proper representation is afforded Black family caregivers when asking questions related to mental health (Rosales & Walker, 2021).

Community support services have historically been inaccessible, unaffordable, culturally unresponsive, and unsustainable for the Black caregiving community (Fields et al., 2021). Participants in the focus agreed that elements of caregiving are financially prohibitive, nursing can better support these caregivers by assessing the financial needs and resources of Black caregivers and provide them with information and assistance to access financial support programs or benefits that can help them cope with the costs of caregiving. For example, nurses can provide guidance or help them apply for Medicaid, Medicare, Supplemental Security Income, or other public or private programs that can cover some of the expenses of medical care, respite care, home modifications, or assistive devices (Fields et al., 2021).

Both the secondary data analysis and the focus group participants highlighted feelings of loneliness and lack of familial support. The lack of support services use by Black caregivers can have serious implications for the health and well-being of both the Black caregivers and their care recipient. This can lead to an increased risk of burnout, depression, and increased stress levels, which can have long-term health consequences (Whitney et al., 2023). The social isolation due to the loss of old friendships and the lack of family support seems to have a substantial negative impact on caregivers' personal and social life.

Another implication for nursing clinical research is to design and test interventions that are culturally appropriate and responsive for Black dementia caregivers. These interventions might prevent or reduce stress, depression, and anxiety among caregivers and enhance their coping skills, resilience, and quality of life. For example, culturally tailored interventions may include elements such as acknowledging the historical and social context of Black caregiving, incorporating spirituality or faith-based practices, addressing stigma and mistrust of mental health services, or using peer mentors or role models. A study by Robinson et al. (2013) demonstrated the effectiveness of one such intervention, which involved behavioral skills training for Black dementia caregivers. The intervention taught caregivers how to identify and manage behavioral problems in their care recipients, such as agitation, aggression, or wandering. The study found that caregivers who received the intervention reported lower levels of depression than those who received usual care (Robinson et al., 2013). This suggests that culturally tailored interventions can improve the mental health outcomes of Black dementia caregivers.

Moreover, the economic impact of dementia caregiving is substantial, with caregivers often having to take time away from work or reduce their hours to care for their loved ones. As a result, there is a need for public health interventions that focus on providing support and resources to dementia caregivers. This can include providing access to respite care, as well as providing education and support for caregivers. Public health interventions can also focus on increasing access to appropriate medical care and treatments for those with dementia. (Kanjilal, S., & Muraleedharan, V., 2019).

Enhancing the access to resources and support for Black caregivers requires increasing the awareness, representation, and opportunities for this population, as well as advocating for policy change, strengthening the Black communities, and supporting research to better understand their specific needs. These objectives can be achieved by providing them with financial assistance, access to mental health services, support groups, training and educational materials, healthcare reform, paid family leave, and better access to providers. As we learned from the focus group, Black caregivers noted that they would appreciate information on the different phases and stages of dementia, behavior management and self-care tips, affordable community support such as low cost or free respite care services. **Appendix D** demonstrates the concepts for future considerations of the Perlin caregiver stress framework based on this mixed method dissertation, particularly information obtained from the focus group. We learned that social isolation, stigma, time demands, and lack of dementia training served as primary stressors for Black caregivers.

The Pearlin stress process framework focuses on contextual variables and distinguishes between stressors that are directly related to the caregiving role (e.g., care recipient behavioral problems), and indirectly related sources of stress (e.g., financial problems). The model views caregiver stress because of a process comprising several interrelated conditions, including the socioeconomic characteristics and resources of caregivers and the primary and secondary stressors to which they are exposed.

Based on the information we obtained from the focus group interviews, it appears that social isolation, stigma, time demands, and lack of dementia training served as primary stressors for Black caregivers. These could be considered when adjusting or adding to the Pearlin framework for future considerations.

The secondary stressors were updated to include financial strain/burden, emotional demands, and guilt. Our focus group participants talked about fear of what the future holds and the increased responsibility as their PLWD's condition progressed, this was added to the secondary role strains. Finally, in addition to impact on mental health and wellbeing, self-care was added as an outcome because Black caregivers not only ignore their mental health, but they also neglect the importance of self-care. The critical findings of this research have serious implications for the future, and further investigation is necessary to determine the best course of action.

4.3 Limitations of this study

A limitation of this study is the small sample size of Black participants in the NHATS and NSOC dataset, the dataset was limited in the scope of questions that the participants were asked regarding barriers and facilitators of community support use. A small sample size can limit the generalizability of the results because it may not be representative of the larger population. This means that the results may only apply to the just Black caregivers and may not be applicable to other groups or populations. Additionally, a small sample size can increase the likelihood of sampling error and reduce the statistical power of the study, making it more difficult to detect significant differences or relationships.

The survey data does not offer an opportunity for participants to give in-depth responses. The survey data was collected in 2015 and although they overrecruited Black participants, the sample size was much smaller than the general population.

Since this was a pilot focus group, we were only able to evaluate the depth and breadth of barriers and facilitators from a single group. We reached saturation with this one group; it is unknown whether these themes would emerge in other groups. Additional research should include more focus groups to ensure a deeper understanding. Another limitation of the focus group is that hosting the meeting virtually made it more difficult to read non-verbal cues and interpret the body language of the participants.

4.4 Recommendations for future research

The findings of this study have important implications for future research in the field. Considering the focus group results, several key areas have been identified that warrant further investigation to deepen our understanding of the topic and inform the development of effective interventions. Through our focus group interview, we learned that being part of a large family did not equate to having additional support, so a recommendation for future research would be investigating the impact of social support on the mental health and wellbeing of Black family caregivers of PLWD.

A participant talked about the guilt feelings of being tired and bitter at times, future research could examine the emotional demands and guilt on the mental health and wellbeing of Black family caregivers. Our participants also mentioned not having time to take care of themselves, research could explore the role of self-care in promoting positive mental health outcomes among Black family caregivers of PLWD. Research could also develop and test interventions that address fear and uncertainty about the future among these caregivers.

Participants of the focus group discussed their concerns about future time requirements and the uncertainties of the future. Financial constraints of community support services were a common theme among the focus group participants, the secondary data analysis revealed that Black caregivers earned less than their White counterparts, therefore, it is important that future research investigates the effectiveness of interventions that reduce financial burden/strain among Black caregivers of PLWD.

This study's findings have identified several key areas for future research to deepen our understanding of the unique challenges faced by Black family dementia caregivers and inform the development of effective and targeted interventions. These areas include investigating the impact of social support, emotional demands and guilt, self-care, and financial burden/strain on the mental health and wellbeing of Black family caregivers of PLWD. Additionally, research could explore interventions that address fear and uncertainty about the future among these caregivers.

Based on the above summary, some potential policies to address the challenges faced by Black family caregivers of people living with dementia (PLWD) could include: 1. Increasing funding for dementia training and education programs that target Black family caregivers and provide information on the availability of community support services (CSS) by . 2. Developing and implementing outreach programs to engage Black family caregivers in available CSS and provide them with the support they need. 3. Investing in training for healthcare providers who work with Black family caregivers to ensure that they are knowledgeable about the needs and experiences of these carers. 4. Implementing policies that address systemic barriers (e.g., discrimination, lack of access to healthcare) that may impact the mental health and wellbeing of Black family caregivers of PLWD. 5. Supporting research into developing and testing culturally tailored interventions that address the unique stressors faced by Black family caregivers of PLWD. These policies could help improve Black family caregivers' lives by providing them with the support, resources, and education they need to effectively care for their loved ones while promoting their own mental health and wellbeing.

Chapter 5 Discussion & Conclusions

5.1 Discussion

Black family caregivers of people living with dementia (PLWD) face unique challenges that require targeted policies and interventions. These challenges can include a lack of access to community support services (CSS), inadequate training and education on dementia care, and systemic barriers such as discrimination and lack of access to healthcare. To address these challenges, potential policies could include increasing funding for dementia training and education programs, developing outreach programs to engage Black family caregivers in available CSS, investing in training for healthcare providers, implementing policies that address systemic barriers, and supporting research into developing culturally tailored interventions.

A study on the challenges faced by Black family caregivers of people living with dementia (PLWD) and potential policies to address these challenges would be of interest to a wide range of stakeholders. These stakeholders could include policy makers, who could use the study's findings to inform the development and implementation of policies that support Black family caregivers; insurance providers, who could use the study's findings to develop insurance products that meet the needs of Black family caregivers; and interventionists, who could use the study's findings to develop and implement interventions that address the unique stressors faced by Black family caregivers. Additionally, anyone who ages or knows someone who ages a stakeholder in this study is, as the findings could inform efforts to improve the lives of Black family caregivers and their loved ones.

In addition to the stakeholders mentioned above, several other that may be interested in this study on the challenges faced by Black family dementia caregivers and potential policies to address these challenges. These stakeholders could include the caregivers themselves, who could use the study's findings to advocate for their needs and rights; providers, who could use the study's findings to improve the care and support they provide to Black family caregivers and their loved ones and provide dementia training; agencies such as area agencies on aging, respite providers, home care agencies, adult daycare providers, that have interests in the wellbeing of caregivers, who could use the study's findings to develop and implement programs and services that support Black family caregivers; insurance companies, who could use the study's findings to develop insurance products such as long-term care insurance that meet the needs of Black family caregivers, this might allow some family members to be reimbursed to provide care (USAGov, 2023); policymakers, who could use the study's findings to inform the development and implementation of policies that support Black family caregivers such as passing federal policy that allows caregivers to benefit from the billions of dollars they save society and healthcare systems by developing a fund that they could tap into to defray the costs of support services (AARP, 2021); employers, who could use the study's findings to develop workplace policies that support employees who are Black family caregivers by simplifying the process for applying for family leave medical ; and labor unions, who could use the study's findings to advocate for the rights and needs of their members who are Black family caregivers, ensuring that their jobs are secure if they need to take a leave to provide care to their loved one.

5.2 Conclusion

This mixed-method research adds to current literature by providing a comprehensive overview of the challenges faced by dementia caregivers and how neighborhood cohesion can affect their mental health. The study highlights the need for more dementia training and education on the availability of community support services (CSS) and provides insight into the unique stressors related to being a Black dementia caregiver. The focus group revealed that financial strains and social isolation can impact the caregiving experience and that some caregivers would find an app with supportive information useful. The study also explored how race, culture, and lack of CSS use can influence caregiving experiences and underscored the need for providers to acknowledge the actions that led to mistrust of the healthcare system.

The research provides insight into a largely understudied population and can help inform interventions and social policies to better support Black dementia caregivers. This study builds upon existing research to further explore and analyze the caregiving experiences of Black families. It aims to provide a foundation for informing current and future initiatives that support Black caregivers. The study highlights the need for investment in training for providers who work with Black family caregivers and for more targeted outreach to engage them in available services. By providing direction to relevant resources and increasing their understanding of caregiving, this research could improve the lives of Black caregivers.

This study builds upon existing research to explore further and analyze the caregiving experiences of Black families. By doing so, it aims to provide a foundation for informing current and future initiatives that aim to support Black caregivers. Furthermore, various resources are available to provide support to Black caregivers; yet these caregivers are often unaware of these resources and are not provided with adequate education on them. Therefore, this research could be used to improve the lives of Black caregivers by providing direction to relevant resources and increasing their understanding of caregiving. This study also highlights the need for investment in training for providers who work with Black family caregivers to ensure that they are knowledgeable about the needs and experiences of these caregivers must also be increased. Finally, interventions could be developed to address systemic barriers and improve access to mental health services for Black family caregivers. Targeted outreach can educate them in available services and provide the support they need.

Tables

Table 1 Dementia Classification

Dementia Classification	**No Dementia (n= 1165)**	**Probable Dementia (n= 724)**	**Possible Dementia (n= 303)**
	n(%)[95% CI]	n(%)[95% CI]	n(%)[95% CI]
Caregiver Characteristics			
Age			
55-64 years old	271 (34%) [29%, 39 %]	257 (55%) [49%, 61%]	87 (41%) [31%, 53%]
65+	505 (66%) [61%, 71%]	242 (45%) [39%, 51%]	122 (59%) [47%, 69%]
Sex, weighted (%)			
Male	395 (39%) [34%, 44%]	213 (34%) [29%, 40%%]	106 (36%) [32% 47%]
Female	761 (61%) [56%, 66%]	507 (66%) [60%, 71%]	195 (64%) [53%, 68%]
Education			
High School or less	499 (43%) [39%, 48%]	315 (43%) [37%, 50%]	143 (47%) [26%, 32%]
Some college or associate degree	322 (29%) [26%, 32%]	194 (28%) [22%, 35%]	84 (30%) [23%, 37%]
Graduate or advanced degree	327 (28%) [24%, 32%]	206(29%) [24%, 35%]	70 (23%) [18%, 29%]
Caregiver Income			
$49,000 and under	364 (56%) [50%, 63%]	234 (48%) [38%, 57%]	111 (51%) [42%, 60%]
$50,000 and over	271 (44%) [37%, 50%]	216 (52%) [43%, 62%]	68 (49%) [40%, 58%]
Relationship to the care recipient			
Spouse/partner	304 (25%) [22%, 28%]	111 (14%) [11%, 18%]	55 (23%) [16%, 30%]
Child	515 (40%) [36%, 43%]	412 (56%) [52%, 60%]	151 (46%) [38%, 54%]
Other	346 (36%) [31%, 40%]	201 (30%) [26%, 35%]	97 (31%) [24%, 40%]
Helps care recipients with bills			
Yes	627 (49%) [45%, 54%]	506 (65%) [59%, 71%]	197 (61%) [55%, 68%]
No	538 (51%) [46%, 55%]	218 (35%) [29%, 41%]	106 (39%) [32%, 45%]
Helps care recipients with shopping			
Yes	863 (68%) [67%, 75%]	551 (64%) [65%,76%]	230 (82%) [67%, 78%]
No	301 (32%) [25%, 33%]	169 (36%) [24%, 35%]	72 (18%) [22%, 33%]
Felt anxious/nervous			
Yes	404 (37%) [34%, 42%]	264 (37%) [33%, 41%]	99 (32%) [26%, 38%]
No	738 (63%) [58%, 66%]	448 (63%) [59%, 67%]	197 (68%) [62%, 74%]
Felt down/depressed			
Yes	293 (27%) [24%, 32%]	214 (30%) [26%, 34%]	78 (26%) [20%, 33%]
No	850 (73%) [68%, 76%]	498 (70%) [66%, 74%]	221 (74%) [67%, 80%]

Felt alone			
Yes	252 (22%) [19%, 26%]	189 (27%) [22%, 32%]	70 (23%) [16%, 28%]
No	900 (78%) [74%, 81%]	530 (73%) [68%, 78%]	231 (77%) [72%, 84%]
Family talk			
Yes	989 (87%) [85%, 89%]	628 (88%) [85%, 91%]	257 (84%) [79%, 88%]
No	170 (13%) [11%, 15%]	91 (12%) [09%, 15%]	46 (16%) [12%, 21%]
Family help with activities			
Yes	610 (53%) [50%, 57%]	427 (58%) [53%, 62%]	167 (56%) [50%, 63%]
No	550 (47%) [43%, 50%]	291 (42%) [38%, 47%]	135 (44%) [37%, 50%]
Family help with the care recipient			
Yes	775 (68%) [63%, 72%]	535 (75%) [70%, 80%]	215 (68%) [60%, 75%]
No	383 (32%) [28%, 37%]	184 (25%) [20%, 30%]	88 (32%) [25%, 40%]
Support group			
Yes	35 (4%) [02%, 06%]	40 (5%) [03%, 08%]	10 (3%) [01%, 06%]
No	1124 (96%) [94%, 98%]	679 (95%) [92%, 97%]	293 (97%) [94%, 99%]
Time away			
Yes	134 (10%) [08%, 12%]	197 (27%) [22%, 32%]	53 (16%) [12%, 22%]
No	1025 (90%) [88%, 92%]	522 (73%) [68%, 78%]	248 (84%) [78%, 88%]
Received dementia training			
Yes	80 (7%) [05%, 09%]	73 (9%) [05%, 12%]	17 (7%) [03%, 14%]
No	1080 (93%) [91%, 95%]	646 (91%) [88%, 95%]	285 (93%) [86%, 97%]
Stress Measures			
Do you enjoy spending time with CR?			
Yes	1131 (97%) [96%, 98%]	692 (95%) [92%, 97%]	296 (97%) [94%, 99%]
No	29 (3%) [02%, 04%]	29 (5%) [03%, 08%]	7 (3%) [01%, 06%]
Does CR argue with you?			
Yes	289 (73%) [25%, 31%]	216 (33%) [26%, 41%]	77 (25%) [20%, 32%]
No	873 (27%) [69%, 75%]	507 (67%) [59%, 74%]	226 (75%) [68%, 80%]
Does CR appreciate what you do?			
Yes	1113 (97%) [96%, 98%]	660 (94%) [91%, 95%]	289 (96%) [93%, 98%]
No	38 (3%) [02%, 04%]	46 (6%) [05%, 09%]	12 (4%) [02%, 07%]
Does CR get on your nerves?			
Yes	315 (30%) [26%, 35%]	248 (38%) [31%, 46%]	90 (29%) [23%, 36%]
No	843 (70%) [65%, 74%]	473 (62%) [54%, 69%]	213 (71%) [64%, 77%]
Does helping CR make you more confident in your abilities?			
Yes	943 (82%) [80%, 84%]	596 (80%) [74%, 84%]	253 (84%) [79%, 88%]
No	214 (18%) [16%, 20%]	124 (20%) [16%, 26%]	47(16%) [12%, 21%]
Does helping CR bring you closer to CR?			

Yes	1066 (92%) [90%, 94%]	650 (89%) [85%, 92%]	280 (92%) [88%, 95%]
No	97 (8%) [06%, 10%]	69 (11%) [08%, 15%]	23 (8%) [05%, 12%]
Care Recipient Characteristics			
Gender			
Male	329 (39%) [25%, 35%]	260 (41%) [32%, 49%]	88 (29%) [24%, 39%]
Female	836 (61%) [65%, 75%]	464 (59%) [51%, 68%]	215 (71%) [61%, 76%]
Health Conditions			
No health conditions	33 (3%) [02%, 06%]	33 (4%) [02%, 08%]	9 (3%) [01%, 08%]
One health condition	86 (8%) [05%, 12%]	86 (10%) [07%, 14%]	30 (13%) [08%, 21%]
2 or more health conditions	1046 (89%) [84%, 92%]	605 (86%) [81%, 90%]	264 (84%) [75%, 90%]
ADL / IADLs (CR)			
Help with eating			
Yes	115 (13%) [09%, 18%]	261 (39%) [33%, 46%]	67 (21%) [15%, 30%]
No	1050 (87%) [82%, 91%]	454 (61%) [54%, 67%]	235 (79%) [70%, 85%]
Help with bathing			
Yes	252 (21%) [16%, 27%]	434 (44%) [48%, 64%]	95 (27%) [20%, 36%]
No	913 (79%) [73%, 84%]	283 (56%) [36%, 52%]	208 (73%) [64%, 80%]
Help with toileting			
Yes	78 (8%) [05%, 12%]	210 (29%) [23%, 35%]	26 (11%) [06%, 18%]
No	1086 (92%) [88%, 95%]	510 (71%) [65%, 77%]	277 (89%) [82%, 94%]
Help with dressing			
Yes	422(40%) [35%, 44%]	427 (47%) [49%, 66%]	102 (34%) [26%, 43%]
No	741 (60%) [56%, 65%]	277 (53%) [34%, 51%]	198 (66%) [57%, 74%]
Neighborhood Cohesion			
People can be trusted			
Yes	976(87%) [81%, 91%]	570 (82%) [70%, 90%]	233 ((80%) [68%, 89%]
No	123 (13%) [09%, 19%]	108 (18%) [10%, 30%]	42 (20%) [11%, 32%]
People will help each other			
Yes	995 (85%) [78%, 90%]	580 (81%) [68%, 90%]	246 (82%) [73%, 89%]
No	130 (15%) [10%, 22%]	99 (19%) [10%, 32%]	42 (18%) [11%, 27%]
People know each other well			
Yes	899 (78%) [73%, 82%]	546 (76%) [66%, 84%]	232 (76%) [17%, 33%]
No	243 (22%) [18%, 27%]	156 (24%) [16%, 34%]	63 (24%) [67%, 83%]

Table 2 All Caregivers by Race

Characteristic	Non-Hispanic White (n=1318)	Non-Hispanic Black (n=609)
	n(%)[95% CI]	n(%)[95% CI]
Caregiver Characteristics		
Age		
55-64 years old	378 (51%) [35%, 41%]	171 (48%) [43%, 54%]
65+	615 (49%) [59%, 65%]	181 (52%) [46%, 57%]
Sex, weighted (%)		
Male	424 (34%) [30%, 35%]	190 (36%) [28%, 35%]
Female	885 (66%) [65%, 70%]	415 (64%) [65%, 72%]
Education		
High School or less	534 (40%) [38%, 43%]	311 (52%) [48%, 56%]
Some college or associate degree	329 (24%) [23%, 28%]	162 (29%) [24%, 31%]
Graduate or advanced degree	446 (36%) [32%, 37%]	124 (19%) [18%, 24%]
Caregiver Income		
$49,000 and under	323 (34%) [40%, 48%]	273 (74%) [68%, 77%]
$50,000 and over	412 (66%) [52%, 60%]	100 (26%) [23%, 32%]
Relationship to the care recipient		
Spouse/partner	342 (17%) [24%, 28%]	86 (12%) [12%, 17%]
Child	634 (55%) [45%, 51%]	329 (53%) [50%, 58%]
Other	342 (28%) [24%, 28%]	194 (35%) [28%, 36%]
Helps care recipients with bills		
Yes	743 (35%) [54%, 59%]	418 (68%) [65%, 72%]
No	575 (65%) [41%, 46%]	191 (32%) [28%, 35%]
Helps care recipients with shopping		
Yes	901 (64%) [66%, 71%]	526 (82%) [84%, 89%]
No	415 (36%) [29%, 34%]	82 (18%) [11%, 16%]
Felt anxious/nervous		
Yes	523 (39%) [38%, 43%]	158 (25%) [23%, 30%]
No	777 (61%) [57%, 62%]	435 (75%) [70%, 77%]
Felt down/depressed		
Yes	371 (30%) [26%, 31%]	137 (23%) [20%, 26%]
No	927(70%) [69%, 74%]	462 (77%) [74%, 80%]
Felt alone		
Yes	289 (23%) [20%, 24%]	145 (24%) [21%, 28%]
No	1023 (77%) [76%, 80%]	458 (76%) [72%, 79%]
Family talk		
Yes	1141 (88%) [85%, 89%]	518 (86%) [82%, 88%]
No	174 (12%) [12%, 15%]	89 (14%) [12%, 18%]
Family help with activities		
Yes	682 (55%) [49%, 55%]	373 (64%) [58%, 65%]

No	632 (45%) [45%, 51%]	233 (36%) [35%, 42%]
Family help with the care recipient		
Yes	888 (74%) [65%, 70%]	458 (74%) [72%, 79%]
No	425 (26%) [30%, 35%]	149 (26%) [21%, 28%]
Support group		
Yes	46 (4%) [03%, 05%]	28 (3%) [03%, 07%]
No	1269 (96%) [95%, 97%]	579 (97%) [93%, 97%]
Time away		
Yes	261 (29%) [18%, 22%]	89 (13%) [13%, 18%]
No	1052 (71%) [78%, 82%]	518 (87%) [82%, 87%]
Received dementia training		
Yes	71 (29%) [04%, 07%]	77 (13%) [10%, 16%]
No	1244 (71%) [93%, 96%]	530 (87%) [84%, 90%]
Stress Measures		
Do you enjoy spending time with CR?		
Yes	1272 (96%) [96%, 98%]	594 (97%) [96%, 99%]
No	41 (4%) [02%, 04%]	15 (3%) [01%, 04%]
Does CR argue with you?		
Yes	349(32%) [24%, 29%]	157 (27%) [22%, 29%]
No	966 (68%) [71%, 75%]	452 (73%) [71%, 78%]
Does CR appreciate what you do?		
Yes	1244 (93%) [94%, 97%]	569 (95%) [93%, 96%]
No	56 (7%) [03%, 06%]	30 (5%) [04%, 07%]
Does CR get on your nerves?		
Yes	523 (38%) [29%, 33%]	158 (25%) [22%, 29%]
No	777 (62%) [67%, 71%]	435 (75%) [71%, 78%]
Does helping CR make you more confident in your abilities?		
Yes	1016 (76%) [75%, 80%]	556 (92%) [89%, 93%]
No	295 (24%) [20%, 25%]	52 (8%) [07%, 11%]
Does helping CR bring you closer to CR?		
Yes	1169 (87%) [87%, 91%]	578 (96%) [93%, 97%]
No	145 (13%) [09%, 13%]	30 (4%) [03%, 07%]
Care Recipient Characteristics		
Gender		
Male	421 (41%) [29%, 35%]	170 (29%) [24%, 32%]
Female	897 (59%) [65%, 71%]	439 (71%) [68%, 76%]
Dementia classification		
Probable dementia	390 (25%) [27%, 32%]	221 (27%) [33%, 40%]
Possible dementia	143 (10%) [09%, 13%]	116(21%) [16%, 22%]
No dementia	775 (65%) [57%, 62%]	271 (52%) [41%, 49%]
Health Conditions		
No health conditions	48 (03%) [02%, 05%]	19 (03%) [01%, 07%]

One health condition	132 (10%) [07%, 13%]	48 (08%) [05%, 14%]
2 or more health conditions	1138 (87%) [83%, 90%]	542 (89%) [84%, 92%]
ADL / IADLs (CR)		
Help with eating		
Yes	260 (30%) [18%, 22%]	104 (25%) [14%, 20%]
No	1052 (70%) [78%, 82%]	501 (75%) [80%, 86%]
Help with bathing		
Yes	432 (48%) [30%, 35%]	260 (49%) [39%, 47%]
No	881 (52%) [65%, 70%]	347 (51%) [53%, 61%]
Help with toileting		
Yes	180 (23%) [12%, 16%]	82 (16%) [11%, 16%]
No	1134 (77%) [84%, 88%]	526 (84%) [84%, 89%]
Help with dressing		
Yes	550 (47%) [39%, 45%]	285 (52%) [43%, 51%]
No	755 (53%) [55%, 61%]	317 (48%) [49%, 57%]
Neighborhood Cohesion		
People can be trusted		
Yes	1110 (87%) [82%, 91%]	97 (82%) [77%, 87%}
No	130 (13%) [09%, 18%]	464 (18%) [13%, 23%]
People will help each other		
Yes	1127 (86%) [80%, 91%]	496 (85%) [79%, 90%]
No	141 (14%) [10%, 20%]	79 (15%) [10%, 21%]
People know each other well		
Yes	989 (77%) [71%, 81%]	479 (78%) [71%, 84%]
No	298 (23%) [19%, 29%]	117 (22%) [16%, 29%]

Table 3 Dementia Classification & Race

Characteristic	**Probable Dementia Non-Hispanic White (n=390)**	**Probable Dementia Non-Hispanic Black (n=221)**	**Possible Dementia Non-Hispanic White (n=143)**	**Possible Dementia Non-Hispanic Black (n=116)**	**Non-Hispanic White (n=775)**	**Non-Hispanic Black (n=271)**
	n (%) [95% CI]	n (%) [95% CI]	n (%) [95% CI]	n (%) [95% CI]	N (%) [95% CI]	n (%) [95% CI]
Caregiver Characteristics						
Age						
55-64 years old	147 (55%) [47 %, 63%]	79 (50%) [38%, 63%]	42 (40%) [28% 54%]	34 (43%) [31%, 57%]	187 (38%) [27%, 36%]	58 (43%) [28%, 50%]
65+	146 (45%) [37%, 53%]	67 (50%) [37%, 52%]	71 (60%) [46%, 72%]	30 (57%) [43%, 69%]	394 (62%) [64%, 73%]	83 (57%) [50%, 72%]
Sex, weighted (%)						
Male	116 (35%) [27%, 43%]	272 (31%) [24%, 38%]	58 (33%) [24%, 43%]	162 (43%) [32%, 55%]	258 (36%) [32%, 42%]	89 (36%) [33%, 45%]
Female	46 (65%) [57%, 73%]	97 (69%) [62%, 76%]	43 (67%) [57%, 76%]	71 (57%) [45%, 68%]	510 (64%) [58%, 68%]	181 (64%) [55%, 67%]
Education						
High School or less	156 (40%) [34%, 47%]	108 (51%) [41%, 61%]	58 (40%) [30%, 51%]	63 (55%) [44%, 65%]	320 (43%) [37%, 47%]	139 (54%) [16%, 18%]
Some college or associate degree	87 (22%) [17%, 29%]	63 (29%) [22%, 36%]	38 (29%) [21%, 39%]	30 (28%) [20%, 39%]	201 (26%) [23%, 29%]	69 (27%) [18%, 32%]
Graduate or advanced degree	144 (32%) [30%, 46%]	47 (20%) [13%, 29%]	45 (31%) [23%, 39%]	19 (17%) [10%, 27%]	250 (31%) [27%, 37%]	58 (19%) [14%, 25%]
Caregiver Income						
$49,000 and under	101 (34%) [25%, 44%]	34 (69%) [60%, 77%]	86 (36%) [27%, 45%]	63 (81%) [62%, 92%]	188 (43%) [40%, 58%]	124 (75%) [68%, 82%]
$50,000 and over	152 (66%) [56%, 75%]	48 (31%) [23%, 40%]	43 (64%) [55%, 73%]	10 (19%) [08%, 38%]	205 (57%) [42%, 60%]	46 (25%) [18%,32%]
Relationship to the care recipient						
Spouse/partner	74 (16%) [11%, 20%]	23 (11%) [07%, 17%]	31 (21%) [14%, 31%]	14 (14%) [08%, 25%]	236 (25%) [25%, 32%]	49 (14%) [11%, 20%]
Child	221 (58%) [51%, 65%]	134 (57%) [49%, 64%]	72 (46%) [37%, 56%]	59 (47%) [34%, 61%]	334 (45%) [36%, 44%]	135(49%) [32%, 56%]
Other	95 (26%) [20%, 32%]	64 (32%) [26%, 40%]	40 (33%) [23%, 44%]	43 (39%) [24%, 56%]	205 (30%) [27%, 35%]	87 (37%) {31%, 45%]
Helps care recipients with bills						
Yes	277 (68%) [61%, 75%]	154 (65%) [57%, 73%]	85 (55%) [46%, 64%]	84 (73%) [61%, 82%]	378 (52%) [41%, 50%]	179 (54%) [54%, 68%]
No	113 (32%) [25%, 39%]	67 (35%) [27%, 43%]	58 (45%) [36%, 54%]	32 (27%) [18%, 39%]	397 (48%) [50%, 59%]	92 (46%) [32%, 46%]
Helps care recipients with shopping						

Yes	272 (46%) [56%, 71%]	186 (79%) [70%, 85%]	97(64%) [54%, 73%]	97 (86%) [79%, 91%]	526 (66%) [61%, 71%]	242 (86%) [86%, 93%]
No	116 (36%) [29%,44%]	35 (21%) [15%, 30%]	46 (36%) [27%,46%]	19 (14%) [09%, 21%]	249 (34%) [29%, 39%]	28 (14%) [07%, 14%]
Felt anxious/nervous						
Yes	176 (41%) [37%, 46%]	52 (24%) [19%, 30%]	55 (34%) [27%, 41%]	28 (26%) [15%, 40%]	289 (39%) [35%, 44%]	78 (36%) [21%, 36%]
No	209 (59%) [54%, 63%]	165 (76%) [70%, 81%]	86 (66%) [59%, 73%]	83 (74%) [60%, 85%]	475 (69%) [56%, 65%]	186 (74%) [64%, 79%]
Felt down/depressed						
Yes	131 (31%) [26%, 36%]	42 (22%) [18%, 28%]	49 (29%) [21%, 38%]	25 (23%) [16%, 33%]	198 (28%) [23%, 31%]	63 (23%) [17%, 30%]
No	252 (69%) [64%, 74%]	100 (78%) [72%, 82%]	169 (71%) [62%, 79%]	88 (77%) [67%, 84%]	565 (72%) [69%, 77%]	204 (77%) [70%, 83%]
Felt alone						
Yes	97 (24%) [19%, 31%]	111 (26%) [21%, 31%]	57 (19%) [12%, 26%]	27 (21%) [14%, 32%]	159 (22%) [18%, 25%]	61 (26%) [20%, 36%]
No	291 (76%) [69%, 81%]	31 (74%) [69%, 79%]	163 (81%) [74%, 88%]	88 (79%) [68%, 86%]	613 (78%) [75%, 82%]	206 (74%) [64%, 81%]
Family talk						
Yes	346 (91%) [86%, 94%]	191 (88%) [82%, 93%]	118 (82%) [76%, 87%]	100 (83) [71%, 91%]	668 (88%) [85%, 90%]	226 (15%) [77%, 89%]
No	42 (09%) [06%, 14%]	28 (12%) [07%, 18%]	25 (18%) [13%, 24%]	16 (17%) [09%, 29%]	106 (12%) [10%, 15%]	45 (85%) [11%, 23%]
Family help with activities						
Yes	217 (55%) [50%, 61%]	145 (55%) [59%, 75%]	76 (55%) [48%, 62%]	67 (60%) [49%, 70%]	382 (52%) [45%, 55%]	161 (64%) [55%, 71%]
No	170 (45%) [39%, 50%]	74 (32%) [25%, 41%]	67 (45%) [38%, 52%]	48 (40%) [30%, 51%]	392 (48%) [45%, 55%]	110 (36%) [29%, 45%]
Family help with the care recipient						
Yes	288 (74%) [68%, 72%]	169 (74%) [65%, 70%]	97 (74%) [72%, 79%]	87 (72%) [61%, 81%]	495 (69%) [61%, 70%]	202 (74%) [67%, 80%]
No	100 (26%) [28%, 32%]	50 (26%) [30%, 35%]	46 (26%) [21%, 28%]	29 (28%) [19%, 39%]	277 (31%) [30%, 39%]	69 (26%) [20%, 33%]
Support group						
Yes	18 (04%) [02%, 06%]	15 (05%) [02%, 10%]	8 (05%) [02%, 09%]	2 (01%) [00%, 05%]	20 (3%) [02%, 05%]	11 (4%) [02%, 08%]
No	370 (96%) [94%, 98%]	204 (95%) [90%, 98%]	135 (95%) [91%, 98%]	114 (99%) [95%, 100%]	754(97%) [95%, 98%]	260 (96%) [92%, 98%]
Time away						
Yes	133 (31%) [25%, 38%]	39 (15%) [100%, 23%]	35 (23%) [17%, 31%]	10 (11%) [06%, 20%]	90 (17%) [08%, 13%]	37 (13%) [09%,19%]
No	255 (69%) [62%, 75%]	180 (85%) [77%, 90%]	106 (77%) [69%, 83%]	103 (89%) [80%, 94%]	684 (83%) [87%, 92%]	234 (87%) [81%, 91%]
Received dementia training						
Yes	31 (07%) [04%, 12%]	31 (14%) [09%, 20%]	2 (01%) [00%, 03%]	11 (10%) [05%, 20%]	38 (5%) [04%, 08%]	35 (13%) [09%, 19%]

No	357 (93%) [88%, 96%]	188 (86%) [80%, 91%]	141 (99%) [97%, 100%]	105 (90%) [80%, 95%]	736 (95%) [92%, 96%]	236 (87%) [81%, 91%]
Stress Measures						
Do you enjoy spending time with CR?						
Yes	373 (96%) [91%, 98%]	213 (97%) [93%, 98%]	138 (96%) [91%, 98%]	114 (97%) [97%, 99%]	753 (97%) [96%, 99%]	266 (77%) [97%, 99%]
No	15 (4%) [02%, 09%]	8 (3%) [02%, 07%]	5 (4%) [02%, 09%]	2 (03%) [01%, 13%]	19 (3%) [01%, 04%]	5 (23%) [01%, 03%]
Does CR argue with you?						
Yes	121 (35%) [25%, 47%]	60 (24%) [19%, 32%]	31 (24%) [17%, 33%]	36 (30%) [19%, 44%]	192 (29%) [23%, 31%]	61 (24%) [16%, 28%]
No	268 (65%) [53%, 75%]	161 (76%) [68%, 81%]	112 (76%) [67%, 83%]	80 (70%) [56%, 81%]	581 (71%) [69%, 77%]	210 (76%) [72%, 84%]
Does CR appreciate what you do?						
Yes	354 (92%) [88%, 95%]	202 (94%) [90%, 97%]	137 (96%) [90%, 99%]	112 (95%) [86%, 98%]	745 (96%) [96%, 99%]	254 (96%) [94%, 98%]
No	27 (08%) [05%, 12%]	14 (6%) [03%, 10%]	5 (4%) [01%, 10%]	4 (05%) [02%, 14%]	23 (4%) [01%, 04%]	12 (4%) [02%, 06%]
Does CR get on your nerves?						
Yes	149 (41%) [31%, 52%]	55 (22%) [16%, 30%]	45 (31%) [23%, 40%]	32 (28%) [17%, 42%]	217 (33%) [25%, 36%]	66 (24%) [18%, 31%]
No	241 (59%) [48%, 69%]	165 (78%) [70%, 84%]	98 (69%) [60%, 77%]	84 (72%) [58%, 83%]	554 (67%) [64%, 75%]	204 (76%) [69%, 82%]
Does helping CR make you more confident in your abilities?						
Yes	298 (75%) [67%, 81%]	202 (93%) [87%, 96%]	110 (80%) [73%, 85%]	108 (91%) [82%, 96%]	601 (79%) [77%, 83%]	245 (91%) [84%, 94%]
No	91 (25%) [19%, 33%]	18 (07%) [04%, 13%]	32 (20%) [15%, 27%]	8 (09%) [04%, 18%]	169 (21%) [17%, 23%]	26 (9%) [06%, 16%]
Does helping CR bring you closer to CR?						
Yes	338 (87%) [81%, 91%]	207 (96%) [93%, 97%]	125 (87%) [81%, 97%]	112 (97%) [93%, 99%]	697 (89%) [88%, 93%]	258 (96%) [93%, 98%]
No	49 (13%) [09%, 19%]	13 (04%) [03%, 07%]	18 (13%) [08%, 19%]	4 (03%) [01%, 07%]	77 (11%) [07%, 12%]	13 (4%) [02%, 07%]
Care Recipient Characteristics						
Gender						
Male	239 (58%) [48%, 67%]	151 (66%) [56%, 76%]	91 (61%) [34%, 71%]	89 (77%) [62%, 87%]	215 (33%) [67%, 77%]	73 (29%) [59%, 80%]
Female	151 (42%) [33%, 52%]	70 (34%) [24%, 44%]	52 (39%) [29%, 51%]	27 (23%) [13%, 38%]	560 (67%) [23%, 33%]	198 (71%) [20%, 41%]
Dementia classification						

Probable dementia	611 (63%) [30%, 34%]	390 (25%) [27%, 32%]	221 (27%) [33%, 40%]	349 (22%) [41%, 50%]	390 (25%) [21%, 30%]	222 (27%) [21%, 33%]
Possible dementia	259 (25%) [12%, 15%]	143 (10%) [09%, 13%]	116(21%) [16%, 22%]	97 (18%) [23%, 26%]	143(10%) [08%, 12%]	116 (21%) [17%, 27%]
No dementia	96 (9%) [49%, 57%]	96 (9%) [49%, 57%]	96 (9%) [49%, 57%]	1046 (12%) [52%, 57%]	775 (65%) [60%, 70%]	271 (52%) [45%, 58%]
Health Conditions						
No health conditions	21 (05%) [03%, 10%]	9 (03%) [01%, 08%]	7 (05%) [01%, 14%]	2 (03%) [01%, 15%]	20 (02%) [01%, 04%]	8 (03%) [01%, 08%]
One health condition	43 (09%) [06%, 13%]	30 (10%) [05%, 18%]	20 (15%) [08%, 26%]	8 (12%) [05%, 28%]	68 (09%) [06%, 14%]	9 (05%) [02%, 16%]
2 or more health conditions	326 (85%) [79%, 90%]	182 (87%) [78%, 92%]	116 (81%) [68%, 89%]	106 (84%) [68%, 93%]	687 (89%) [84%, 92%]	254 (92%) [84%, 96%]
ADL / IADLs (CR)						
Help with eating						
Yes	149 (35%) [29%, 41%]	60 (29%) [20%, 41%]	29 (19%) [11%, 30%]	26 (19%) [10%, 32%]	79 (19%) [08%, 18%]	18 (14%) [02%, 14%]
No	236 (65%) [59%, 71%]	157 (71%) [59%, 80%]	113 (81%) [70%, 89%]	90 (81%) [68%, 90%]	696 (81%) [82%, 92%]	253 (86%) [86%, 98%]
Help with bathing						
Yes	232 (56%) [42%, 63%]	139 (62%) [54%, 70%]	46 (30%) [20%, 42%]	40 (33%) [21%, 48%]	151 (31%) [17%, 29%]	81 (37%) [18%, 37%]
No	153 (44%) [37%, 52%]	80 (38%) [30%, 46%]	97 (70%) [58%, 80%]	76 (67%) [52%, 79%]	624 (69%) [71%, 83%]	190 (63%) [63%, 82%]
Help with toileting						
Yes	114 (27%) [22%, 34%]	60 (26%) [19%, 34%]	11 (10%) [04%, 21%]	6 (04%) [01%, 19%]	55 (14%) [06%, 15%]	16 (11%) [02%, 12%]
No	273 (73%) [66%, 78%]	160 (74%) [66%, 81%]	132 (90%) [79%, 96%]	110 (96%) [81%, 99%]	719 (86%) [85%, 94%]	255 (89%) [88%, 98%]
Help with dressing						
Yes	219 (54%) [44%, 63%]	147 (72%) [61%, 81%]	41 (29%) [19%, 41%]	42 (28%) [17%, 42%]	286 (43%) [36%, 48%]	96 (42%) [23%, 44%]
No	161 (46%) [37%, 56%]	68 (28%) [19%, 39%]	101 (71%) [59%, 81%]	73 (71%) [58%, 83%]	487 (57%) [52%, 64%]	175 (58%) [56, 77]
Neighborhood Cohesion						
People can be trusted						
Yes	326 (83%) [68%, 92%]	165 (79%) [68%, 87%]	117 (83%) [71%, 91%]	85 (90%) [80%, 95%]	660 (89%) [84%, 92%]	213 (81%) [72%, 88%]
No	45 (17%) [08%, 32%]	43 (21%) [13%, 32%]	16 (17%) [09%, 29%]	14 (10%) [05%, 20%]	69 (11%) [08%, 16%]	40 (19%) [12%, 28%]
People will help each other						
Yes	322 (81%) [64%, 91%]	176 (86%) [79%, 91%]	121 (86%) [77%, 92%]	94 (86%) [73%, 94%]	677 (88%) [84%, 92%]	225 (84%) [73%, 91%]
No	49 (19%) [09%, 36%]	31 (14%) [09%, 21%]	16 (14%) [08%, 23%]	14 (14%) [06%, 27%]	73 (12%) [08%, 16%]	34 (16%) [09%, 27%]
People know each other well						
Yes	291 (77%) [64%, 85%]	170 (82%) [71%, 89%]	107 (77%) [67%, 85%]	91 (77%) [61%, 88%]	585 (88%) [84%, 92%]	218 (84%) [73%, 91%]
No	89 (23%) [15%, 35%]	44 (18%) [11%, 29%]	31 (23%) [15%, 33%]	23 (23%) [12%, 39%]	174 (12%) [08%, 16%]	50 (16%) [09%, 27%]

Table 4 Logistic Regression Models. Bivariate association of stress measures predicting anxiety and depression by dementia classification

Stress Measure	**No dementia White (OR)[95% CI]**	**No dementia Black (OR)[95% CI]**	**Prob. dementia White (OR)[95% CI]**	**Prob. dementia Black (OR)[95% CI]**	**Poss. dementia White (OR) [95% CI]**	**Poss. dementia Black (OR) [95% CI]**
	Anxiety	**Anxiety**	**Anxiety**	**Anxiety**	**Anxiety**	**Anxiety**
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Alone	3.23 [2.11, 49.5]***	3.56 [1.42, 8.92]**	4.09 [2.14, 7.80]***	6.52 [2.45, 17.30] ***	2.90[1.13, 7.43] **	1.59 [.42, 6.11]
Enjoy	0.46 [.16, 1.36]	0.96 [.12, 7.56]	0.57 [.13, 2.57]	0.29 [.04, 1.89]	0.60 [9.00, 4.10]	0.66 [.04, 1.16]
Argue	2.21 [1.54, 3.19]***	3.12 [1.65, 5.89]***	2.00 [1.36, 2.85]***	2.70 [1.30, 5.62] ***	4.36 [1.68, 11.33]***	1.72 [.48, 6.21]
Appreciated	1.03 [.45, 2.85]	0.23 [.06, .94]*	0.65 [.26, 1.59]	0.83 [.21, 3.35]	2.81 [36, 217]	1.24 [.10, 1.48]
Get on nerves	2.65 [1.67, 40.18] ***	2.53 [1.33, 4.80] ***	1.91 [1.34, 2.71] ***	3.32 [1.46, 7.56] ***	2.93 [1.28, 6.70]**	4.75 [1.23, 1.83]**
Bring closer	0.50 [.27, .90]**	0.28 [.06, 1.26]	0.44 [.08, 1.06]	1.27 [.32, 5.00]	2.03 [.83, 4.96]	0.59 [.04, 8.65]
	Depressed	**Depressed**	**Depressed**	**Depressed**	**Depressed**	**Depressed**
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Alone	7.83 [4.74, 12.90] ***	3.82 [1.65, 8.84] ***	4.36 [2.19, 8.69] ***	7.6 [3.26, 17.80] ***	4.58 [2.01, 10.40] ***	5.9 [1.43, 2.46] **
Enjoy	0.52 [.9, 1.39]	0.21 [.02, 2.09]	0.69 [.19, 2.44]	0.26 [.04, 1.70]	0.09 [.00, 1.06] *	1.00 [.00,0.00]
Argue	2.01 [.27, 3.18]	1.46 [.72, 3.00]	1.71 [.91, 3.20]	2.38 [1.22, 4.66] **	4.78 [1.96, 11.60] ***	0.74 [.25, 22.10]
Appreciated	0.39 [.16, 9.40]	0.20 [.06, 6.50] ***	0.67 [.27, 1.65] *	0.53 [.10, 2.93]	1.00 [.29, 6.50] ***	1.41 [.11, 1.77]
Get on CG’s nerves	2.77 [1.82, 4.20] ***	2.30 [1.25, 4.24] **	1.42 [.81, 2.48]	2.19 [.88, 5.44]	5.64 [2.48, 12.80] ***	1.37 [.45, 4.20]
Bring closer	0.42 [.25, 7.2]	0.42 [.08, .91]*	0.42 [.21, .87] **	1.00 [.20, 4.80]	0.69 [.18, 2.72]	0.52 [.04, 7.52]

Table 5 Bivariate Neighborhood Cohesion Predicting Depression/Anxiety by Dementia Classification

Neighborhood cohesion	**No dementia OR [95% CI]**	**Probable dementia OR [95% CI]**	**Possible dementia OR [95% CI]**	**All caregivers OR [95% CI]**
	Anxiety	**Anxiety**	**Anxiety**	**Anxiety**
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Trusted	1.15 [.69, 1.92]	0.90 [.58, 1.41]	1.07 [.43, 2.71]	1.07 [.73, 1.56]
Help each other	1.25 [.86, 1.80]	1.17 [.70, 1.94]	1.32 [.59, 2.98]	1.23 [.96, 1.58]
Know each well	0.93 [.66, 1.35]	0.84 [.51, 1.40]	1.22 [.58, 2.59]	0.94 [.74, 1.20]
	Depression	**Depression**	**Depression**	**Depression**
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Trusted	0.63 [.42, 1.11]	1.05 [.39, 2.79]	1.19 [.37, 3.83]	0.83 [.56, 1.24]
Help each other	0.88 [.54, 1.42]	1.09 [.53, 2.25]	1.42 [.45, 4.51]	0.99 [.72, 1.34]

Table 6 Bivariate Logistic Regression Showing Stress Measures Associated with CSS Use (OR/95% CI)

Outcome Measure	**No dementia OR [95% CI]**	**Probable dementia OR [95% CI]**	**Possible dementia OR [95% CI]**	**All Caregivers OR [95% CI]**
	Anxiety	**Anxiety**	**Anxiety**	**Anxiety**
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Dementia Training	1.42 [.74, 2.71]	0.80 [.43, 1.49]	0.37 [.09, 1.57]	0.90 [.52, 1.55]
Family help care	1.08 [.84, 1.39]	1.29 [.85, 1.98]	1.57 [.86, 2.85]	0.79 [.61, 1.02]
Family help act	0.90 [.69, 1.18]	1.03 [.57, 1.88]	1.23 [.71, 2.14]	0.95 [.74, 1.22]
Family talk	1.41 [.95, 2.10]	0.89 [.49, 1.62]	1.47 [.66, 3.27]	0.62 [.44, .89]
Support group	2.32 [.78, 6.89]	1.02 [.44, 2.33]	2.52 [.38, 1.66]	1.48 [.67, 3.31]
Time away	1.10 [.67, 1.82]	1.54 [.96, 2.46]	0.37 [.09, 1.57]	1.38 [1.01, 1.89]
	Depressed	**Depressed**	**Depressed**	**Depressed**
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Dementia Training	0.85 [.40, 1.84]	0.82 [.39, 1.74]	1.13 [.29, 4.48]	0.88 [.52, .150]
Family help care	0.76 [.51, 1.13]	0.71 [.47, 1.07]	1.03 [.56, 1.97]	1.28 [.99, 1.65]
Family help act	0.71 [.51, .97]	0.65 [.40, 1.06]	1.29 [.62, 2.64]	1.36 [1.05, 1.74]
Family talk	0.55 [.35, .88]	0.35 [.19, .64]	56 [.23, 1.38]	2.03 [1.36, 3.05]
Support group	2.46 [.87, 6.98]	1.15 [.54, 2.45]	4.77 [.73, 3.10]	2.05 [1.03, 4.09]
Time away	1.07 [.64, 1.78]	1.49 [.90, 2.47]	1.53 [.63, 3.76]	1.31 [.94, 1.84]

Table 7 Bivariate: Neighborhood Cohesion Stratified by Dementia Classification and Race

Independent Measure	**No dementia White OR [95% CI]**	**No dementia Black OR [95% CI]**	**Prob. dementia White OR [95% CI]**	**Prob. dementia Black OR [95% CI]**	**Poss. dementia White OR [95% CI]**	**Poss. dementia Black OR [95% CI]**
	Anxiety	**Anxiety**	**Anxiety**	**Anxiety**	**Anxiety**	**Anxiety**
Trusted	0.81 [.39, 1.68]	0.44 [.20, .98]	0.90 [.59, 1.37]	0.24 [.09, .65]	0.97 [.22, 4.26]	1.95 [.45, 8.47]
Help each other	0.77 [.43, 1.38]	0.69 [.27, 1.76]	1.39 [.84, 2.31]	0.30 [.10, .92]	0.82 [.22, 3.06]	2.09 [.46, 9.49]
Know each well	0.88 [.58, 1.34]	0.61 [.32, 1.13]	0.90 [.56, 1.46]	0.49 [.20, 1.17]	0.50 [.22, 1.12]	3.20 [.81, 10.26]
	Depressed	**Depressed**	**Depressed**	**Depressed**	**Depressed**	**Depressed**
Trusted	0.56 [.32, .99]	0.60 [.22, 1.67]	1.36 [.45, 4.17]	0.18 [.60, .53]	1.18 [.26, 5.32]	5.13 [.90, 2.92]
Help each other	0.70 [.2, 1.16]	1.20 [.39, 3.76]	1.16 [.60, 2.25]	0.23 [.07, .70]	0.90 [.21, 3.85]	2.67 [.42, 1.68]
Know each other well	0.78 [.47, 1.29]	0.63 [.34, 1.16]	1.10 [.43, 2.77]	0.82 [.32, 2.13]	0.78 [.32, 1.92]	1.50 [.47, 4.82]

Table 8 Bivariate association between community support services and stress measures assessing depression and anxiety by race.

Independent Measures	**All Caregivers (White) OR [95% CI]**	**All caregivers (Black) OR [95% CI]**
Neighborhood Cohesion	**Anxiety**	**Anxiety**
Trusted	0.86 [.54, 1.38]	0.43 [.24, .77] ***
Help each other	0.93 [.63, 1.37]	0.67 [.33, 1.35]
Know each other well	0.84 [.62, 1.13]	0.76 [.49, 1.19]
Community Support Services	**Anxiety**	**Anxiety**
Family to talk to	1.52 [1.06, 2.16] **	0.91 [.43, 1.89]
Family to help with activities	1.13 [.87, 1.47]	0.93 [.58, 1.49]
Family to help with CR	1.16 [.91, 1.48]	1.42 [.81, 2.51]
Support Group	2.09 [.95, 4.59]	0.33 [.08, 1.38]
Time away	1.29 [.90, 1.86]	1.00[.62, 1.61]
Dementia training	1.95 [1.14, 3.35]**	0.48 [.26 .87]
Stress Measures	**Anxiety**	**Anxiety**
Enjoy spending time	0.54 [.27, 1.08]	0.55 [.16, 1.93]
CR agues with CG	2.26 [1.70, 3.00] ***	2.57 [1.60, 4.12] ***
CR appreciate	0.91 [.54, 1.53]	0.53 [.21, 1.29]
Bring you closer	0.56 [.37, .84]	0.49 [.20, 1.22]
	Depression	**Depression**
Trusted	0.78 [.47, 1.28]	0.49 [.23, 1.04]
Help each other	0.83 [.55, 1.24]	0.83 [.38, 1.82]
Know each other well	0.85 [.57, 1.26]	0.80 [.47, 1.33]
Community Support Services	**Depression**	**Depression**
Family to talk to	0.61 [.39, .97]	0.51 [.27, .96]
Family to help with activities	0.82 [.60, 1.11]	0.51 [.27, .96]
Family to help with CR	0.80 [.58, 1.11]	1.06 [.58, 1.92]
Support Group	2.17 [1.05, 4.50]	1.01 [.41, 2.52]
Time away	1.32 [.95, 1.83]	0.90 [.43, 1.92]
Dementia training	1.24 [.65, 2.36]	0.94 [.47, 1.88]
Stress Measures	**Depression**	**Depression**
Enjoy spending time	0.48 [.24, .94]	0.49 [.11, 2.14]
CR ague	2.09 [1.45, 2.99] ***	1.44 [.87, 2.39]
CR appreciate	0.61 [.32, 1.17]	0.43 [.16, 1.17]
Bring you closer	0.44 [.30, .66] ***	0.44 [.21, .90]

Table 9 Logistic Regression Model. Bivariate (Community Support Predicting Anxiety/Depression) by Race and Dementia Classification

Community Support Service	**No dementia White OR [95% CI]**	**No dementia Black OR [95% CI]**	**Prob. dementia White OR [95% CI]**	**Prob. dementia Black OR [95% CI]**	**Poss. dementia White OR [95% CI]**	**Poss. dementia Black OR [95% CI]**
	Anxiety	**Anxiety**	**Anxiety**	**Anxiety**	**Anxiety**	**Anxiety**
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Family talk	1.73 [1.07, 2.80] **	0.63 [.27, 1.47]	0.80 [.38, 1.69]	1.00 [.32, 3.17]	1.95 [.65, 5.83]	2.53 [.47, 1.36]
Family help w/acct	1.19 [.86, 1.64]	0.57 [.31, 1.04]	1.05 [.54, 2.03]	1.54 [.85, 2.80]	0.98 [.47, 2.01]	1.88 [.58, 6.11]
Family help w/care	1.14 [.85, 1.53]	1.25 [.57, 2.74]	1.33 [.81, 2.18]	1.79 [.77, 4.14]	0.94 [.41, 2.18]	1.51 [.40, 5.70]
Support group	2.77 [.85, 9.00]	0.19 [.02, 1.64]	1.02 [.36, 2.84]	0.71 [.12, 4.20]	3.01 [.32, 2.82]	1.00 [0.00,0.00]
Time away	0.99 [.55, 1.80]	1.15 [.57, 2.34]	1.75 [1.06, 2.89]	0.32 [.52, 3.18]	1.37 [.65, 2.88]	0.32 [.03, 3.27]
Training	2.37 [1.20, 4.71] **	0.26 [.09, .79] **	1.11 [.55, 2.23]	1.56 [.56, 4.36]	1.00 [0.00, 0.00]	0.10 [.01, .68]
	Depressed	**Depressed**	**Depressed**	**Depressed**	**Depressed**	**Depressed**
	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]	OR [95% CI]
Family talk	0.62 [.36, 1.06]	0.46 [.20, 1.03]	0.48[.23, 1.03]	0.62 [.19, 2.00]	0.80 [.23, 2.75]	0.56 [.15, 2.13]
Family help w/acct	0.85 [.60, 1.20]	0.44 [.21, 1.02]	0.68 [.41, 1.12]	1.12 [.69, 1.82]	1.07 [.42, 2..71]	1.45 [.48, 5.55]
Family help w/care	0.72 [.46, 1.13]	0.44 [.48, 2.81]	0.68 [.69, 1.59]	1.12 [.55, 3.40]	1.07 [.30, 2.12]	1.45 [.23, 1.88]
Support group	2.19 [.76, 6.26]	0.36 {.06, 2.12]	1.61 [.50, 2.23]	1.92 [.55, 6.69]	3.89 [.49, 3.11]	10.55 [.63, 1.77]
Time away	0.88 [.51, 1.51]	1.33 [.52, 3.38]	1.69 [1.06, 2.69] **	1.08 [.34, 3.41]	1.81 [.63, 5.17]	1.00 [0.00, 0.00]
Training	1.28 [.57, 2.88]	0.46 [.13, 1.25]	0.98 [.38, 2.53]	1.48 [.65, 3.36]	1.00 [0, 0]	2.70 [.47, 1.57]

Table 10 Bivariate All caregivers by race and neighborhood cohesion

Independent Measures	**No dementia OR [95% CI]**	**Possible Dementia OR [95% CI]**	**Probable Dementia OR [95% CI]**
Neighborhood Cohesion	**Anxiety**	**Anxiety**	**Anxiety**
Trusted	1.15 [.69, 1.92]	.90 [.58, 1.41]	1.08 [.43, 2.71]
Help each other	1.25 [.86, 1.80]	1.17 [.70, 1.94]	1.32 [.59, 2.98]
Know each other well	.94 [.66, 1.35]	.84 [.51, 1.40]	1.22 [.58, 2.59]
Community Support Services	**Anxiety**	**Anxiety**	**Anxiety**
Family to talk to	1.41 [.95, 2.10]	.89 [.49, 1.62]	1.47 [.66, 3.27]
Family to help with activities	.90 [.69, 1.18]	1.03 [.57, 1.88]	1.23 [.71, 2.14]
Family to help with CR	1.08 [.84, 1.39]	1.29 [.85, 1.98]	1.57 [.86, 2.85]
Support Group	2.32 [.78, 6.89]	1.02 [.44, 2.33]	2.52 [.38, 16.56]
Time away	1.10 [.67, 1.82]	1.54 [.96, 2.46] *	1.50 [.79, 2.87]
Dementia training	1.42 [.74, 2.71]	.80 [.43, 1.49]	.37 [.09, 1.57]
Stress Measures	**Anxiety**	**Anxiety**	**Anxiety**
Enjoy spending time	.64 [.24, 1.73]	.75 [.27, 2.09]	.62 [.13, 3.04]
CR ague	2.29 [1.59, 3.32] ***	2.14 [1.50, 3.06] ***	2.95 [1.41, 6.17] **
CR appreciate	.94 [.43, 2.03]	.47 [.22, 1.03]	2.00 [.51, 7.93]
Bring you closer	.49 [.28, .87] **	.46 [.21, 1.00] *	1.59 [.71, 3.57]
	Depression	**Depression**	**Depression**
Trusted	.68 [.42, 1.11]	1.05 [.39, 2.79]	1.19 [.37, 3.83]
Help each other	.88 [.54, 1.42]	1.09 [.53, 2.25]	1.42 [.45. 4.51]
Know each other well	.90 [.61, 1.35]	1.26 .54, 2.95]	1.24 [.49, 3.13]
Community Support Services	**Depression**	**Depression**	**Depression**
Family to talk to	.55 [.35, .88] ***	.35 [.19, .64] ***	.56 [.23, 1.38]
Family to help with activities	.71 [.51, .97] **	.65 [.40, 1.06] *	1.28 [.62, 2.64]
Family to help with CR	.76 [.51, 1.13]	.71 [.47, 1.07]	1.03 [.54, 1.97]
Support Group	2.46 [.87, 6.98] *	1.15 [.54, 2.45]	4.77 [.73, 31.03]
Time away	1.07 [.64, 1.78]	1.49 [.90, 2.47]	1.53 [.63, 3.76]
Dementia training	.85 [.40, 1.84]	.82 [.39, 1.74]	1.13 [.29, 4.48]
Stress Measures	**Depression**	**Depression**	**Depression**
Enjoy spending time	.77 [.35, 1.71]	,80 [.31, 2.07]	,22 [.03, 1.53]
CR ague	2.15 1.41, 3.27] ***	2.02 [1.30, 3.15] ***	2.93 [1.40, 6.13] ***
CR appreciate	.43 [.20, .93] **	.47 [.21, 1.08] *	3.77 [.69, 20.61]
Bring you closer	.50 [.32, .78] ***	.46 [.22, .94] **	.61 [.17, 2.15]

Table 11 Multivariate adjusting by Race

	Black Caregivers AOR [95% CI]	**White Caregivers AOR [95% CI]**	**Black Caregivers AOR [95% CI]**	**White Caregivers AOR [95% CI]**
	Anxiety	**Anxiety**	**Depression**	**Depression**
Support group	.46 [.08, 2.75]	2.46 [.48, 12.59]	2.26 [.70, 7.31]	2.98 [.65, 13.60]
Training	1.21 [.47, 3.15]	4.26 [1.47, 12.32]	2.40 [.64, 8.96]	1.07 [.45, 2.55]
Time Away	2.45 [.73, 8.29]	1.40 [.80, 2.45]	1.70 [.51, 5.68]	1.07 [.45, 2.55]
Fam Help acc	.67 [.28, 1.60]	1.26 [.74, 2.14]	1.01 [.39, 2.65]	1.29 [.62, 2.69]
Fam Help CR	1.96 [.54, 7.14]	1.11 [.63, 1.96	1.29 [.62, 2.69]	2.37 [.71, 7.94]
Family Talk	.49 [.14, 1.73]	2.47 [1.00, 6.10]	.52 [.15, 1.81]	.53 [.20, 1.38]
Trusted	.30 [.10, .87]	1.24 [.58, 2.66]	.24 [.10, .54]	1.34 [.66, 2.69]
Help each other	.52 [.11, 2.43]	.80 [.37, 1.73]	.49 [.15, 1.68]	1.16 [.53, 2.52]
Know each other well	.61 [.17, 2.21]	1.05 [.56, 1.97]	.65 [.21, 2.01]	1.07 [.54, 2.11]

Table 12 Multivariate. Adjusting for Race/Dementia Classification

Outcome Measure	**Independent Variables** OR [95% CI]	**Covariant (CG age) Black** OR [95% CI]	**Covariant (Gender) Black** OR [95% CI]	**Covariant (Income) Black** OR [95% CI]	**Covariant (education) Black** OR [95% CI]	**Covariant (CG-CR relationship) Black** OR [95% CI]	**Covariant (CR age) Black** OR [95% CI]
Anxiety	Support Group .55 [.09, 3.55]	1.07 [.35, 3.26]	1.57 [.53 4.69]	1.07 [.50, 2.27]	.86 [.46, 1.59]	.76 [.24, 2.42]	1.37 [.41, 4.65]
Depression	1.30 [.43, 3.89]	.94 [.32, 2.78]	2.19 [.93, 5.17] *	.95 [.47, 1.91]	.68 [.36, 1.31]	.90 [.29, 2.79]	.63 [.26, 1.56]
Anxiety	Training 1.21 [.47, 3.15]	1.09 [.35, 3.37]	1.55 [.51, 4.73]	1.11 [.52, 2.34]	.84 [.44, 1.61]	.76 [.24, 2.38]	1.33 [.40, 4.46]
Depression	2.40 [.64, 8.96]	1.05 [.33, 3.35]	2.01 [.82, 4.94]	1.00 [.48, 2.06]	.67 [.34, 1.32]	.95 [.32, 2.81]	.63 [.26, 1.55]
Anxiety	Time Away	.99 [.35, 2.82]	1.53 [.51, 4.59]	1.09 [.51, 2.35]	.87 [.46, 1.64]	.84 [.29, 2.41]	1.35 [.42, 4.40]
Depression	1.71 [.51, 5.68]	.91 [.33, 2.53]	2.17 [.92, 5.10] *	.94 [.46, 1.90]	.70 [.37, 1.33]	.97 [.33, 2.86]	.65 [.27, 1.55]
Anxiety	Fam Help Act .67 [.28, 1.60]	.98 [.32, 2.98]	1.58 [.53, 4.73]	1.08 [.52, 2.25]	.88 [.47, 1.64]	.75 [.22, 2.50]	1.31 [.37, 4.58]
Depression	1.01 [.39, 2.65]	.95 [.31, 2.94]	2.19 [.94, 5.10] *	.93 [.46, 1.90]	.69 [.34, 1.37]	.91 [.29, 2.83]	.65 [.26, 1.62]
Anxiety	Fam Help CR 1.96 [.54, 7.14]	1.10 [.37, 3.23]	1.42 [.45, 4.67]	1.08 [.53, 2.22]	.86 [.45, 1.63]	.86, [.31, 2.38]	1.27 [.39,4.17]
Depression	2.37 [.71, 7.94]	.94 [.33, 2.65]	1.92 [.81, 4.52]	.92 [.48, 1.77]	.71 [.48, 1.77]	1.16 [.43, 3.09]	.60 [.23, 1.56]
Anxiety	Fam Talk .49 [.14, 1.73]	1.05 [.36, 3.13]	1.60 [.53, 4.83]	1.25 [.59, 2.67]	.80 [.42, 1.53]	.74 [.23, 240]	.136 [.39, 4.70]
Depression	.52 [.15, 1.81]	.93 [.31, 2.77]	2.21 [.94, 5.20] *	1.05 [.50, 2.22]	.65 [.34, 1.25]	.92 [.29, 2.85]	.65 [.26, 1.66]
Anxiety	Trusted .30 [.10, .83]	.93 [.30, 2.91]	1.31 [.46, 3.69]	1.15 [.54, 2.44]	.98 [.50, 1.93]	.79 [.24, 2.65]	1.12 [.29, 4.31]
Depression	.24 [.10, .54]***	.74 [.22, 2.44]	1.88 [.82, 4.34]	.87 [.43, 1.75]	.82 [.43, 1.54]	1.19 [.36, 3.95]	.61 [.222, 1.69]
Anxiety	Help ea other .52 [.11, 2.43]	.93 [.32, 2.68]	1.61 [.55, 4.73]	1.05 [.42, 2.62]	.80 [.43, 1.50]	.88 [.25, 3.04]	1.41 [.42, 4.69]
Depression	.49 [.15, 1.68]	.79 [.24, 2.57]	2.23 [.95, 5.27] *	.92 [.40, 2.11]	.64 [.33, 1.22]	1.11 [.33, 3.76]	.67 [.25, 1.80]
Anxiety	Know ea well .61 [.17, 2.21]	1.07 [.34, 3.35]	1.73 [.51, 5.83]	1.02 [.48, 2.20]	.86 [.44, 1.67]	.77 [.22, 2.72]	1.46 [.40, 5.27]
Depression	.65 [.21, 2.01]	.95 [.31, 2.88]	2.39 [.89, 6.43]*	.89 [.44, 1.78]	.70 [.35, 1.39]	.92 [.29, 2.97]	.70 [.26, 1.85]
Outcome Measure	**Independent Variables**	**Covariant (CG age) White**	**Covariant (Gender) White**	**Covariant (Income) White**	**Covariant (education) White**	**Covariant (CG-CR relationship) White**	**Covariant (CR age) White**
Anxiety	Support Group 2.46 [.48, 12.59]	.78 [.50, 1.21]	2.31 [1.57, 3.93]***	1.02 [.66, 1.58]	1.11 [.80, 1.54]	.59 [.39, .90]**	1.27 [.64, 2.54]
Depression	2.98 [.65, 13.60]	.63 [.35, 1.13]	2.14 [1.26, 3.63]***	.51 [.30, .84]	.99 [.76, 1.29]	.43 [.20, .94] **	.40 [.18, .90]**
Anxiety	Training 4.26 [1.47, 12.32]	.79 [.51, 1.22]	2.50 [1.70, 3.68]***	.93 [.59, 1.48]	1.16 [.83, 1.61]	.62 [.41, .95] **	1.33 [.64, 2.78]*
Depression	1.07 [.45, 2.55]	.63 [.35, 1.12]	2.18 [1.28, 3.72] **	.50 [.30, .84] **	.99 [.77, 1.29]	.44 [.20, .96]**	.41 [.19, .92]**

Anxiety	Time Away 1.40 [.80, 2.45]	.77 [.50, 1.17]	2.32 [1.60, 3.05] ***	1.00 [.64, 1.57]	1.09 [.78, 1.52]	.61 [.39, .94]***	1.30 [.64, 1.57]
Depression	2.04 [1.19, 3.50]	.62 [.35, 1.09]	2.24 [1.27, 3.98]**	.49 [.29, .82]**	.94 [.72, 1.21]	.44 [.20, .97]**	.40 [.19, .87]**
Anxiety	Fam Help Acc 1.26 [.74, 2.14]	.77 [.50, 1.19]	2.34 [1.59, 3.44]***	1.00 [.64, 1.57]***	1.10 [.80, 1.50]	.61 [.39, .97]**	1.29 [.63, 2.61]
Depression	.92 [.53, 1.58]	.63 [.35, 1.13]	2.18 [1.28, 3.70]**	.50 [.30, .84]**	1.00 [.77, 1.30]	.43 [.19, .96]**	.42 [.19, .92]**
Anxiety	Fam Help CR 1.11 [.63, 1.96]	.78 [.50, 1.21]	2.33[1.57, 3.46]***	1.00[.64, 1.55]	1.11 [.81, 1.52]	.61 [.39, .95]**	1.30 [.65, 2.61]
Depression	1.29 [.62, 2.69]	.64 [.36, 1.14]	2.16 [1.27, 3.70]**	.49 [.30, .82]**	.98 [.76, 1.27]	.45 [.20, 1.00]	.41 [.19, .91]**
Anxiety	Fam Talk 2.47 [1.00, 6.10]*	.76 [.49, 1.18]	2.15 [1.47, 3.15]***	.93 [.61, 1.43]	1.08 [.77, 1.51]	.58 [.38, .89]**	1.21 [.62, 2.38]
Depression	.53 [.20, 1.38]	.63 [.35, 1.12]	2.37 [1.33, 4.22]***	.54 [.32, .90]**	1.02 [.79, 1.31]	.44 [.20, .98]*	.44 [.20, .95]**
Anxiety	Trusted 1.24 [.58, 2.66]	.80 [.52, 1.25]	2.57 [1.69, 3.91]	.91 [.58, 1.44]	1.17 [.83, 1.65]	.55 [.36, .84]	1.08 [.52, 2.22]
Depression	1.34 [.66, 2.69]	.67 [.37, 1.22]	2.31 [1.32, 4.05]***	.46 [.28, .77]***	1.02 [.78, 1.34]	.35 [.17, .73]**	.35 [.16, .79]**
Anxiety	Help ea other .80 [.37, 1.73]	.73 [.47, 1.13]	2.41 [1.61, 3.61]	.92 [.57, 1.51]	1.20 [.85, 1.68]	.54 [.35, .85]	1.28 [.62, 2.64]
Depression	1.16 [.53, 2.52]	.62 [.34, 1.12]	2.24 [1.29, 3.89]**	.47 [.28, .81]**	1.03 [.79, 1.34]	.39 [.18, .84]	.37 [.17, .86]
Anxiety	Know ea well 1.05 [.56, 1.97]	.80 [.51, 1.26]	2.22 [1.51, 3.27]***	1.04 [.67, 1.62]	1.11 [.80, 1.55]	.59 [.38, .92]**	1.29 [.64, 2.58]
Depression	1.07 [.54, 2.11]	.64 [.35, 1.17]	2.23 [1.28, 3.91]**	.50 [.29, .85]**	.97 [.75, 1.27]	.41 [.18, .91]**	.40 [.18, .89]**
Outcome Measure	**Independent Variables**	**Covariant (CG age) No dementia**	**Covariant (Gender) No dementia**	**Covariant (Income) No dementia**	**Covariant (education) No dementia+**	**Covariant (CG-CR relationship) No dementia**	**Covariant (CR age) No dementia**
Anxiety	Support Group 15.64 [1.26, 193.41]**	.64 (.36, 1.15)	1.91 (1.12, 3.25)**	.93 (.49, 1.77)	1.21 (.50, 2.92) .90 (.36, 2.26)	.62 (.33, 1.17)	1.23 (.63, 2.40)
Depression	15.21 [1.53, 150.91]**	.43 (.20, .92)**	2.33 (1.10, 4.95)**	.32 (.17, .59)***	1.39 (.54, 3.62) .82 (.37, 1.81)	.34 (.13, .86)**	.25 (.11, .59)**
Anxiety	Training 5.57 [1.41, 21.98]**	.53 (.25, 1.11)	1.52 (.68, 3.43)	.76 (.39, 1.50)	1.01 (.45, 2.31) 1.02 .80 (.32, 1.97)	.80 (.39, 1.63)	1.07 (.49, 2.36)
Depression	.85 [.24, 3.02]	.34 (.14, .82)**	1.70 (.72, 4.10)	.29 (.16, .53)***	1.15 (.47, 2.82) .68 (.32, 1.42)	.42 (.16, 1.09)*	.24 (.11, .56)***
Anxiety	Time Away 1.02 [.42, 2.51]	.53 (.25, 1.11)	1.45 (.68, 3.11)	.82 (.43, 1.57)	1.01 (.46, 2.23) 1.02 .77 (.31, 1.94)	.74 (.36, 1.50)	1.08 (.51, 2.28)
Depression	1.17 [.51, 2.67]	.34 (.14, .81)**	1.71 (.72, 4.15)	.29 (.16, .54)***	1.11 (.44, 2.79) .66 (.31, 1.38)	.43 (.16, 1.17)	.25 (.11, .58)**
Anxiety	Fam Help Act 1.49 [.73, 3.05]	.53 (.26, 1.08)*	1.51 (.75, 3.07)	.82 (.42, 1.59)	1.0 (.43, 2.36) .72 (.28, 1.84)	.74 (.36, 1.55)	1.08 (.51, 2.27)
Depression	1.34 [.68, 2.64]	.34 (.14, .80)**	1.77 (.78, 4.02)	.29 (.16, .54)	1.13 (.46, 2.78)	.42 (.161.09)*	.24 (.11, .55)***

					.65 (.29, 1.45)		
Anxiety	Fam Help CR 1.45 [.70, 2.99]	.54 (.26, 1.09)*	1.49 (.73, 3.05)	.80 (.41, 1.54)	1.05 (.45, 2.42) .76 (.30, 1.91)	.38 (.75, 1.31)	1.06 (.49, 2.26)
Depression	1.96 [.98, 3.94]*	.35 (.15, .78)	1.79 (.77, 4.18)	.29 (.16, .52)***	1.25 (.50, 3.10)*** .66 (.32, 1.37)	.47 (.17, 1.26)	.24 (.10, .56)
Anxiety	Fam Talk 1.61 [.56, 4.62]	.53 (.26, 1.10)*	1.43 (68, 3.00)	.77 (.40, .146)	.100 (.42, 2.38) .75 (.30, .187)	.74 (.36, 1.50)	1.05 (.49, .223)
Depression	.69 [.21, 2.28]	.34 (.14, .82)**	1.71 (.70, 4.19)	.31 (.17, .58)***	1.18 (.49, 2.80) .69 (.33, 1.46)	.42 (1.6, 1.15)	.25 (.11, .58)**
Anxiety	Trusted .60 [.27, 1.37]	.54 (.27, 1.10)*	1.49 (.67, 3.35)	.76 (.39, 1.50)	1.05 (.45, 2.44) .72 (.27, 1.96)	.75 (.35, 1.60)	.98 (.46, 2.10)
Depression	.53 [.21, 1.37]	.37 (.14, .94)*	1.71 (.69, 4.22)	.29 (.16, .52)***	.99 (.37, 2.66) .63 (.28, 1.41)	.37 (.15, .96)*	.21 (.09, .51)***
Anxiety	Help ea other .52 [.25, 1.11]*	.53 (.26, 1.09)*	1.38 (.60, 3.16)	.81 (.41, 1.56)	1.05 (.43, 2.56) .78 (.30, 2.03)	.74 (.35, 1.56)	1.12 (.52, 2.37)
Depression	.95 [.43, 2.12]	.35 (.15, .83)**	1.61 (.65, 3.98)	.29 (.16, .53)***	1.23 (.49, 3.08) .69 (.31, 1.51)	.41(.16, 1.05)*	.23 (.10, .54)***
Anxiety	Know ea well 1.23 [.66, 2.30]	.54 (.26, 1.14)	1.35 (.63, 2.89)	.84 (.43, 1.63)	1.04 (.46, 2.37) .74 [.30, 1.84]	.80 (.38, 1.68)	1.13 (.54, 2.36)
Depression	1.76 [.94, 3.28]*	.35 (.14, .88)**	1.70 (.74, 3.89)	.28 (.15, .52)***	1.20 (.51, 2.83) .67 (.32, 1,40)	.45 (.17, 1.20)	.25 (.11, .56)***
Outcome Measure	**Independent Variables**	**Covariant (CG age) poss dementia**	**Covariant (Gender) poss dementia**	**Covariant (Income) poss dementia**	**Covariant (education) poss dementia**	**Covariant (CG-CR relationship) poss dementia**	**Covariant (CR age) poss dementia**
Anxiety	Support Group .98 [.26, 3.64]	.58 (.30, 1.12)	1.57 (.76, 3.23)	.84 (.52, 1.37)	1.29 (.58, 2.90) 2.07 (.98, 4.40)*	.51 (.22, 1.22)	.66 (.16, 2.73)
Depression	1.20 [.33, 4.39]	.56 (.32, .98)*	1.65 (.70, 3.88)	.69 (.34, 1.40)	.76 (.32, 1.84) .84 (.42, 1.69)	.82 (.30. 2.26)	.81 (.21, 3.22)
Anxiety	Training 1.49 [.61, 3.63]	.48 (.30, 1.13)	1.55 (.75, 3.18)	.83 (.51, 1.36)	1.32 (.59, 2.98) 2.12 (.99, 4.53)*	.52 (.22, 1.24)	.67 (.16, 2.84)
Depression	.78 [.32, 1.92]	.56 (.32, .97)**	1.67 (.71, 3.89)	.69 (.34, 1.43)	.75 (.31, 1.82) .83 (.41, 1.67)	.82 (.30, 2.26)	.82 (.20, 3.31)
Anxiety	Time Away 1.45 [.77, 2.73]	.57 (.30, 1.10)	1.55 (.76, 3.18)	.82 (.51, 1.32)	1.35 (.61, 2.98) 2.05 (.99, 4.29)*	.50 (.21, 1.18)	.61 (.15, 2.53)
Depression	1.92 [1.07, 3.45]	.55 (.32, .97)**	1.65 (.72, 3.76)	.65 (.32, 1.31)	.81 (.34, 1.94) .81 (.40, 1.61)	.80 (.30, 2.13)	.73 (.17, 3.01)
Anxiety	Fam Help Act 1.46 [.76, 2.81]	.59 (.30, 1.13)	1.56 (.75, 3.24)	.83 (.51, 1.36)	1.25 (.55, 2.83) 2.04 (.95, 4.37)	.53 (.22, 1.29)	.60 (.15, 2.46)
Depression	1.02 [.48, 2.15]	.56 (.32, .98)**	1.65 (.71, 3.82)	.69 (.34, 1.40)	.76 (.31, 1.87) .84 (.42, 1.68)	.83 (.30, 2.29)	.82 (.20, 3.30)
Anxiety	Fam Help CR 1.33 [.55, 3.23]	.60 (.31, 1.18)	1.54 (.75, 3.17)	.84 (.51, 1.37)	1.26 (.55, 2.88) 1.99 (.91, 4.34)*	.52 (.21, 1.24)	.59 (.16, 2.16)
Depression	1.20 [.44, 3.25]	.58 (.33, 1.00)*	1.64 (.71, 3.78)	.68 (.33, 1.40)	.75 (.31, 1.81) .81 (.39, 1.68)	.83 (.30, 2.32)	.77 (.20, 2.93)

Anxiety	Fam Talk 1.72 [.56, 5.25]	.57 (.29, 1.13)	1.47 (.73, 2.95)	.84 (.51, 1.37)	1.31 (.59, 2.91) 1.98 (.90, 4.36)*	.51 (.21, 1.20)	.69 (.17, 2.76)
Depression	.32 [.10, 1.07]*	.54 (.32, .91)**	1.97 (.78, 5.01)	.69 (.34, 1.41)	.76 (.30, 1.89) .97 (.47, 2.00)	.82 (.30, 2.25)	.69 (.15, 3.08)
Anxiety	Trusted 1.17 [.42, 3.24]	.45 (.22, ,92)**	1.92 (1.01, 3.68)*	.83 (.49, 1.42)	2.01 (.91, 4.43)* 2.94 (1.36, 6.36)***	.55 (.23, 1.31)	.26 (.07, 1.02)*
Depression	1.5 [.56, 4.15]	.46 (.25, .84)**	2.35 (.95, 5.84)*	.56 (.25, 1.26)	.83 (.36, 1.88) 1.02 (.49, 2.12)	.72 (.26, 1.97)	.36 (0.9, 1.46)
Anxiety	Help ea other 1.08 [.36, 3.29]	.43 (.22, .83)**	2.07 (1.02, 4.19)**	.62 (.35, 1.12)	2.35 (1.09, 5.07)** 3.56 (1.62, 7.78)***	.44 (.18, 1.07)*	.33 (.08, 1.34)
Depression	1.08 [.38, 3.07]	.45 (.24, .84)**	2.09 (.84, 5.19)	.60 (.26, 1.37)	1.20 (.53, 2.74) 1.13 (.52, 2.43)	.86 (.29, 2,53)	.48 (.12, 2.01)
Anxiety	Know ea well 1.20 [.38, 3.86]	.55 (.29, 1.04)*	1.50 (.75, 3.00)	.88 (.51, 1.51)	1.51 (.71, 3.21) 2.42 (1.13, 5.17)**	.46 (.18, 1.21)	.57 (.13, 2.40)
Outcome Measure	**Independent Variables**	**Covariant (CG age) prob dementia**	**Covariant (Gender) prob dementia**	**Covariant (Income) prob dementia**	**Covariant (education) prob dementia**	**Covariant (CG-CR relationship) prob dementia**	**Covariant (CR age) prob dementia**
Depression	1.80, .60, 5.43]	.56 (.31, 1.03)*	2.08 (.82, 5.29)	.59 (.26, 1.31)	.69 (.33, 1.47) .93 (.47, 1.83)	.55 (.19, 1.57)	.59 (.15, 2.27)
Anxiety	Support Group 12.50 (.72, 216.56)*	3.03 (.96, 9.51)*	4.81 (1.24, 18.65)**	2.51 (.87, 7,20)	.66 (.21, 2.10) .48 (.18, 1.27)	.54 (.16, 1.84)	.64 (.13, 3.09)
Depression	1	1.68 (.35, 8.20)	1.41 (.41, 4.84)	2.78 (.81, 9.45)	.89 (.30, 2.63) .40 (.12, 1.40)	.54 (.14, 2.10)	.42 (.09, 1.89)
Anxiety	Training 7.34 (.97, 55.81)	3.15 (.96, 10.36)*	5.07 (1.39, 18.51)**	2.36 (.85, 6.59)	.61 (.19, 2.00) .51 (.19, 1.33)	.49 (.14, 1.65)	.59 (.12, 2.81)
Depression	10.10 (1.48, 68.95)	1.76 (.36, 8.55)	1.43 (.44, 4.65)	2.44 (.74, 8.08)	.86 (.28, 2.66) .45 (.14, 1.50)	.46 (.12, 1.86)	.38 (.08, 1.75)
Anxiety	Time Away .91 (.27, 3.03)	2.88 (.90, 9.25)	4.15 (1.04, 16.53)*	2.28 (.78, 6.66)	.73 (.24, 2.26) .56 (.20, 1.54)	.51 (.15, 1.69)	.66 (.14, 3.17)
Depression	1.65 (.39, 6.97)	1.43 (.32, 6.41)	1.10 (.32, 3.79)	1.96 (.60, 6.45)	1.02 (.35, 3.01) .46 (.13, 1.72)	.52 (.15, 1.85)	.45 (.10, 1.97)
Anxiety	Fam Help Act .78 (.27, 2.22)	2.91 (.92, 9.26)	4.27 (1.12, 6.25)	2.33 (.83, 6.55)	.68 (.21, 2.23) .50 (.19, 1.29)	.49 (.14, 1.74)	.63 (.13, 3.09)
Depression	1.26 (.39, 4.07)	1.73 (.37, 8.16)	1.27 (.39, 4.17)	2.11 (.65, 6.85)	1.09 (.37, 3.22) .48 (.14, 1.63)	.51 (.14, 1.89)	.44 (0.9, 2.08)
Anxiety	Fam Help CR .83 (.23, 2.99)	2.88 (.82, 10.11)	4.41 (1.18, 16.51)**	2.32 (.79, 6.82)	.74 (.25, 2.17) .51 (.19, 1.36)	.51 (.15, 1.72)	.67 (.13, 3.40)
Depression	.98 (.26, 3.70)	1.68 (.34, 8.22)	1.25 (.37, 4.16)	2.21 [.64, 7.60]	. 1.05 (.36, 3.05) 47 (.14, 1.60)	.49 (.14, 1.79)	.43 (.09, 2.00)
Anxiety	Fam Talk .96 (.21, 4.44)	2.98 (.99, 9.19)*	4.39 (1.12, 17.21)**	2.22 (.79, 6.29)	.72 (.23, 2.27) .52 (.20, 1.38)	.51 (.16, 1.70)	.65 (.13, 3.18)
Depression	.99 (.19, 5.22)	1.69 (.35, 8.29)	1.25 (.36, 4.28)	2.20 (.67, 7.27)	1.05 (.36, 3.05) .47 (.14, 1.57)	.49 (.13, 1.81)	.43 (0.9, 1.96)

Anxiety	Trusted 1.38 (.27, 7.15)	2.88 (.88, 9.36)*	3.96 (1.00, 15.67)*	1.66 (.59, 4.63)	.85 (.26, 2.80) .70 (.26, 1.90)	.53 (.16, 1.78)	.47 (.09, 2.33)
Depression	5.4 (.66, 44.57)	1.80 (.35, 9.24)	.95 (.31, 2.94)	1.34 (.41, 4.42)	1.59 (.49, 5.16) .81 (.19, 3.37)	.47 (.14, 1.64)	.26 (.06, 1.22)*
Anxiety	Help ea other 2.15 (.47, 9.86)	3.07 (.94, 10.02)*	3.78 (.99, 14.40)*	2.23 (.80, 6.21)	.68 (.21, 2.12) .50 (.18, 1.38)	.52 (.16, 1.69)	.62 (.14, 2.76)
Depression	1.24 (.25, 6.26)	1.90 (.38, 9.46)	1.27 (.37, 4.32)	2.13 (.64, 7.09)	.99 (.34, 2.89) .41 (.13, 1.26)	.49 (.13, 1.83)	.41 (.09, 1.81)
Anxiety	Know ea well 2.15 (.47, 9.86)	3.07 (.94, 10.02)*	.378 (.99, 14.40)*	2.23 (.80, 6.21)	.68 (.21, 2.12) .50 (.18, 1.38)	.52 (.16, 1.69)	.62 (.14, 2.76)
Depression	.51 (.16, 1.63)	1.53 (.31, 7.56)	1.46 (.44, 4.79)	2.18 (.58, 8.16)	.96 (.31, 2.93) .40 (.10, 1.57)	.53 (.13, 2.16)	.43 (.10, 1.80)

*>.05, **>.01, ***> .00   + upper data for some college/lower data graduate

Appendices

Appendix A: Family Caregiver Focus Group Interview Questions

1. The following script will be used for the focus groups:
    a. Thank you all so much for joining us. I'm Dr. Sheria Robinson-Lane and I will be facilitating the group today. Please call me Sheria. I'm joined with by (note study team staff present and roles). Before we begin, if you have not done so already, we want to make sure that your listed name is the pseudonym that you have selected for yourself. We will take few minutes to assist you with updating your names.
    b. Now that that has been completed, we will just go over a bit of housekeeping information. The group intends to get some feedback from you all regarding a program we plan to trial in the next year. We want to hear openly and honestly what you think about our planned support program for family caregivers including, what you like most, what you dislike, and what you think is missing. We also want to be sure to hear from all of you. So, once you respond to a question, please allow others to respond before contributing again to the same question. We will record this meeting so that we can review and think about what you have said. Though Zoom automatically records both audio and video. We will delete the video following this meeting and just retain the audio. We will also be using an auto transcription function in zoom. If at any time someone would like us to pause the recording to say something, please let us know. If you are uncomfortable with any of the questions, please feel free not to respond. We already have mailing information, so your gift cards will be mailed out at the conclusion of this meeting. Are there any questions or concerns before we get started? (Answer/ address any questions). Then let's get started.
    c. (Begin recording and transcribing)
    d. First just to get us chatting a bit please introduce yourself to the group using your pseudonym. We would like to know how you are related to the person you are/ or were providing care for, and how long you either have been or currently are a caregiver.
    e. Where did you get information about dementia or what was going on with the person you were supporting?
    f. Were there any organizations that you found particularly helpful in providing information about dementia or helping you to get resources to support you as a

caregiver? If so, how did you become connected with the organizations that provided support?

g. What would you say are the greatest challenges that you have had as a caregiver?
h. What are the ways in which you have felt supported as a caregiver?
i. (Provide an overview of the caregiver support program.) What are your thoughts about the program's length of time and structure?
j. What do you think would be the greatest challenges to someone completing this program?
k. (Provide a listing of topical areas to be included in the program.) This is the content that we plan to cover over the 12-week program. What looks most interesting to you? What looks least interesting? What seems least helpful here? What seems most helpful? Any other thoughts about the planned program?
l. If you could provide one piece of advice for a future caregiver, what would it be?
m. Any final thoughts?

Data Management and Security

Prescreening questionnaires – electronic questionnaires will be maintained in Qualtrics and exported into a Stata data file. At the conclusion of the of the study, the Qualtrics data will be destroyed. The Stata data file will be maintained for 7 years in a secure electronic file only accessible by study team members and then destroyed.

Demographic survey – electronic demographic survey will be maintained on Qualtrics and exported into a Stata data file. At the conclusion of the study, the Qualtrics data will be destroyed. The Stata data will be maintained for 7 years in a secure electronic file only accessible by study team members and then destroyed.

Zoom video data – Zoom recording result in both audio and video files. Video files will be deleted upon confirmation of clean audio files at the conclusion of the focus group meeting.

Zoom Audio data – Zoom audio files will be maintained in a secure file and only accessible by the study team members as necessary. Audio files will be maintained until transcription cleaning has been completed and then they will be destroyed. If there is an issue with Zoom generated transcripts, audio files will be transcribed using a HIPAA compliant transcription service such as REV.

Focus group transcripts – De-identified focus group meeting transcripts will be maintained in secure electronic files and then uploaded to Deep Blue for archiving following the conclusion of analysis.

Appendix B: Focus Group Demographic Survey

Q0_1
I understand that my PARTICIPATION IS VOLUNTARY. I have the right to decline to be in this study, or to withdraw at any time without penalty.

YES, I wish to participate in the Family Caregiver Focus Groups

NO, I do NOT wish to participate in the Family Caregiver Focus Groups.

Skip To: End of Survey If I understand that my PARTICIPATION IS VOLUNTARY. I have the right to decline to be in this study,... = NO, I do NOT wish to participate in the Family Caregiver Focus Groups.

Q1 Age

Q4 Highest level of education completed (if currently enrolled, highest degree received):

Less than high school diploma

High school graduate, diploma or equivalent (e.g., GED)

Some college, no degree

Associate degree

Bachelor’s degree

Master’s degree

Professional degree (e.g., MD, DDS, DVM)

Doctorate (e.g., PhD, EdD)

Q117 What gender do you identify with?

Male

Trans Male

Female

Trans Female

Non-binary /Non-Conforming/Gender Fluid

Other ____

Prefer not to answer.

Q118 What is your sexual orientation?

- Heterosexual/ Straight (Attracted to a person of the opposite gender)
- Homosexual/ Gay/ Lesbian (Attracted person of the same gender)
- Bisexual (Attracted to both men and women)
- Asexual (Not attracted to anyone)
- ____
- Prefer not to answer.

Q7 Marital Status:

- Single, never married.
- Married or living together as married.
- Widowed
- Divorced
- Separated

Q8 Which best describes your employment status:

- Employed full-time (40 or more hours per week)
- Employed part-time (up to 39 hours per week)
- Unemployed and currently looking for work.
- Unemployed and not currently looking for work.
- Student
- Retired
- Homemaker
- Self-employed
- Unable to work.

Q9 Household Income:

Less than $20,000
$20,000 to $34,999
$35,000 to $49,999
$50,000 to $74,999
$75,000 to $99,999
Over $100,000

Q12 How is the person with dementia that you care related to you?

My Parent
My Grandparent
My Spouse or Significant Other
My Ex-spouse
Another Relative
My Friend or Neighbor

Q13 About how long have you been providing care for them?

Less than one year
1-2 years
3-5 years
More than five years

Q14 Do you live in the same home as the person you are providing care for?

Yes
No

Q15 What would you say is your relative's main problem or illness (check all that apply)?

Alzheimer’s disease

Vascular dementia or stroke

Frontal temporal dementia

Parkinson’s disease

Lewy body dementia

Dementia (not specified)

Traumatic brain injury

Other ____

Q112 Select the score that most closely corresponds to your relative's current level of ability (or level of ability while you were providing care assistance) for each of the following 10 items. Record actual, not potential, functioning.

Q114 Bowels:

0 = incontinent (no control over bowels or needs to be given enemata)

1 = occasional accident (once/week)

2 = continent (uses the toilet, commode, or bed pan)

Q116 Bladder:

0 = incontinent (no control over urine)

1 = occasional accident (max. once per 24 hours)

2 = continent (uses, toilet, commode, or bed pan for over 7 days)

Q118 Grooming:

0 = needs help with personal care

1 = independent face/hair/teeth/shaving (implements provided)

Q120 Toilet use:

0 = dependent (needs help with toileting)

1 = needs some help, but can do somethings alone

2 = independent (able to get on or off the toilet, dress, and wipe)

Q122 Feeding:

0 = unable to feed self

1 = needs help cutting, spreading butter, etc.

2 = independent (can eat without assistance if food provided within reach)

Q124 Transfer:

0 = unable to move from a bed to chair alone (no sitting balance)
1 = major help (one or two people, physical), can sit
2 = minor help (verbal or physical assistance needed)
3 = independent (no assistance required)

Q127 Mobility:

0 = immobile/ unable to move independently
1 = wheelchair independent, including corners, etc.
2 = walks with help of one person (verbal or physical)
3 = independent (but may use any aid, e.g., cane)

Q132 Dressing:

0 = dependent on others for assistance
1 = needs help, but can do about half unaided
2 = independent (including buttons, zips, laces, and selecting appropriate clothing for occasion/ weather)

Q129 Stairs:

0 = unable to navigate stairs alone
1 = needs help (verbal, physical, carrying aid)
2 = independently can go up and down stairs

Q131 Bathing:

0 = dependent on others to bathe
1 = independent (can bathe alone)

Q122 Indicate the response to the statement that most closely corresponds to your relative's current functional ability for each task.

Q124 Ability to use the telephone:

- Operates telephone on own initiative; looks up and dials numbers, etc.
- Dials a few well-known numbers
- Answers telephone but does not dial
- Does not use telephone at all

Q125 Shopping:

- Takes care of all shopping needs independently
- Shops independently for small purchases
- Needs to be accompanied on any shopping trip
- Completely unable to shop

Q128 Food preparation:

- Plans, prepares, and serves adequate meals independently
- Prepares adequate meals if supplied with ingredients
- Heats and serves prepared meals, or prepares meals but does not maintain adequate diet
- Needs to have meals prepared and served

Q131 Housekeeping:

- Maintains house alone or with occasional assistance (e.g., "heavy work domestic help")
- Performs light daily tasks such as dish washing, bed making
- Performs light daily tasks but cannot maintain acceptable level of cleanliness
- Needs help with all home maintenance tasks
- Does not participate in any housekeeping tasks

Q133 Laundry:

Does personal laundry completely

Launders small items; rinses stockings, etc.

All laundry must be done by others

Q135 Mode of transportation:

Travels independently on public transportation or drives own car

Arranges own travel via taxi, but does not otherwise use public transportation

Travels on public transportation when assisted or accompanied by another

Travel limited to taxi or automobile with assistance of another

Does not travel at all

Q137 Responsibility for own medications:

Is responsible for taking medication in correct dosages at correct time

Takes responsibility if medication is prepared in advance in separate dosages

Is not capable of dispensing own medication

Q139 Ability of handle finances:

Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank), collects and keeps track of income

Manages day-to-day purchases, but needs help with banking, major purchases, etc.

Incapable of handling money

Q110 Below are some statements with which some people agree and others disagree. Please read each statement and indicate the response most appropriate for you. There is no right or wrong answer.

	Strongly disagree	Disagree	Somewhat disagree	Neutral	Somewhat agree	Agree	Strongly agree
There is someone I feel close to who makes me feel secure							

I belong to a group in which I feel important
People let me know that I do well at my work (job, homemaking)
I have enough contact with the person who makes me feel special
I spend time with others who have the same interests that I do
Others let me know that they enjoy working with me (job, committees, projects)
There are people who are available if I need help over an extended period of time
Among my group of friends we do favors for each other
I have the opportunity to encourage others to develop their

interests and skills	
I have relatives or friends who will help me out even if I can't pay them back	
When I am upset, there is someone I can be with who lets me be myself	
I know that others appreciate me as a person	
There is someone who loves and cares about me	
I have people to share social events and fun activities with	
I have a sense of being needed by another person	

Q18 How many children under the age of 18 are you responsible for?

- 0
- 1
- 2
- 3 or more

Q130 In general, would you say your health is:

- Excellent
- Very Good
- Good
- Fair
- Poor

Q20 In general, would you quality of life is:

- Excellent
- Very Good
- Good
- Fair
- Poor

Q21 In general, how would you rate your physical health?

- Excellent
- Very Good
- Good
- Fair
- Poor

Q131 In general, how would you rate your mental health, including your mood and your ability to think?

- Excellent
- Very Good
- Good
- Fair
- Poor

Q23 In general, how would you rate your satisfaction with your social activities and relationships?

- Excellent
- Very Good
- Good
- Fair
- Poor

Q25 To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

- Completely
- Mostly
- Moderately
- A little
- Not at all

Q26 In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

- Never
- Rarely
- Sometimes
- Often
- Always

Q28 In the past 7 days, how would you rate your pain on average?

0 No Pain
1
2
3
4
5
6
7
8
9
10 Worst pain imaginable

Appendix C: Variable Definitions

Community support services

- Family talk: caregiver (CG) has family to talk to
- Family help w/acct: CG has family/friends to help with the care receiver's (CR) activities.
- Family help w/care: CG has family/friends to help care for CR.
- Support group: CG has attended a support group.
- Time away: CG has been able to take time away from caregiving.
- Training: CG has received dementia training

Neighborhood cohesion

- Trusted: neighbors feel they can trust each other
- Help other: neighbors help one another.
- Know well: neighbors know each other well.

Stress measures

- Alone: CG felt alone
- Enjoy spending time: CR enjoyed spending time with CR.
- CR argue: CR argues with CG.
- CR Apprec: CG feels appreciated by CR.
- Get on nerves: CR gets on CG's nerves.
- Bring closer: caring for CR brings CG closer to CG.

Appendix D: Perlin Stress Framework

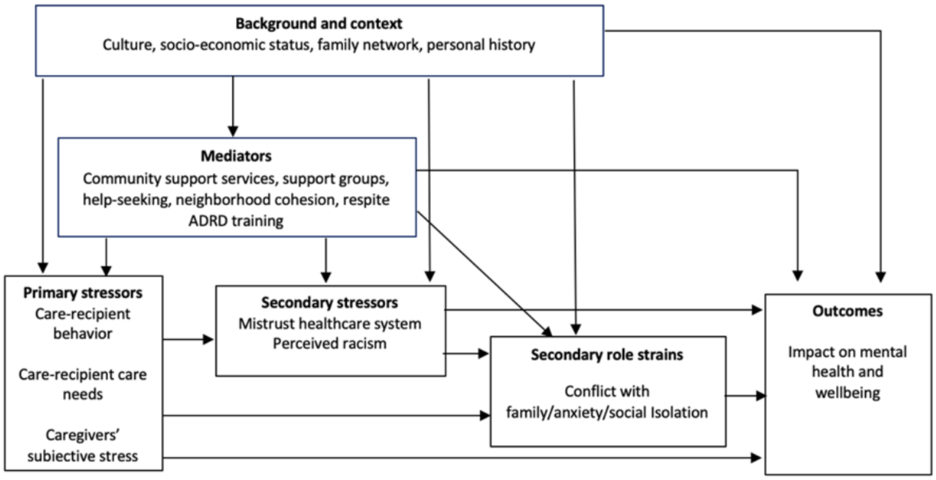

Figure 2 Original Perlin Framework

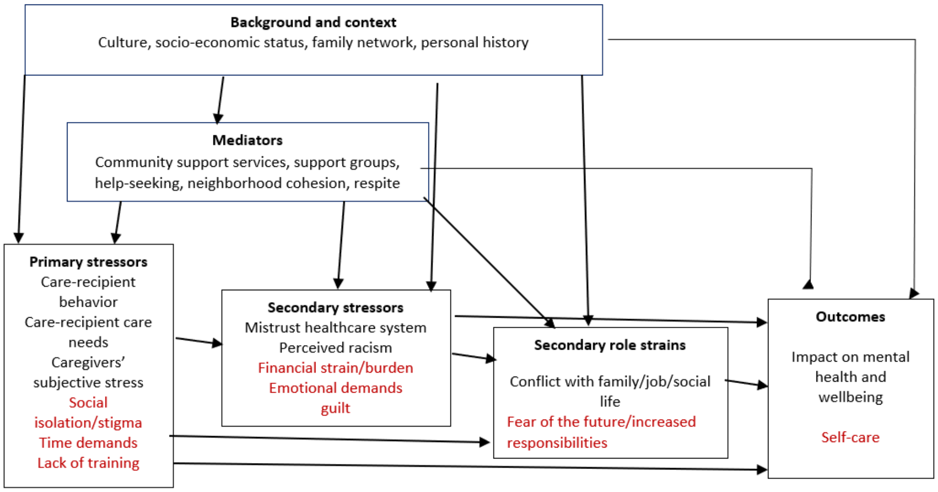

Figure 3 Updated Perlin Framework

Bibliography

AARP. (2021, October 15). How to receive pay when becoming a family caregiver. https://www.aarp.org

Abramsohn, E. M., Jerome, J., Paradise, K., Kostas, T., Spacht, W. A., & Lindau, S. T. (2019). Community resource referral needs among African American dementia caregivers in an urban community: A qualitative study. *BMC Geriatrics 19*, 311. https://doi.org/10.1186/s12877-019-1341-6

American Psychological Association. (2011). Cultural diversity and caregiving. https://www.apa.org/pi/about/publications/caregivers/faq/cultural-diversity

American Psychological Association. (2015, March 15). Mental and physical health effects of family caregiving. https://www.apa.org.

American Psychological Association (2021, April 1). The imperative of self-care. *Monitor on Psychology, 52*(4), 10-14. https://www.apa.org/monitor/2021/04/feature-imperative-self-care.

American Psychological Association, APA Working Group on Stress and Health Disparities. (2017). Stress and health disparities: Contexts, mechanisms, and interventions among populations of racial/ethnic minorities and low-socioeconomic status. http://www.apa.org/pi/health-disparities/resources/stress-report.aspx

Aranda, M. P., Kremer, I. N., Hinton, L., Zissimopoulos, J., Whitmer, R. A., Hummel, C. H., Trejo, L., & Fabius, C. (2021). Impact of dementia: Health disparities, population trends, care interventions, and economic costs. *Journal of the American Geriatrics Society*, *69*(7), 1774–1783. https://doi.org/10.1111/jgs.17345

Babulal, G. M., Quiroz, Y. T., Albensi, B. C., Arenaza-Urquijo, E., Astell, A. J., Babiloni, C., Bahar-Fuchs, A., Bell, J., Bowman, G. L., Brickman, A. M., Chételat, G., Ciro, C., Cohen, A. D., Dilworth-Anderson, P., Dodge, H. H., Dreux, S., Edland, S., Esbensen, A., Evered, L., …O'Bryant, S. E. (2018). Perspectives on ethnic and racial disparities in Alzheimer's disease and related dementias: Update and areas of immediate need. *Alzheimer's & Dementia,15*(2), 292–312. https://doi.org/10.1016/j.jalz.2018.09.009

Bailey, R. K., Patel, M., Barker, N. C., Ali, S., & Jabeen, S. (2011). Major depressive disorder in the African American population. *Journal of the National Medical Association*, *103*(7), 548–557. https://doi.org/10.1016/s0027-9684(15)30380-1

Balls-Berry, J. J. E., & Babulal, G. M. (2022). Health Disparities in Dementia. *Continuum* (Minneapolis, Minn.), *28*(3), 872–884. https://doi.org/10.1212/CON.0000000000001088

Bangerter, L. R., Liu, Y., Kim, K., & Zarit, S. H. (2021). Adult day services and dementia caregivers' daily effect: The role of distress response to behavioral and psychological symptoms of dementia. *Aging & Mental Health, 25*(1), 46–52. https://doi.org/10.1080/13607863.2019.1681934

Barnett, A. J., Baggio, J. A., Shin, H. C., Yu, D. J., Perez-Ibarra, I., Rubinos, C., Brady, U., Ratajczyk, E., Rollins, N., Aggarwal, R., Anderies, J. M., & Janssen, M. A. (2016). An iterative approach to case study analysis: Insights from qualitative analysis of quantitative inconsistencies. *International Journal of the Commons, 10*(2), 467. https://doi.org/10.18352/ijc.632

Bertrand, R. M., Fredman, L., & Saczynski, J., (2006, August). Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *Journal of Aging and Health, 18*, 534–551. https://doi:10.1177/0898264306289620

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217–228. https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty

Cabote, C. J., Bramble, M., & McCann, D. (2015). Family caregivers' experiences of caring for a relative with younger onset dementia: A qualitative systematic review. *Journal of Family Nursing, 21*(3), 443–468. https://doi.org/10.1177/1074840715573870

Cagney, K. A., Glass, T. A., Skarupski, K. A., Barnes, L. L., Schwartz, B. S., & Mendes de Leon, C. F. (2009, May). Neighborhood-level cohesion and disorder: Measurement and validation in two older adult urban populations. *The Journals of Gerontology: Series B,* 64*B*(3), 415–424. https://doi.org/10.1093/geronb/gbn041

Chen, C., Thunell, J., & Zissimopoulos, J., (2020, November 2). Changes in physical and mental health of Black, Hispanic, and White caregivers and non-caregivers associated with onset of spousal dementia. *Alzheimer's & Dementia: Translational Research & Clinical Interventions, 6*(1). https://doi.org/10.1002/trc2.12082

Chin, A. L., Negash, S., & Hamilton, R. (2011). Diversity and disparity in dementia: The impact of ethnoracial differences in Alzheimer's disease. *Alzheimer's Disease and Associated Disorders*, *25*(3), 187–195. https://doi.org/10.1097/WAD.0b013e318211c6c9

Cothran, F. A., Chang, E., Beckett, L., Bidwell, J. T., Price, C. A., & Gallagher-Thompson, D. (2021, December 4). A landscape of subjective and objective stress in African American dementia family caregivers. *Western Journal of Nursing Research, 44*(3), 239–249. https://doi.org/10.1177/01939459211062956

Cotton, Q. D., Kind, A. J. H., Kim, A. J., Block, L. M., Thyrian, J. R., Monsees, J., Shah, M. N., & Gilmore-Bykovskyi, A. (2021, October 26). Dementia caregivers' experiences engaging supportive services while residing in under-resourced areas. *Journal of Alzheimer's Disease, 84*(1), 169–177. https://doi.org/10.3233/JAD-210609

Cox, C. (2022). *4 Oppression and Diversity. Human Rights and Social Justice: Key Issues and Vulnerable Populations, 119*.

Dilworth-Anderson, P., Goodwin, P. Y., & Williams, S. W. (2004, May). Can culture help explain the physical health effects of caregiving over time among African American caregivers? *The Journals of Gerontology: Series B,* 59(3), S138–S145. https://doi.org/10.1093/geronb/59.3.s138

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002, 1 April). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980- 2000). *The Gerontologist 42*(2), 237–272. https://doi.org/10.1093/geront/42.2.237

Dong, X., & Bergren, S. M. (2016). The associations and correlations between self-reported health and neighborhood cohesion and disorder in a community-dwelling U.S. Chinese population. *The Gerontologist*, *57*(4), 679–695. https://doi.org/10.1093/geront/gnw050

Dong, X., & Bergren, S. M. (2017). The associations and correlations between self-reported health and neighborhood cohesion and disorder in a community-dwelling U.S. Chinese Population. *The Gerontologist*, *57*(4), 679–695. https://doi.org/10.1093/geront/gnw050

Ejem, D. B., Drentea, P., & Clay, O. J. (2014). The effects of caregiver emotional stress on the depressive symptomatology of the care recipient. *Aging & Mental Health*, *19*(1), 55–62. https://doi.org/10.1080/13607863.2014.915919

Evertson, L. C., Jennings, L. A., Reuben, D. B., Zaila, K. E., Akram, N., Romero, T., & Tan, Z. S. (2021). Caregiver outcomes of a dementia care program. *Geriatric Nursing, 42*(2), 447 –459. https://doi.org/10.1016/j.gerinurse.2021.02.003

Ferguson, W. J., & Candib, L. M. (2002). Culture, language, and the doctor-patient relationship. *Family Medicine and Community Health Publications, 34*(5), 353–361. http://hdl.handle.net/20.500.14038/31007

Fields, J. A., Forsberg, L. K., Knutson, M., Seifert, S. J., Farah-Milller, E. A., Melius, J. L., Miller, J. K., Knopman, D. S., Boeve, B. F., Petersen, R. C., Kramer, K. M., & Lunde, A. M. (2021). Assessing the needs of Black/African American dementia caregivers seeking emotional support. *Alzheimer's & Dementia*, *17*(S8). https://doi.org/10.1002/alz.056579

Fortinsky R. H. (2001). Health care triads and dementia care: Integrative framework and future directions. *Aging & Mental Health, 5*(sup1), 35–48. https://doi.org/10.1080/713649999

Gallagher-Thompson, D., Choryan Bilbrey, A., Apesoa-Varano, E. C., Ghatak, R., Kim, K. K., & Cothran, F., (2020). Conceptual framework to guide intervention research across the trajectory of dementia caregiving. The Gerontologist 60(suppl 1), S29–S40. https://doi.org/10.1093/geront/gnz157

Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Pérez-Miguel, A., Pedroso-Chaparro, M., Márquez-González, M (2020). "I Feel Guilty." Exploring guilt-related dynamics family caregivers of people with dementia. *Clinical Gerontologist*, *45:5*, 1294-1303. https://doi: 10.1080/07317115.2020.1769244.

Gardiner, T., Abraham, S., Clymer, O., Rao, M., & Gnani, S. (2021). Racial and ethnic health disparities in healthcare settings. *BMJ*, 372, n605. https://doi.org/10.1136/bmj.n605

Gaugler, J. E., Kane, R. L., & Kane, R. A. (2002). Family care for older adults with disabilities: Toward more targeted and interpretable research. The International Journal of Aging and Human Development, 54(3):205–231. https://doi.org/10.2190/FACK-QE61-Y2J8-5L68

Gaugler, J. E., Kane, R. L., & Newcomer, R. (2007). Resilience and transitions from dementia caregiving. *The Journals of Gerontology: Series B, 62*(1), P38–P44. https://doi.org/10.1093/geronb/62.1.p38

Gaugler, J. E., Yu, F., Davila, H. W., & Shippee, T. (2014). Alzheimer's disease and nursing homes. *Health Affairs (Project Hope)*, *33*(4), 650–657. https://doi.org/10.1377/hlthaff.2013.1268

Gilmore-Bykovskyi, A. L., Jin, Y., Gleason, C., Flowers-Benton, S., Block, L. M., Dilworth-Anderson, P., Barnes, L. L., Shah, M. N., & Zuelsdorff, M., (2019). Recruitment and retention of underrepresented populations in Alzheimer's disease research: A systematic review. *Alzheimer's & Dementia: Translational Research & Clinical Interventions 5,* 751–770. https://doi.org/10.1016/j.trci.2019.09.018

Gitlin, L. N., Kales, H. C., & Lyketsos, C. G. (2012). Nonpharmacologic management of behavioral symptoms in dementia. *Journal of the American Medical Association, 308*(19), 2020–2029. https://doi.org/10.1001/jama.2012.36918

Goh, A. M., Doyle, C., Gaffy, E., Batchelor, F., Polacsek, M., Savvas, S., Malta, S., Ames, D., Winbolt, M., Panayiotou, A., Loi, S. M., Cooper, C., Livingston, G., Low, L.-F., Fairhall, A., Burton, J., & Dow, B. (2022). Co-designing a dementia-specific education and training program for home care workers: The 'Promoting Independence Through Quality Dementia Care at Home'project. Dementia, 21(3), 899-917. https://doi: 10.1177/14713012211065377

Gundumogula, Manju. (2020). Importance of Focus Groups in Qualitative Research. *The International Journal of Humanities & Social Studies. 8*(11). 10.24940/theijhss/2020/v8/i11/HS2011-082.

Hailu, E. M., Lewis, T. T., Needham, B. L., Lin, J., Seeman, T. E., & Mujahid, M. S. (2021). Longitudinal associations between discrimination, neighborhood social cohesion, and telomere length: The multi-ethnic study of atherosclerosis. *The Journal of Gerontology. Series A, Biological sciences and medical sciences*, glab193. Advance online publication. https://doi.org/10.1093/gerona/glab193

Harandi, T. F., Taghinasab, M. M., & Nayeri, T. D. (2017). The correlation of social support with mental health: A meta-analysis. *Electronic Physician, 9*(9), 5212–5222. https://doi.org/10.19082/5212

Hermanns, M., & Mastel-Smith, B. (2012). Caregiving: A qualitative concept analysis. *The Qualitative Report, 17*(Art. 75), 1–18. https://www.nova.edu/ssss/QR/QR17/hermanns.pdf

Hill, T. D. & Maimon, D., (2013). Neighborhood context and mental health. In C.S. Aneshensel, J.C. Phelan, & A. Bierman (Eds.). *Handbook of the Sociology of Mental Health* (pp. 479–501). *Handbooks of Sociology and Social Research*. Springer. https://doi:10.1007/978-94-007-4276-5_23

Ice, G. H., Sadruddin, A. F., Vagedes, A., Yogo, J., & Juma, E. (2012). Stress associated with caregiving: An examination of the stress process model among Kenyan Luo elders. *Social Science & Medicine (1982), 74*(12), 2020–2027. https://doi.org/10.1016/j.socscimed.2012.02.018

Institute of Medicine (U.S.) Committee on the Consequences of Uninsurance. Coverage matters: Insurance and health care. Washington (D.C.): National Academies Press (U.S.); 2001. 1, Why Health Insurance Matters. https://www.ncbi.nlm.nih.gov/books/NBK223643/

Johnson, R. L., Saha, S., Arbelaez, J. J., Beach, M. C., Cooper, L. A. (2004). Racial and ethnic differences in patient perceptions of bias and cultural competence in health care. *Journal* *of General Internal Medicine 19*, 101–110. https://doi:10.1111/j.1525-1497.2004.30262.x

Jones, K. (2021, July). Black older adults are being left behind in the fight against racial injustice-The time to advocate for them is now. *Newsone*, 21, https://newsone.com/4176048/black-older-adults-racial-justice

Kasper, J. D., Freedman, V. A., & Spillman, B. C. (2013). National Study of Caregiving User Guide. Baltimore: Johns Hopkins University School of Public Health. http://www.nhats.org

Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The Disproportionate Impact of Dementia On Family And Unpaid Caregiving To Older Adults. Health Affairs, 34(10), 1642–1649. https://doi.org/10.1377/hlthaff.2015.0536

Kinalski, D. D. F., Paula, C. C. D., Padoin, S. M. D. M., Neves, E. T., Kleinubing, R. E., & Cortes, L. F. (2017). Focus group on qualitative research: experience report. *Revista Brasileira De Enfermagem, 70*(2), 424–429. https://doi.org/10.1590/0034-7167-2016-0091

Klagge, J. (2018). *Guidelines for Conducting Focus Groups*. 10.13140/RG.2.2.33817.47201.

Kokorelias, K. M., Gignac, M., Naglie, G., Rittenberg, N., Mackenzie, J., D'Souza, S., & Cameron, J. I. (2020). A grounded theory study to identify caregiving phases and support needs across the Alzheimer's disease trajectory. *Disability and Rehabilitation, 44*(7), 1050–1059. https://doi.org/10.1080/09638288.2020.1788655

Lavretsky, H., Siddarth, P., & Irwin, M. R. (2010). Improving depression and enhancing resilience in family dementia caregivers: A pilot randomized placebo-controlled trial of escitalopram. *The American Journal of Geriatric Psychiatry, 18*(2), 154–162. https://doi.org/10.1097/jgp.0b013e3181beab1e

Lee, H. S., Kim, D. K., & Kim, J. (2006). Stress in caregivers of demented people in Korea—A modification of Pearlin and colleagues' stress model. *Int J Geriatr Psychiatry 21*: 784–791. https://doi.org/10.1002/gps.1563

Lu, N., Jiang, N., Sun, Q., & Lou, V. W. Q. (2020). Community social capital and positive caregiving experiences among adult-children's caregivers of older adults with disabilities in urban China. *Research on Aging, 42*(1), 3–12. https://doi.org/10.1177/0164027519876095

Macleod, A., Tatangelo, G., McCabe, M., & You, E. (2017). There isn't an easy way of finding the help that's available. Barriers and facilitators of service use among dementia family caregivers: A qualitative study. *International Psychogeriatrics*, *29*(5), 765–776. https://doi.org/10.1017/S1041610216002532

Majoka, M. A., & Schimming, C., (2021). Effect of social determinants of health on cognition and risk of Alzheimer's disease and related dementias. *Clinical Therapeutics 43*, 922–929. https://doi: 10.1016/j.clinthera.2021.05.005

Mallery, C. (2020, October 20). Caregiver or care partner? What evolving terminology means. Health Central. www.healthcentral.com/article/caregiver-vs-care-partner

McCarthy, M. J., Garcia, Y. E., Remiker, M., Hustead, M. L. R., Bacon, R., Williamson, H. J., Dunn, D. J., & Baldwin, J. (2022, January 31). Diverse rural caregivers for individuals with Alzheimer's disease or related dementias: Analysis of health factors at the individual, interpersonal, and community level. *Aging & Mental Health*. https://doi.org/10.1080/13607863.2022.2026880

McLennon, S. M., Habermann, B., Rice, M., (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging & Mental Health 15*, 522–530. https://doi.org/10.1080/13607863.2010.543656

Merrilees, J. (2016). The impact of dementia on family caregivers: What is research teaching us? *Current Neurology and Neuroscience Reports, 16*(10): 88. https://doi10.1007/s11910-016-0692-z

Millar, R. J., (2020). Neighborhood cohesion, disorder, and physical function in older adults: An examination of racial/ethnic differences. *Journal of Aging and Health 32*, 1133–1144. https://doi.org/10.1177/0898264319890944

Moore, P. (2021). Thematic analysis in focus groups. Retrieved from https://www.researchgate.net/publication/337526673_Thematic_Analysis_in_Focus_Groups

MCUAAAR (2020). Healthier Black Elders Center. Retrieved from https://mcuaaar.org/cores/community-liaison-and-recruitment-core/healthier-black-elders-center.

Na, P. J., Yaramala, S. R., Kim, J. A., Kim, H., Goes, F. S., Zandi, P. P., Vande Voort, J. L., Sutor, B., Croarkin, P., & Bobo, W. V. (2018). The PHQ-9 item 9 based screening for suicide risk: A validation study of the Patient Health Questionnaire (PHQ)-9 item 9 with the Columbia Suicide Severity Rating Scale (C-SSRS). *Journal of Affective Disorders, 232*, 34–40. https://doi.org/10.1016/j.jad.2018.02.045

National Alliance for Caregiving and AARP (2020, May 14). Caregiving in the U.S. 2020. National Alliance for Caregiving. https://www.caregiving.org/ caregiving-in-the-us-2020

National Center for Health Statistics. *Healthy People 2020 Final Review.* (2021). https://dx.doi.org/10.15620/cdc:111173

National Healthcare Quality and Disparities Report. (2021). Agency for Healthcare Research and Quality. *AHRQ Pub. No. 21*(22)-0054-EF. https://www.ncbi.nlm.nih.gov/books/NBK578529/

National Institute on Aging. (2020). What is respite care? Retrieved from https://www.nia.nih.gov/health/what-respite-care.

National Institute of Health-National Institute on Aging. (2021). Data shows racial disparities in Alzheimer's disease diagnosis between Black and White research study participants. https://www.nia.nih.gov/news/data-shows-racial-disparities-alzheimers-disease-diagnosis-between-black-and-white-research

National Institute of Neurological Disorders and Stroke (2022, March 29). Focus on Alzheimer's Disease and Related Dementias. https://ninds7.prod.nindsweb.com

Novak, P., Chu, J., Ali, M. M., & Chen, J. (2020). Racial and ethnic disparities in serious psychological distress among those with Alzheimer's disease and related dementias. *The American Journal of Geriatric Psychiatry 28*(4), 478–490. https://doi.org/10.1016/j.jagp.2019.08.010

Nyumba, T., Wilson, K., Derrick, C. J., & Mukherjee, N. (2018). The use of focus group discussion methodology: Insights from two decades of application in conservation. *Methods in Ecology and Evolution, 9*(1), 20–32. https://doi.org/10.1111/2041-210x.12860

Ong, H. L., Vaingankar, J. A., Abdin, E., Sambasivam, R., Fauziana, R., Tan, M. E., Chong, S. A., Goveas, R. R., Chiam, P. C., & Subramaniam, M. (2018). Resilience and burden in caregivers of older adults: Moderating and mediating effects of perceived social support. *BMC Psychiatry, 18*(1), 27. https://doi.org/10.1186/s12888-018-1616-z

Ornstein, K. A., Gaugler, J. E., Devanand, D. P., Scarmeas, N., Zhu, C. W., & Stern, Y. (2013). Are there sensitive time periods for dementia caregivers? The occurrence of behavioral and psychological symptoms in the early stages of dementia. *International Psychogeriatrics, 25*(9), 1453–1462. https://doi.org/10.1017/s1041610213000768

Ornstein, K. A., Wolff, J. L., Bollens-Lund, E., Rahman, O.-K., & Kelley, A. S. (n.d.). Spousal Caregivers Are Caregiving Alone in the Last Years of Life. Aging & Health. https://doi: 10.1377/hlthaff.2019.00087

Parkinson, M., Carr, S. M., Rushmer, R., & Abley, C. (2017). Investigating what works to support family carers of people with dementia: A rapid realist review. *Journal of Public Health 39*(4), e290–e301. https://doi.org/10.1093/pubmed/fdw100

Penning, M. J., & Wu, Z. (2016). Caregiver stress and mental health: Impact of caregiving relationship and gender. *The Gerontologist, 56*(6), 1102–1113. https://doi.org/10.1093/geront/gnv038

Podgorski, C. (2018). Research on caregiver stress: Time for integration and application. *International Psychogeriatrics, 30*(8), 1085–1087. https://doi:10.1017/S1041610218001035

Quiñones, A. R., Kaye, J., Allore, H. G., Botoseneanu, A., & Thielke, S. M. (2020, September 24). An agenda for addressing multimorbidity and racial and ethnic disparities in Alzheimer's disease and related dementias. *American Journal of Alzheimer's Disease and Other Dementias, 35,* https://doi.org/10.1177/1533317520960874

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care. In R. G. Hughes (Ed.), *Patient safety and quality: An evidence-based handbook for nurses.* (pp. 341–404). National Institutes of Health. https://www.ncbi.nlm.nih.gov/books/NBK2665/

Riffin, C., Van Ness, P. H., Wolff, J. L., & Fried, T. (2017). Family and other unpaid caregivers and older adults with and without dementia and disability. *Journal of the American Geriatrics Society, 65*(8), 1821–1828. https://doi.org/10.1111/jgs.14910

Robinette, J. W., Charles, S. T., & Gruenewald, T. L., (2018). Neighborhood cohesion, neighborhood disorder, and cardiometabolic risk. *Social Science & Medicine 198*, 70–76. https://doi: 10.1016/j.socscimed.2017.12.025

Robinson-Lane, S. & Johnson, F.U. (2023, March 17). Family Caregiver Focus Groups. University of Michigan School of Nursing.

Robinson-Lane, S. G., Zhang, X., Patel, A. (2020). Coping and adaptation to dementia family caregiving: A pilot study. *Geriatric Nursing, 42*(2), 473-479. https://doi: 10.1016/j.gerinurse.2020.08.008

Roohafza, H. R., Afshar, H., Keshteli, A. H., Mohammadi, N., Feizi, A., Taslimi, M., & Adibi, P. (2014). What's the role of perceived social support and coping styles in depression and anxiety? *Journal of Research in Medical Sciences*, *19*(10), 944–949. https://www.semanticscholar.org/paper/What's-the-role-of-perceived-social-support-and-in-Roohafza-Afshar/79dc83e9ae69a5d299ebdb2e0e6ad323c240bfd2

Rosales, J., & Walker, T. (2021, March 20). The racist beginnings of standardized testing. NEA. https://www.nea.org/advocating-for-change/new-from-nea/racist-beginnings-standardized-testing

Roth, A. R. (2020). Informal caregiving and social capital: A social network perspective. Research on Aging, 42(9-10), 272–280. https://doi.org/10.1177/0164027520912659

Sanders, A. E. (2016). Caregiver stress and the patient with dementia. Continuum (Minneapolis, Minn.), 22(2 Dementia), 619–625. https://doi.org/10.1212/CON.0000000000000301

Santos, O. A., Pedraza, O., Lucas, J. A., Duara, R., Greig-Custo, M. T., Hanna Al-Shaikh, F. S., Liesinger, A. M., Bieniek, K. F., Hinkle, K. M., Lesser, E. R., et al. (2019). Ethnoracial differences in Alzheimer's disease from the Florida autopsied multi-ethnic (FLAME) Cohort. *Alzheimer's & Dementia, 15*(5), 635–643. https://doi.org/10.1016/j.jalz.2018.12.013

Sapra, A., Bhandari, P., Sharma, S., Chanpura, T., & Lopp, L. (2020, May 21). Using Generalized Anxiety Disorder-2 (GAD-2) and GAD-7 in a primary care setting. *Cureus, 12*(5). https://doi.org/10.7759/cureus.8224

Shepherd, C., McCann, H., & Halliday, G. M. (2009). Variations in the neuropathology of familial Alzheimer's disease. *Acta Neuropathol 118***,** 37–52. https://doi.org/10.1007/s00401-009-0521-4

Sheppard, V. (2020, April 6). *Research Methods for the Social Sciences: An Introduction.* Pressbooks. https://pressbooks.bccampus.ca/jibcresearchmethods

Siegler, E. L., Lama, S. D., Knight, M. G., Laureano, E., & Reid, M. C. (2015). Community-based supports and services for older adults: A primer for clinicians. *Journal of geriatrics,* 678625. https://doi.org/10.1155/2015/678625

Son, J., Erno, A., Shea, D. G., Femia, E. E., Zarit, S. H., & Parris Stephens, M. A. (2007). The caregiver stress process and health outcomes. *Journal of Aging and Health, 19*(6), 871–887. https://doi.org/10.1177/0898264307308568

Sörensen, S., Duberstein, P., Gill, D., & Pinquart, M. (2006). Dementia care: Mental health effects, intervention strategies, and clinical implications. *The Lancet Neurology, 5*(11), 961–973. https://doi.org/10.1016/s1474-4422(06)70599-3

Sutter, M., Perrin, P. B., Chang, Y. P., Hoyos, G. R., Buraye, J. A., & Arango-Lasprilla, J. C. (2014). Linking family dynamics and the mental health of Colombian dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, *29*(1), 67–75. https://doi.org/10.1177/1533317513505128

USA.gov. (2023, April 6). Get paid as a caregiver for a family member. https://www.usa.gov

Vance, T.A. (2019). Addressing mental health in the Black community. Columbia University Department of Psychiatry. https://www.columbiapsychiatry.org/news/addressing-mental-health-black-community

Van't Leven, N., Prick, A., Groenewoud, J., Roelofs, P., De Lange, J., & Pot, A. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review. *International Psychogeriatrics*, *25*(10), 1581–1603. https://doi:10.1017/S1041610213000860

Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003) Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*, 946–972. http://dx.doi.org/10.1037/0033-2909.129.6.946

Wake Forest University (2020). Black mental health: Statistics, resources, and services for the Black community. https://counseling.online.wfu.edu/blog/black-mental-health-resources

Waligora, K. J., Bahouth, M. N., & Han, H. (2019). The self-care needs and behaviors of dementia informal caregivers: A systematic review. *The Gerontologist*, *59*(5), e565-e583. https://doi.org/10.1093/geront/gny076

Watkins, D. C. (2017). Rapid and Rigorous Qualitative Data Analysis: The "RADaR" technique for applied research. International Journal of Qualitative Methods, 16(1). Https://doi.org/10.1177/1609406917712131

Weijenberg, R. A. F., Lobbezoo, F., Knol, D. L., Tomassen, J., & Scherder, E. J. A. (2013). Increased masticatory activity and quality of life in elderly persons with dementia-a longitudinal matched cluster randomized single-blind multicenter intervention study. *BMC Neurology*, *13*(1), 26. https://doi.org/10.1186/1471-2377-13-26

Weil, A. R., (2022). Racism and health. *Health Affairs, 41*(2), 157–157. https://doi.org/10.1377/hlthaff.2022.00033

Wilson, M. R., Van Houtven, C. H., Stearns, S. C., & Clipp, E. C. (2007). Depression and missed work among informal caregivers of older individuals with dementia. *Journal of Family and Economic Issues, 28*(4), 684–698. https://doi.org/10.1007/s10834-007-9081-8

Whitney, R. L., Bell, J. F., Kilaberia, T. R., Link, B. M., Choula, R. B., Reinhard, S. C., & Young, H. M. (2023). Diverse demands and resources among racially/ethnically diverse caregivers. Ethnicity & Health, DOI: 10.1080/13557858.2023.2179022.

Worley, B. (2012). A Stress process model for anxiety symptom severity: Comparing racial and ethnic minority adults. https://ir.ua.edu/handle/123456789/1444

Xian, M., & Xu, L. (2020). Social support and self-rated health among caregivers of people with dementia: The mediating role of caregiving burden. *Dementia*, *19*(8), 2621–2636. https://doi.org/10.1177/1471301219837464

Young, H. M., Bell, J. F., Whitney, R. L., Ridberg, R. A., Reed, S. C., & Vitaliano, P. P. (2020). Social determinants of health: Underreported heterogeneity in systematic reviews of caregiver interventions. *The Gerontologist*, *60*(Suppl 1), S14–S28. https://doi.org/10.1093/geront/gnz148

Zahed S, Emami M, & Eslami A. (2020). Stress as a challenge in promoting mental health among dementia caregivers. *Journal of Education and Health Promotion. 9*:65. https://doi: 10.4103/jehp.jehp_445_19

Zaheed, A. B., Sharifian, N., Kraal, A. Z., Sol, K., Hence, A., & Zahodne, L. B. (2019, November 27). Unique effects of perceived neighborhood physical disorder and social cohesion on episodic memory and semantic fluency. *Archives of Clinical Neuropsychology*, *34*(8), 1346–1355. https://doi: 10.1093/arclin/acy098 https://doi.org/10.1093/arclin/acy098

Zerbak, K., Campione, J., & Burns, W. (2019, October). Factors associated with the impact of caregiving on employment among informal caregivers. *Issue Brief*. https://www.researchgate.net/publication/337544256