DESKINS, BARBARA POLLARD, Ph.D. African American Male Caregiving for Adult Care Recipients During the COVID-19 Pandemic. (2021)
Directed by Dr. Susan Letvak. 267 pp.

This qualitative descriptive study describes the experiences of 13 African American (AA) men who acted as caregivers to adult chronically ill or debilitated loved ones during the COVID-19 pandemic. The increased prevalence of caregivers for this vulnerable group of AA men will enhance the need for more formal and informal caregiving resources. Due to caregivers' evolving demographic landscape, men have assumed an increased role as family caregivers across the U.S. The experiences of African American male caregivers are lacking in the caregiver literature. Given the study's time, COVID-19 has persisted, exposing the study participants to the pandemic's unprecedented effects.

The Revised Sociocultural Stress and Coping Model (SSCM) guided the study. Interviews using a semi-structured guide facilitated the discourse between the researcher and the participants, which led to the participants addressing the following research questions:

1. How do African American male caregivers describe their decision to become caregivers?
2. How do African American male caregivers perceive their caregiver role?
3. What coping strategies and support systems do African American caregivers use?
4. What has been the impact of the COVID-19 pandemic on the lives of African American male caregivers?

5. What are significant stressors described by African American male caregivers before, during, or after the pandemic?

Findings indicated that the participants saw the caregiver role as positive, highlighting attributes such as honor, commitment, reciprocity, and duty. Adverse effects were exemplified as decreased social interactions, sacrifice, financial burden, and physical and/or emotional impact resulting from the caregiving demands. Mediating factors such as coping styles, support groups, spirituality, and religious beliefs were influenced by AA caregiving men's cultural values and beliefs. Study findings demonstrate a lack of awareness of respite care availability and a lack of social relationships with other men. Additional results include (a) hesitancy in accepting the COVID-19 vaccine, (b) the lack of health care providers' awareness of the caregiver's physical and/or emotional health status, and (c) a lack of disclosure on sexuality and intimacy as a secondary (adverse) consequence of being a male caregiver. Study findings have implications for nursing practice, education, and policy development. Future research needs are also identified.

AFRICAN AMERICAN MALE CAREGIVING FOR ADULT CARE RECIPIENTS DURING THE COVID-19 PANDEMIC

by

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A Dissertation Submitted to
The Faculty of The Graduate School at
The University of North Carolina at Greensboro
in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Greensboro
2021

Approved by

Susan Letvak
Committee Chair

I dedicate this dissertation to my husband, William T. Deskins, my mother, Lula Pollard Burton, my sons, Darrius and Wesley Cooper, my daughters, Aisha Deskins and Shante Boone, my granddaughters, Nyla and Zy'Nyiah Cooper, and my first family, Wanda Pollard-Jones, Martha J. Pollard, and Robert Pollard, Jr.

William, thank you for your unconditional love and support in this academic milestone of personal and professional achievement. Your encouragement, prayers, and words of wisdom have sustained me throughout this journey. You have been a source of hope in times of despair and a guide when the road seemed dim. We have endured many challenges during this journey, but God has kept us strong, committed, and steadfast.

Mama, I know you may never read these words, but I know that you are here in spirit and would be cheering me on as I walk in pride and honor. Your strength has inspired confidence, resilience, and determination within me. Your faith sustains me. I'm reminded of the words in Jeremiah 29:11: "For I know the plans I have for you declares the Lord. Plans to prosper you and not to harm you. Plans to give you hope and a future." For my children and granddaughters, I thank you for giving me space to endure the race. You've answered my desperate calls for help. You've seen me through lost files, Internet issues, empty ink cartridges, and many other challenges. You've been there when holidays, birthdays, and special occasions were scaled back to support the work that has brought me to this place. I hope and pray that what you have seen in this commitment to achieving this degree will inspire and encourage each of you to reach your full potential. To my siblings, nieces, and nephews, the thread that binds us is truly the heartstrings that unite us. We are ONE. We are Pollard-strong!

APPROVAL PAGE

This dissertation, written by BARBARA POLLARD DESKINS, has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

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May 11, 2021
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May 11, 2021
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ACKNOWLEDGMENTS

I want to express my sincere appreciation to my dissertation chair, Dr. Susan Letvak. Your guidance has supported me through the rigorous, challenging, and well-rounded experience in this academic quest to attain this degree. I truly am honored that you said “yes” that you would guide and direct me. You have talked me from the ledge, and you’ve made me laugh. I will never forget SNL!!

A very special “thank you” to a wonderful colleague, mentor, and friend, Dr. Denise Rhew, whose faith-filled strength and wisdom have directed me through this personal and professional accomplishment. To my committee members, Drs. Rowsey, Bedini, and Kennedy-Malone, you’ve educated, inspired, and enhanced my preparedness as I navigated the twists and turns of comprehensive exams to defending this dissertation research. I thank you for your guidance and feedback.

To my outstanding colleagues, you have given me such positive energy, advice, and encouragement. Jenn, I will never forget your support, friendship, and well-wishes. Laurie, I would be remiss if I didn't express how truly honored I am to have had you in my corner—always have the right word to fill in my XXXs. You have been such a mentor, colleague, and exceptional friend and officemate!

For my very dear friends, Brenda and Eva, to describe how much I have missed our near-daily talks would be an understatement! You've given me space to do this work, but I know I was always surrounded by your love, inspiration, and encouragement. You ladies have always been a beacon of light and my north stars. God has blessed me beyond words by having you in my life.

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CHAPTER I

INTRODUCTION

According to the American Association of Retired Persons (AARP) and the National Alliance for Caregiving (NAC) Public Policy Institute's Caregiving in the U.S. 2020 Report (AARP and National Alliance for Caregiving Policy Institute [AARP/NAC], 2020), an estimated 48 million Americans are caregivers to an adult. The nation's older adults, ages 65 and older, is projected to nearly double from 49 million in 2016 to 95 million by 2060 (U.S. Census Bureau, 2020); with the 85 years and older group expected to double from 6.5 million (2020) to 11.8 million (2030) and triple to 19 million by 2060. Further, due to an increased prevalence for caregivers of disabled adults and/or older adults with chronic health conditions, the need for more formal and informal caregiving resources will be required. Therefore, given the projected need for informal care delivery, it is crucial to support the families who will be informal caregivers for these adult care recipients.

As the demographics of the population changed, men have assumed increased roles as family caregivers (Sharma et al., 2016). A range of sociodemographic factors, which include an aging population and smaller family size, has influenced the availability of family caregivers (Accius, 2017). This change is illustrated by an increasing baby boomer population requiring more care, workforce shortages in health care systems, and an increasing number of Americans who are self-identifying as caregivers (AARP/NAC, 2020). These men play a significant part in the league of family caregivers providing care across the country (Accius, 2019). Currently, 40% or 16 million U.S. caregivers are male, with more than 15% African American men (Brooks, 2020). Matthews's (2005) caregiver study of paired adult siblings (as cited in Collins, 2014) regarded the relationship with sons and their older parents as more filial or egalitarian when compared to daughter caregivers. The findings indicated that the son often waited until assistance in daily living was requested of them by their parents. In a different study, researchers reported male caregivers sought advice and requested help with problems in the caregiving process; however, they were less likely to open up to others when they felt stressed or overwhelmed by their caregiving responsibilities (Ianzito, 2017). Clinical experts relate African American men feel too vulnerable to open up and talk about how they feel. Moreover, it was postulated that these men do not seek professional help because they do not feel therapy will work for them (Brooks, 2020). Research on this phenomenon of caregiving has demonstrated a paucity of scholarly inquiry that provides an extensive view of caregiving for African American males. Furthermore, research on African American male caregiver experiences is substantially underrepresented in current empirical research (Collins, 2014; Mott et al., 2019). The emergence of the COVID-19 pandemic has posed significant challenges to global society. The U.S. population, particularly African Americans, are challenged with this crisis's current status and the impact of its rippling effects. The prospect of becoming infected caused significant stress and anxiety within society, especially in view that the availability of a vaccine or a cure was not in sight. African Americans, as a population, already face compounding inequities and detrimental effects as caregivers. The unprecedented effects imposed by the unpredictable lethality and lack of coordinated mitigation of the novel coronavirus have left many communities of color disproportionately susceptible to harm from the pandemic (Artiga et al., 2020; Munn, 2020). Within the caregiving body of literature, identifiable gaps in the role and need for African American male caregivers, especially during a pandemic, is limited. For these caregivers, the relative lack of discourse around self-care and well-being continues to evolve as the impact of COVID-19 takes its toll across racial/ethnic groups.

Background

Introduction to the Problem

The caregiver role, for men, may present new or different challenges than those experienced by women. While men also challenged with the caregiving burden have access to fewer social networks, they underutilize community services that help them cope with this burden (Lopez-Anuarbe & Kohli, 2019). Out of the 16 million male caregivers, nearly half decided to assist their care recipient by choice, and 63% identified as primary caregivers (Lopez-Anuarbe & Kohli, 2019). Within the caregiving body of knowledge, significant gaps in the role and the support needs for African American male caregivers exist. During the current pandemic, as the immense challenges for adults and their caregivers continue to develop, health care professionals, administrators, and legislators are faced with the enduring difficulties of COVID-19 while learning how to better prepare for future public health issues (Young & Fick, 2020).

Supply and Demand Issues for Caregivers

Decreasing fertility rates and increasing longevity with chronic illness and disability (Feinberg & Spillman, 2019; Health Services Research, 2018) are demographic trends that change population structures and life courses. An aging baby-boomer generation contributes to increased population rates (Feinberg & Spillman, 2019; Russell, 2007). Currently, the 65 and older population represent 14.5% of the total U.S. population, up from 12% in 2000 (Goldman, 2017). These population trends drive the demand for older adult care as people live with chronic illnesses, such as Alzheimer’s disease, which could more than double by 2050 to 13.8 million, from 5.8 million today, and more family caregivers will be needed (Alzheimer’s Association, 2019). Other factors that have led to the demand for more caregivers and caregivers’ availability include delayed marriages and high divorce rates among people ages 50 and older (Feinberg & Spillman, 2019). Additional factors include an evolving family structure with more women in the labor force and unaffordable long-term care insurance (Health Services Research, 2018). Women, traditionally the primary caregivers for aging adults, are now managing careers, balancing family and work, and caregiving.

Adverse Effects of Male Caregiving

Being a male family caregiver to a spouse, parent, grandparent, or family kin can be adversely challenging. The high demands of the role can stretch caregiving’s endurance to a point where the caregiver suffers adverse physical effects. These effects are demonstrated as physical, psychosocial, psychological or emotional, and financial impacts on the caregiver and family (Schulz & Eden, 2016). These effects lead male caregivers to experience caregiver burden and self-esteem issues. Caregiver burden is a significant predictor of anxiety and depression. In general, African American men exhibited the highest mortality rate and the worse health profile than other racial/ethnic groups (Hudson et al., 2016; Thorpe & Whitfield, 2018). Culturally, traditional masculinity beliefs of being weak and vulnerable restrict African American men from seeking help for physical and emotional health problems (Rivera & Scholar, 2019). This group's health status is often associated with socioeconomic influences (i.e., structural racism) that influence racial and ethnic minorities' ability to achieve power at a system level (Hudson et al., 2016). The multi-dimensional and complex caregiving role, combined with other psychosocial and physiological factors facing African American men, are critical determinants of health and health behaviors. Yet, research within the phenomenon of caring from the African American male caregivers is underrepresented (Thorpe & Whitfield, 2018), and male caregivers in general (McDonnell & Ryan, 2014; Robinson et al., 2014), which may lead to the production of stereotypical portrayals of how men and women act and react in the context of severe illness (Solli et al., 2018).

Economic Impact of Caregiving

The caregiver literature is replete with the economic challenges related to caregiving activities. Family caregivers increasingly take on the complex care needs of care recipients at home and pay for services to help the person with care needs due to the shift in community-based settings. Besides the reported adverse health effects of caregiving, caring for others has negative financial implications (Hoffman & Wallace, 2018). For example, informal caregivers are at risk of decreased employment opportunities and benefits, lost wages, or out-of-pocket expenses involving care recipients’ needs (Schulz & Eden, 2016). The estimated value of informal care varies substantially. The unpaid care of older adults in 2015 was valued at $552 billion for older adults (Chari et al., 2015), up from an estimated $470 billion in 2013 (Beydoun et al., 2019); and cited by others as $375 billion in 2007 and $450 billion in 2009 (AARP, 2016; Chari et al., 2015; Wohlgemuth et al., 2015). Moreover, these estimates disregard the potential social costs of family care provision, including the possible negative impact on the labor force participation, hours of work, and family caregivers’ productivity and caregiving-related physical and mental strain (Mudrazija & Johnson, 2020). On average, caregivers spend 23.7 hours per week providing care; with a median of 10 hours (AARP/NAC, 2020), African Americans reported 31.2 hours. Within lower-income households (less than $50,000 annual), families have reported increased co-residing with the care recipient. Across all groups, regardless of income, caregivers have reported an increase in co-residency since 2015 (AARP/NAC, 2020). Moreover, family caregivers’ economic impact shows that approximately 30% of dual caregivers spend at least $3,000 each month caring for an aging family member; 34% spend between $1,000 and $2,999, while 35% spend less than $1,000 (Roy, 2020). Also, families spent $7,000 annually to cover out-of-pocket expenses (Feinberg & Spillman, 2019; Roy, 2020).

Support Services

A primary concern for family caregivers is the lack of adequate or affordable services and supports (AARP/NAC, 2020). Illness-specific education and skills training, support groups, and guidance with navigating the health care system are effective intervention strategies. Research suggests that navigating the care system by caregivers and care recipients creates difficulties based on fragmented and intricate processes that lead to frustration, stress, and extreme costs (Schulz & Eden, 2016). The existing gap in paid services imposes pressures on programs, such as Medicaid, that support older adults. Of note, national legislation, such as The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, has been enacted since 2018 to assist in coordinating family caregiving strategies (RAISE ACT, 2017).

Caregiving During COVID-19 Pandemic

As stated by the World Health Organization (WHO), the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is responsible for the disease COVID-19, the novel (new) coronavirus disease 2019 (WHO, 2020a). This global pandemic originated in Wuhan, China (Horesh & Brown, 2020; Kang & Xu, 2020) in December 2019, when an increased incidence of mild to severe respiratory illness symptoms in localized areas in China was seen. The coronavirus is a large species of viruses common in people and many kinds of animals, including camels, cattle, cats, and bats (Young & Fick, 2020). Details of the epidemiology, transmission, and risk factors for infection and death have been reported extensively from the WHO and the Centers for Disease Control and Prevention (CDC), reliable global health information sources, and international and national mass communication sources.

At the time of this writing, May 2, 2021, there have been over 150 million confirmed cases of COVID-19 globally, with an estimated 3.173 million deaths (WHO, 2021). Simultaneously, in the U.S. alone, COVID-19 has shattered families, distressed businesses, and communities, leaving thousands of Americans grieving the loss of life for loved ones. Moreover, the complete clinical picture and overall impact of COVID-19 is not fully known, with over 32 million confirmed cases and a death total reported as 573,000 Americans (CDC, 2021a). Although there are no effective vaccines or drugs for COVID-19 (Dotters-Katz & Hughes, 2020; Wiersinga et al., 2020), several drug agents are being explored in randomized controlled trials to examine the efficacy and safety of these medications (Kang & Xu, 2020).

Adverse Effects of COVID-19 on High-Risk Groups

Older adults and people with serious underlying medical conditions are at higher risk for severe illness from COVID-19 and incur increased mortality with advanced age (CDC, 2021b; Dotters-Katz & Hughes, 2020). Because there is little to no pre-existing immunity against the COVID-19 virus, it has spread worldwide and is considered a global pandemic. During the acute phases of the pandemic, eight out of ten deaths associated with COVID-19 in the U.S. have been among adults aged 65 and older (CDC, 2021b). Family caregivers, particularly during a crisis, may experience more stress due to increased workloads, fatigue, fear, stigma, increased financial expenses, and social isolation (CDC, 2019b). Moreover, the prevailing global and national death rates and fear of contracting the virus have led to social isolation in confined housing, increasing the risks for depression and anxiety, domestic violence, and elder abuse (Young & Fick, 2020).

The COVID-19 pandemic has disproportionately impacted African Americans. Compared to non-Hispanic White individuals, African Americans account for a higher death rate (Gupta & Kakkar, 2020; Yancy, 2020), with the disparity highest in southern states (Gupta & Kakkar, 2020). In every state with racial data available, African Americans have higher contraction rates and higher death rates of COVID-19. For example, in North Carolina, 38% of positive COVID-19 diagnoses have occurred among African American persons, representing 22% of the state’s population (Munn, 2020). In Louisiana, 70% of COVID-19 related deaths have occurred among African American individuals representing 32% of the population (Thebault et al., 2020). For comparison, the northern states of Michigan and Illinois data showed 35% and 30%, respectively, for COVID-19 positive cases, with African Americans representing 15% and 16% of the states’ population (Ray, 2020). The Johns Hopkins University and American Community Survey indicate that in April 2020, of 131 predominantly Black counties in the U.S., the infection rate for COVID-19 was 137.5/100 000, with a death rate estimated at 6.3/100 000 (Thebault et al., 2020). Numerous reasons contributing to this increased vulnerability have been reported. There has been limited data from cities and states that reported racial and ethnic data for COVID-19. The following points of concern describe significant disproportionate conditions that impact African American communities during the pandemic.

Essential Workers

African Americans are exposed to an increased vulnerability related to service sectors such as education, the health services industry, or retail-related employment. Because these forms of employment are considered ‘critical’ or ‘essential’ requirements in the workforce, employees were expected to continue to work during the pandemic

(Munn, 2020). Also, for urban African Americans, public transit services during a pandemic present an increased risk for exposure to infected people (Gupta & Kakkar, 2020; Ray, 2020).

Pre-existing Comorbidities

Due to the heightened risk of severe health problems, such as hypertension, diabetes, or heart disease, African Americans are predisposed to becoming severely ill with COVID-19 (Gupta & Kakkar, 2020; Ray, 2020; Thebault et al., 2020). Unfortunately, these adverse risk infirmities have emerged as the most common underlying risk factors contributing to death from COVID-19 (Munn, 2020).

Isolation from Health Care Providers

Inequities in healthcare access, such as discrimination, distrust of medical professionals, and access to healthcare services (Epps, Skemp, et al., 2016) create gaps in the preventive care and manageability of chronic illness for caregivers (CDC, 2020b; Connley, 2020). Factors cited for these health inequities have been attributed to (a) structural racism, which leaves African Americans vulnerable and marginalized (Connley, 2020), and (b) unemployment, lack of insurance, and limited health system capacity or investment (Artiga et al., 2020).

In response to the effects of racial disparities during the COVID-19 pandemic, the American Hospital Association (AHA; AHA, 2020) issued a statement that acknowledged the racial disparities in the incidence and prevalence of chronic conditions, such as diabetes, asthma, and hypertension—conditions that are believed to aggravate the symptoms of COVID-19. The Association also recognized that “other factors, including but not limited to the social determinants of health, bias, and historical mistrust of America’s healthcare system, may be contributing to higher rates of infection and death in communities of color” (AHA, 2020, para. 3).

Another significant finding regarding COVID-19 and gender data report outcomes that men seem more likely than women to die from the pandemic (Ray, 2020). Although women are employed in more service-related jobs and are more likely to do the caregiving in their household, little is known about the significance of COVID-19 and African American male caregiving. However, minimal findings have been cited about the pandemic and minority caregivers through enduring research on family caregivers and COVID-related effects. Notably, in a study conducted by the University of Pittsburgh (University of Pittsburgh, 2020), minority caregivers reported worse physical and mental health of care recipients, more food insecurity, and negative financial impacts. Moreover, less-educated caregivers reported concerns regarding the inability to afford COVID-19 testing, worsening physical and emotional health, and less able to protect the health of household members. Finally, in this same study, caregivers who co-reside with care recipients reported more social isolation and fatigue, in addition to the findings mentioned above (University of Pittsburgh, 2020).

Significance of the Study

As the elderly population becomes more diverse, more than 50% of Americans will be estimated to identify as members of a minority group by 2044 (Colby & Ortman, 2015). This projection makes it imperative to address the lack of empirical research that focuses precisely on African American male caregivers. In the U.S., men represent 40%

(some sources put the figure close to 45%) of all family caregivers (Accius, 2017; Ianzito, 2017). Research on men’s role as caregivers emerged in the mid-1980s and has demonstrated gradual change as men’s instrumental and personal caregiving contributions became more perceptible. However, empirical studies on African American male caregivers remain vastly underreported (Collins, 2014; Lopez-Anuarbe & Kohli, 2019; Mott et al., 2019), and their experiences have been marginalized and diminished in importance (Kramer, 2002, as cited in Russell, 2007). Despite the fundamental role of family caregivers in the care of older adults with chronic illnesses and dependent, complex care needs, they are often marginalized in delivering health care and public policy (Schulz & Eden, 2016). Dilworth-Anderson et al. (2007) reported issues concerning marginalization and stigma due to some forms of chronic health conditions, such as mental illness. Their findings demonstrated a knowledge deficit in African American churches regarding support for caregivers of older adults with chronic health conditions. One account for the dearth of published male caregiver studies is the methodological challenges and small sample sizes, limiting the findings’ generalizability (Accius, 2017). While studies have cited the dearth of research on male caregivers, reports have also described an averseness for African American male caregivers to self-identify their caregiver roles. According to one AARP report, a general perception exists among male carers about the caregiver role. Specifically, as reported by Brooks (2020), one caregiver support group facilitator indicated African American men were described as ‘uncomfortable’ being caregivers because of a perception that Black men do not serve as caregivers, and people see them as ‘unusual’ as caregivers. It was further cited that an

African American male caregiver was seen as “a brother that slides in and pays the bills and slides back out” (Rita Choula, as cited in Brooks, 2020, “Perception vs. Reality,” para. 1). The caregiver “label” for some male caregivers is seen as a stoic approach to caregiving, leading to their resistance to identify as carers (Fee et al., 2020; Milligan & Morbey, 2016).

This current study will add to the existing literature on male caregivers, specifically African American male caregivers, and their role as carers of debilitated, chronically ill family members in numerous ways. First, traditionally, most of the caregiver research has focused on female caregiving experiences, with male caregivers mainly included as a contrast group to show the additional challenges women face, thereby neglecting men’s unique experience as carers. Their underrepresentation or omission in empirical studies or the obscured results within-group variation (i.e., husbands versus sons) revealed unclear findings (Collins, 2014; Mott et al., 2019). This study will contribute to family caregiving by focusing specifically on male caregivers.

Second, this study will add to male caregivers’ research by exploring African American male caregivers’ unique contributions as the primary phenomenon of study, emphasizing race and gender. Third, based on reported gaps in methodological issues from prior male caregiver research, such as (a) low male samples (small sample sizes); (b) underrepresentation of African American men sampled; and (c) gender analysis limitations (Houde, 2002), this study will seek to address those issues. The current study will include only a representative sample of self-identified African American male caregivers.

The fourth gap addresses ethnicity and culture. This knowledge gap is based on B. G. Knight and Sayegh’s (2010) revision to the Sociocultural Stress and Coping Model (SCCM) highlighting the need for caregiver interventions sensitive to ethnicity and cultural differences in specific groups of caregivers. Specifically, the SSCM examines caregiving’s cultural context by adding a direct measure of cultural values and providing a framework to interpret traditional stress process variables through a cultural lens as proposed to inform this study. This study contributes to understanding the stress and coping process among African American male caregivers by exploring cultural values (i.e., familism, beliefs, and norms).

Fifth, to contribute to clinicians’ safety and competence within various healthcare environments and the communities in which these families reside, assessment processes and interventions need to be individually tailored to meet the caregiver’s unique needs. Engaging in prospective cohort African American male caregiver studies will inform clinicians and providers of cultural competence practices and intervention strategies tailored to this diverse population’s needs. Furthermore, regarding implications for practice, and enhanced awareness of African American family caregiving and intergenerational and multi-generational support systems will contribute to cultural-sensitive interventions and treatment options.

Finally, the effects of the novel COVID-19 offer a unique opportunity to explore African American male caregiving experiences during a global pandemic. The COVID-19 pandemic has instigated a public health crisis, exposing the susceptibility of the U.S.’s public health, education, economic, and family systems (Rollins, 2020). Furthermore, the pandemic effects on racial and ethnic minority groups' health are still evolving; however, the most recent data suggest a disproportionate burden of illness and death among these groups (CDC, 2020b). Presently, 33% of hospitalized patients diagnosed with COVID-19, to date, have been African American, yet only 13% of the U.S. population is African American (Aubrey, 2020; Aubrey & Neel, 2020). During public health crises, severe illness and death rates tend to be higher for racial and ethnic minority groups (Nania, 2020) and affect the poor and marginalized the worst, reinforcing the links between poverty, chronic medical conditions (Hayter, 2015), and social factors (Nania, 2020). Due to African Americans' pre-existing health issues such as diabetes, heart disease, and lung disease, this population has increased morbidity and mortality risk factors associated with COVID-19 (CDC, 2020b; Moore et al., 2020). The adverse effects of COVID-19 can leave deep psychological trauma on many individuals (Horesh & Brown, 2020) and create mental health effects, such as stress and anxiety. Likewise, the risk of social stigma as a response to disease is not a new occurrence during a societal crisis, such as a pandemic (Buseh et al., 2015). In health, social stigma is the negative relationship between an individual or group of people who share certain characteristics and a specific disease (WHO, 2020a). When global or national pandemic crises occur, affected individuals are likely to become labeled, stereotyped, discriminated against, treated separately, and/or experience loss of status because of a perceived link with a disease (Turner-Musa et al., 2020; WHO, 2020b). Other factors related to caregiving during the COVID-19 pandemic stem from social distancing, isolation, or quarantine. Finally, supportive services, formal and informal, are projected to be compromised during the crisis.

Statement of the Problem

Caring for ill or disabled family members can pose challenges to families (Beydoun et al., 2019), healthcare services, providers, and policymakers. Due to the projected population growth rates for older adults and the increase in multiple comorbidities and chronic illnesses in the African American community, a significant concern is how family caregivers can be better prepared and equipped to endure the caregiver role and manage their self-care. A significant knowledge gap exists in understanding African American caregivers' experiences, specifically male carers, who remain "hidden" and underrepresented in the caregiver literature. A closer examination into their caregiving experiences' narratives is warranted to narrow the lack of knowledge in male caregiving and the contributions and challenges of caregiving that African American male caregivers face. Furthermore, given the unprecedented impact of being a caregiver during a global pandemic, compounded with the common caregiver response to burden and stress, the assumption that additional adverse effects will take an adverse toll on this caregiver group is a reality, as currently reported in the national statistics.

Purpose of the Study

The purpose of the study was twofold. The first aim was to describe the experiences of African American male caregivers who are (or were) the primary family caregiver to a dependent, chronically ill family member and explore how caregiving affected their health-related quality of life using the Revised Sociocultural Stress and

Coping Model (SSCM) to guide the study. A second aim was to understand the psychological, physiological, psychosocial, and financial outcomes on the health and well-being of African American male caregivers related to their caregiving experience during a COVID-19 pandemic.

Research Questions

The research questions developed to guide this study were informed by an extensive review of the literature on caregiving's general aspects, with a purposive focus on African American male caregiving for a dependent loved one with a chronic, debilitating illness. According to Dilworth-Anderson et al. (2002), more attention needs to be given to the cultural relevance and sensitivity of the study's instruments regarding data collection for diverse samples. Moreover, the researcher provided specific inquiries, such as "Do the questions reflect the group's lives and experiences under investigation"? and "Do the questions capture the cultural nuances, often the unspoken words and meanings of a group, to know that the appropriate question has been asked"? (Dilworth-Anderson et al., 2002). The current study, using this frame of thought, sought to answer the following research questions to gain a more comprehensive understanding of the caregiving experiences from African American male caregivers' perspectives.

Research Questions and Study Purpose/Aims

Aim 1

To describe the experiences of African American male caregivers who are (or were) the primary family caregiver to a dependent, chronically ill family member and explore how caregiving affected their health-related quality of life using the Revised Sociocultural Stress and Coping Model (SSCM) to guide the study.

RQ1: How do African American male caregivers describe their decision to become caregivers?

RQ2: How do African American male caregivers perceive their caregiver role?

RQ3: What coping strategies and support systems do African American caregivers use?

The first question, “How do African American male caregivers describe their decision to become caregivers?” reflected the background and contextual factors of the conceptual framework. In this research study, the background and contextual factors encompassed specific variables within the care recipient construct and the caregiver characteristics. For example, under the care recipient construct, the type of chronic illness was not delineated. Likewise, specific caregiver characteristics provided descriptive content and developed the background context of the model. In a study conducted by Grigorovich et al. (2016), male caregivers stated that they ‘actively’ chose the caregiver role and felt that they were best suited to it. This response was reported based on their educational and professional training and occupational history in white-collar workplaces (i.e., managerial, professional, or administrative).

The second research question, “How do African American male caregivers perceive their caregiver role?” explored the caregivers’ appraisal of caregiving’s role strain, leading to stress. These serve as mediators encompassed within the conceptual model that caregivers use to buffer, manage, or prevent stress.

The third research question, “What coping strategies and support systems do African American caregivers use?” emphasizes the concepts of coping and support systems. This question addressed the conceptual framework’s mediator and moderator variables (Geiger et al., 2015). Within the SPM framework, understanding the potential stress-buffering or moderating effects of psychosocial coping resources is essential for understanding factors that contribute to adverse outcomes in African American men (Gayman et al., 2018). Pharr et al.’s (2014) qualitative caregiver study using the SSCM to explore the caregiving experiences of various ethnic groups included two of the following research questions in their study: (a) “What are the common stresses in giving care to your elder?” and (b) “How do you cope?”

Aim 2

To understand the psychological, physiological, psychosocial, and financial outcomes on the health and well-being of African American male caregivers related to their caregiving experience during a COVID-19 pandemic.

> RQ4: “What has been the impact of the COVID-19 pandemic on the lives of African American male caregivers?”
>
> RQ5: “What are significant stressors described by African American male caregivers before, during, or after the pandemic?”

The fourth and fifth questions explored the outcomes variables of the conceptual model. This includes the positive or adverse effects perceived by the caregiver. It also includes the specific adverse physiological and psychological effects (i.e., stress/strain) on the caregiver’s health and well-being and the positive/gains on their health outcomes related to the caregiving experience. Overall, the body of evidence on adverse effects far exceeded that of positive effects, as researchers have sought to assess caregiving's public health implications and identify vulnerable at-risk caregivers (Schulz & Eden, 2016). According to Schulz et al. (2020), caregivers are potentially at increased risk for adverse effects on their well-being in virtually every aspect of their lives, including their health and quality of life to their relationships and economic security.

Conceptual Framework

The theoretical or conceptual framework is the structure that can support a theory of a research study. Stress and coping models are the most comprehensive sources of frameworks to guide caregiver studies. The framework introduces and describes the theory and illustrates the research problem. Furthermore, the framework describes the concepts or constructs relevant to the phenomenon of interest in the research study and how the study findings relate to the broader knowledge fields (Walker & Avant, 2011). The conceptual model used to guide this study was based on The Revised Sociocultural Stress and Coping Model (R-SSCM) (See Figure 1).

Evidence of the conceptual framework to guide the current study is drawn from the historical and current literature on The Sociocultural Stress and Coping Model (Aranda & Knight, 1997; B. G. Knight & Sayegh, 2010; Lazarus & Folkman, 1984; Pearlin et al., 1990) as well as the current literature surrounding the novel COVID-19 pandemic (CDC, 2020a; Dotters-Katz & Hughes, 2020; Gupta & Kakkar, 2020; Munn, 2020; Ray, 2020; Thebault et al., 2020) (see Figure 2).

Figure 1

B. G. Knight and Sayegh's (2010) Revised Sociocultural Stress and Coping Model for Caregivers

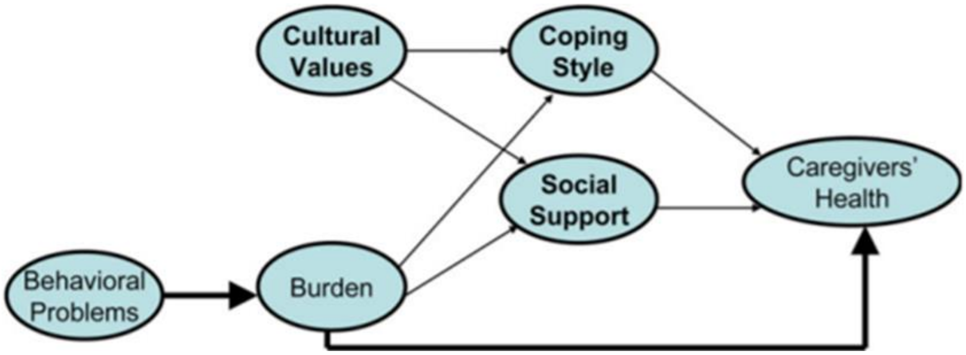
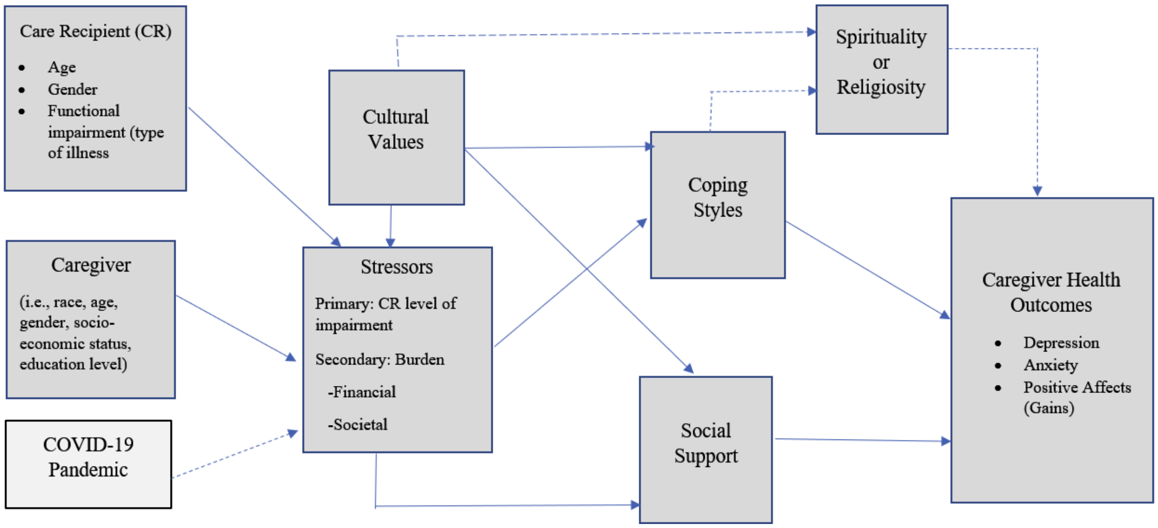


Figure 2

Revised Sociocultural Stress and Coping Model (R-SSCM) Framework for the Current Study



Note. Dashed lines represent new relationships that have been explored in the current paper. Adapted from the original B. G. Knight and Sayegh (2010) SSCM.

Revised Sociocultural Stress and Coping Model (R-SSCM)

As Walker and Avant (2011) have pointed out, the study of caregiving across different ethnic and cultural groups has evolved. Prior studies have included stress and coping models that comprised the following categories of variables: (a) context variables (i.e., gender, age, caregiver's health, caregiver/care recipient relationship); (b) demands on the caregiver, including care recipient behavior problems and functional disability; (c) the caregiver's appraisal of demands as stressful or satisfying; (d) the potential mediators between appraisal and outcomes (i.e., coping styles and social support, and (e) the consequences of caregiving demands, such as emotional distress and health outcomes (B. G. Knight et al., 2000). The SSCM for culturally diverse family caregivers was proposed by Aranda and Knight (1997) to integrate cultural values' influence on the stress and coping process among family caregivers. The conceptual framework supported a common core model that has been consistent across ethnic groups (Losada-Baltar, 2015) and linked care recipients' behavior problems and functional impairments to caregivers' burden appraisals and health outcomes. B. G. Knight and Sayegh (2010) adapted the model, which expounded on the cultural focus group-specific and asserted that cultural values varied by locality, ethnicity, and attitudes about familial obligations. Further, the Revised SCCM suggested that caregiving was seen as a life stressor, leading to adverse outcomes. However, according to the researchers, depending on how a caregiver appraises the caregiving context, the outcome could also be positive; and the caregiver's culture may have played an essential role in how caregivers interpreted their experiences (Richardson et al., 2019; Tang, 2011). Hence, based on the model, Sun

(2014) reported that caregivers appraised their caregiving situations and chose their coping strategies through a “cultural lens.”

The Current Study

As noted previously, the current study’s primary purpose was to apply the *Revised Sociocultural Stress and Coping Model (SSCM)* as a framework for understanding the caregiving experiences of African American male caregivers. A novel addition to the Revised SSCM is the incorporation of COVID-19 as a contextual/background factor and positive aspects of care as a health outcome. During epidemics and/or pandemics, the caregiving role as formal or informal caregivers is not a new phenomenon in the caregiver literature. However, the devastating impacts of the virus, particularly in African American communities, demonstrate adverse effects in the caregiver and care recipient dyads. Given the novelty and magnitude of this pandemic, gaining insight into how serving as a male caregiver during this critical period in global history will support future studies in the areas of burden, coping, and health outcomes. Additionally, by exploring the positive effects of caregiving, along with the commonly explored adverse outcomes, within the conceptual framework, can explain how background factors and mediators/ moderators (i.e., culture, coping strategies, stress (burden), social support, religiosity/spirituality) can potentially influence both aspects of the caregiving experience (see Figure 2).

Definitions

African American Male Caregivers

In various studies, the terms “Black” and “African American” have been used interchangeably. Both terms represent individuals within the U.S. whose familial lineage includes African diaspora members. However, in the present study, “Black male” was associated with African American descendants within the boundaries of the U.S. self-identified men and not immigrants from other ethnic groups (i.e., Caribbean, African, or Central and South American nations). For this study, an African American male caregiver was a son, step-son, adopted son, grandson, father, brother, son-in-law, uncle, male spouse, or partner who is a paid or unpaid carer to an adult chronically ill debilitated family member.

Caregiver

According to the CDC (2019a), caregivers are unpaid (informal) family members or friends or paid (formal caregivers). Pearlin et al. (1990) defined a caregiver as someone who demonstrates caregiving as the “behavioral expression of (one’s) commitment to the welfare of another person” (p. 583). In the current study, a caregiver was a self-identified male carer for a dependent, disabled family member.

Care Recipient

An individual with a chronic medical illness, who requires assistance with activities of daily living (ADLs) and is in a relationship with a caregiver, such as a physician, nurse, friend, or family member, who provides treatment, assistance, or comfort (AARP/NAC, 2020). In this study, the care recipient was the receiver of unpaid services and care from a primary family caregiver, the male caregiver.

Coronavirus (COVID-19)

A novel (new) coronavirus strain caused by SARS-COV2 is a severe acute respiratory syndrome that is potentially fatal and has not been previously identified in humans. The disease can spread from person to person during coughs or exhales via small droplets from the nose or mouth (Gupta & Kakkar, 2020).

Culture

Dilworth-Anderson et al. (2002) describe culture as a way of life shared by members of a population group, includes values that give meaning to experience. For the current study, cultural socialization in the African American community was related to "the beliefs and attitudes about caring for dependent family members that encourage developing coping strategies (resources) to deal with stressors in the caregiving situation" (Dilworth-Anderson et al., 2004).

Informal Caregiver

A non-healthcare professional is usually composed of family members, relatives, friends, neighbors, and/or community and does not receive pay to perform caregiving tasks (Beydoun et al., 2019).

Male Caregiver

A self-identified, male-gendered person who provides care (activities and experiences that involve help and assistance) to a dependent, chronically ill adult care recipient who is unable to provide for oneself.

Assumptions

Theoretical

Using an inductive approach, the researcher sought to understand the data collected from the study participants. Likewise, the researcher offers a philosophical assumption that the conceptual framework, the Revised SCCM, guided the researcher in understanding the male caregiver experiences within the various domains of the model. This means that the researcher supposes that the caregivers' responses and narratives will fall into one of the model's domains. Furthermore, the concepts or constructs will follow a pathway leading to the caregivers' health outcome.

Ontological

Ontology is concerned with what is true or real or the nature of reality. The researcher assumed that the study participants' objective and subjective narratives are their 'truths' and 'sense of 'reality' in their caregiving experiences.

Epistemological

The study's epistemological approach is to acquire knowledge and truth and understand the male caring phenomenon better. The researcher observed and heard what the caregivers had to say about their experience (s) and realities. This approach is vital in qualitative research.

Methodological

This study explored African American males' experiences caring for those who are debilitated, chronically ill, and dependent on the care delivered by caregivers. This study's assumptions are the identification of recurring themes that will present the commonalities and differences in the experiences among the study participants. It is also assumed that the individual experiences are unique and that generalized findings are specific to this study.

Credibility

The researcher maintains the assumption that the caregivers were honest and forthcoming regarding their caregiving experiences.

Summary

The study aimed to better understand African American men's experiences of caregiving to a dependent, chronically ill family member and how the role affected their health-related quality of life. Given that this research is occurring during a global pandemic, a second aim was to comprehend psychological, physiological, psychosocial, and/or financial outcomes(s) that impacted the health and well-being of these carers to their caregiving experience during the COVID-19 pandemic.

The findings from this research can inform healthcare professionals about the unique needs of African American male caregivers. Aside from societal views of most caregivers' 'typical' caregiving experiences, African American male caregivers are increasing in numbers, and their roles as caregivers are evolving. Their actual and perceived health effects are also becoming more alarming on multiple levels. As these caregivers embrace the nuances, innovative technology, and up-to-date science that supports their ability to remain in the role, it is imperative that gender, racial, and ethnic research proliferate. The individual and shared narratives attained from study participants will provide specific contextual background information for healthcare providers and future researchers to develop and incorporate strategies and interventions to support these male cohort groups. It is further alleged that this study's results will inspire and strengthen the caregiver/care recipient relationship and improve or maintain the care recipient's well-being and the provider of informal care. This study can serve as a platform for male caregivers, specifically African American male caregivers, to lift the blinders that hinder their contributions to nursing science, clinical practice, caregiver, and gender research that has lagged in under-representation shadows or not acknowledged in the caregiving literature.

CHAPTER II

LITERATURE REVIEW

Introduction

The purpose of this review of the literature was to synthesize what is known about male caregiving groups and identify gaps in knowledge regarding African American male caregivers. This review of the literature is separated into four sections. The first section describes the search strategy used to retrieve relevant peer-reviewed studies and inform the researcher on the most current state-of-the-science on family caregiving, specifically for male caregivers. The following section provides a synthesis of the caregiving literature on family caregiving (caregivers), African American caregiving, and African American male caregivers. The third section illustrates how the conceptual framework guided the current study was informed by the review of the literature on African American male caregivers. The last section provides the conclusion for the chapter.

Inclusion Criteria

English-language peer-reviewed and scholarly publications that used a qualitative, quantitative, or mixed methods research design were included in this review. The search criteria also included pertinent studies on male caregivers from non-U.S. countries. The focus area included male caregivers (unpaid or informal) to a dependent chronically ill care recipient. The care recipient may be dependent for various reasons; therefore, a specific illness type is not demarcated in this literature review. In this research literature review, particular attention was given to race, ethnicity, and/or culture. The articles included for review examined single racial (i.e., African American) or mixed ethnic group studies (i.e., African American AND non-Hispanic White or Hispanic). Additionally, articles that reported empirical study results of mixed racial/ethnic or mixed-gender participants were only included if the findings were specific to the African American population or African American male caregivers. Electronic books (E-books) and ProQuest dissertation studies relevant to the study's phenomenon are also included in this review. Seminal studies in the caregiving literature that provided a historical perspective to male caregiving or specific to African American male caregivers were also included in this review (i.e., Dilworth-Anderson et al., 2007; Dilworth-Anderson et al., 2005; Dilworth-Anderson et al., 2004; Dilworth-Anderson et al., 2002; Houde, 2002).

Exclusion Criteria

Articles that dealt with the caregiving of institutionalized family members were excluded. Additionally, articles that discussed professional male caregivers as the sample population was excluded.

Search Strategy

The literature review and search strategy included a comprehensive electronic database search for peer-reviewed publications of the most current state of the science on caregiving and male caregiving, specifically, African American male caregivers. Additionally, a manual search of relevant reference lists was reviewed, and related publications were selected for inclusion in this review. Citations in published articles on the phenomenon of the study were cross-checked for references. The addition of a broad range of publication dates was used to conduct this study based on the limited availability of discreet information on this phenomenon of interest—African American male caregivers. The initial search request was set at 5 years; however, the search was expanded to include a broader range of dates due to a lack of sufficient retrievals. The majority of included reviews (*n* = 31) of the 36 studies ranged from 2010 to 2020. Given the limited number of peer-reviewed publications, the geography filter included countries beyond the U. S. The electronic database search included CINAHL, Elsevier, Google Scholar, Scopus, PsycInfo, ProQuest, SocINDEX, and PubMed. Database-specific controlled (i.e., MeSH terms) vocabulary related to broad caregiving search terms were used. These terms included "male caregiver" or "male caregiving" and included "male spouse" or "partner." The search terms for "African American" included "Black Americans" or "Blacks." Other search terms included "African American male caregivers" or "Black male caregivers" or "eldercare" or "older adults" AND "male caregiving" or "caregiver" or "caregiving" or "carer" AND "men" or "male spousal caregivers" or "male partner caregivers." The term "family caregivers" included the terms "informal caregivers" or "relatives or family" or "family members or "carers" or "caregivers." Using terms such as "eldercare" or "elderly care" AND "African American" or "Black or minority" led to many off-topic results. Adding the Boolean phrase "MM caregivers" AND "MW blacks" AND "MW male NOT child" AND "MW family" AND (sex or gender) offered several more relevant publications.

The combined initial search from different databases yielded over 3200 publications that included off-topic abstracts, periodicals, book citations, or did not meet search criteria. Narrowing the search terminology, a second round of the search yielded 175 publications for abstract and title review. Thirty-seven publications were excluded based on care recipient-focused, male caregivers of children or did not meet study criteria. A manual search from reference lists added 63 articles for screening, leading to a total of 201 articles for abstract review. The final number of peer-reviewed articles, books, and dissertations used in this literature review yielded 36 studies for synthesis. The unpublished dissertation studies (*n* = 8) were male-focused, with four specific to African American male caregivers. Two of the peer-reviewed, scholarly publications focused specifically on African American male caregivers and the one book source that reflected the care to a dependent, chronically ill family member with varied illness types.

Organization of the Research Literature

This review of the literature is divided into five sections. The first section describes the literature synthesis followed by what is known about caregiving from the literature (caregiving, African American caregiving, and male caregiving). The following section details the gaps, while section three discusses how this dissertation study can add to the existing body of knowledge on caregiver research by addressing these gaps. Section four discusses the implications for nurse scientists and clinical practice, while the final section concludes the chapter.

Synthesis of the Literature

This synthesis of the literature included 36 sources that spanned from 2007 to 2019. The researcher used landmark publications (Dilworth-Anderson et al., 2007; Dilworth-Anderson et al., 2004) and Houde (2002) to support content relevance and historical perspectives. The researcher also included another highly cited publication (Weinland, 2009) based on the significance of content and the repeated references as an expert in this field of scholarly research. Two unique perspectives of male caregiving are described from (a) the narratives of the care recipient, elderly mothers (Collins, 2014), and (b) the care recipients' views of how caregiving is personified by their caregivers (Pierval et al., 2019).

This review of the literature highlights the ongoing social trend for men to fill the gaps as caregivers to disable, dependent family members. This synthesis also supports the need to study the experiences of African American male caregivers separately and differently. By identifying race and gender-specific needs through a scholarly research approach, an awareness of current gaps, interventions, and strategies can be developed and recommended to promote caregiving efforts while offering self-efficacy recommendations to protect their health.

A review of the articles included in this review revealed a specific trend in the most common medical diagnosis that caused the need for dependent care—dementia/Alzheimer's disease (12). Other medical diagnoses consisted of cancer (5), renal disease (2), HIV/AIDS (2), Stroke (1), mental illness (1), chronic obstructive pulmonary disease (1), and Other (not reported/mixed illness-types) (12). The expanded scope of the search produced studies that have mixed races, ethnicities and include females. The categories of caregiver groups consisted of the following combinations: African American with male and female participants (*n* = 10), male spouses/partners (African American = 3; non-Hispanic White = 9; Australian partners = 1); spouses/adult child (non-Hispanic White = 1, Portuguese = 1); son caregivers (mixed racial/ethnic = 2); mixed-gender/partner, racial/ethnic = 5; racial/ethnic or male/male partner = 2. The significance in understanding these patterns is to analyze the findings that specifically identify gaps, gender, or race-specific details in African American groups, which again supports the need to study African American males separately.

Twenty-seven articles, one electronic book (e-book), and eight dissertation studies represent the current state of the science on male caregiving in this U.S. and selected geographic locations (e.g., Australia, Canada, Ireland, Norway, Portugal, United Kingdom). The studies varied in sample sizes, yielding the following results: qualitative (6 to 303), quantitative (45 to 767), and mixed-methods (12 to 32) caregiver participants. Of the 27 articles and eight dissertation studies, 16 theoretical/conceptual frameworks were used to guide the research. The most cited use of the framework was the stress process model five times, while the sociocultural stress and coping model was used two times, and the stress and coping model was used one time. Other frameworks consisted of the middle range theory of transitions, social justice theoretical framework, grounded theory, social cognitive theory, symbolic interaction theory, exchange theory, and the needs-driven dementia compromised behavior model.

Review of the Literature

In this section of the chapter, the reviewed literature on the phenomenon of caregiving and male caregiving is presented in broad categories shown as (a) Caregiving, (b) African American caregiving, and (c) Male caregivers, which includes African American male caregivers. The overview of “Caregiving” is presented, highlighting the most commonly seen characteristics and concepts among family caregivers. Based on the review of the literature, five major concepts consistent with what is known about caregiving are presented in the categories of (a) stress and burden; (b) social support of the caregiver and care recipient (formal and informal); (c) coping strategies include spirituality/religiosity; (d) culture; and (e) outcomes, which includes adverse and positive effects of caregiving. The “African American Caregiving” section identifies the historical and present-day state of caregiving for African Americans—males and females. This section contains seminal studies that are relevant and specific to this underrepresented area of research. The section that describes “Male Caregiving” includes various racial/ethnic studies and consists of the available research on African American male caregivers’ topic. Due to the dearth of peer-reviewed studies in this area of study, this researcher has included dissertational research studies that reflect African American male caregivers.

Caregiving Literature

Supporting the invisible cadre of caregivers, or carers, has emerged as a national public health priority (CDC, 2019b; Fernandez, 2017; Swartz & Collins, 2019). Family or informal caregivers provide unpaid care or arranges care for a family member (Do et al., 2014; Weinland, 2009). This delivery of uncompensated activities administered to an individual, consisting of one or several tasks of daily living and instrumental activities of living, is described as the “act of caregiving” (AARP/NAC, 2020).

For a family caregiver to a dependent, chronically ill family member with physical, emotional, or debilitating limitations, the experiences can be both rewarding and/or detrimental for caregivers due to the increased risk of adverse health consequences (CDC, 2019b; Lee & Tang, 2015). It is well-established in the caregiver literature details on caregiving's adverse psychological and physiological effects, such as stress, depression, or anxiety (Cothran et al., 2015; Smith et al., 2014; L. A. Williams et al., 2017). Additional adverse effects include a self-reported decline in physical health, higher use of psychoactive medications, and increased risk of early death (CDC, 2019b). Caregiving requires caregivers to sacrifice their time, health, energy, and sometimes employment, often generating negative consequences, including physical, psychological, psychosocial, and financial problems to the caregiver (Epps et al., 2016; Lee & Tang, 2015; Lopez-Anuarbe & Kohli, 2019; Poo & Whitlatch, 2016).

Family Caregiver Characteristics

Most caregivers are non-Hispanic White females. On average, adult care recipients' family caregivers are 49.4 years old (Accius, 2017; Beydoun et al., 2019), with a median age of 51.0 years (AARP/NAC, 2020). Family caregivers spend an estimated 23.7 to 24.4 hours a week on caregiving (AARP/NAC, 2020; Beydoun et al., 2019); however, caregivers who reside with the care recipients spend almost double the time per week (37.4 to 41 hours) on caregiving (AARP/NAC, 2020; Beydoun et al., 2019). African American caregivers report providing more hours of care each week (31.2 hours on average) than either non-Hispanic White (21.2 hours) or Asian American (24.1) caregivers (AARP/NAC, 2020). The average duration of the caregiver role is 4.5 years. However, significant increases are seen in role duration for 5 years or longer in the following groups: ages 50 to 64, lower-hour caregivers (providing care 20 hours or less), carers for long-term physical conditions, and Generation X caregivers (born 1965-1980) (AARP/NAC, 2020).

The caregivers' ability to provide care to the recipient is significantly driven by the caregiver's age, with older caregivers caring more for peers (spouse/partner, siblings, and non-relatives). In comparison, younger caregivers care more for an older generation (parents or grandparents) (AARP/NAC, 2020). Moreover, the results of this national survey database reported other critical changes since 2015. The combined responses from caregiver groups reported significant declines in conversations with care providers about their own needs (e.g., primary caregivers (15% vs. 19%), lower-income caregivers (13%, with incomes < $50, 000 vs. 19%), high school diploma or less (13% vs. 20%), and rural caregivers (10% vs. 20%) (AARP/NAC, 2020). Finally, the expectations of continuing in the caregiver role (over the next 5 years) presented the following findings: non-Hispanic White (58%), Asian American (54%), and Hispanic (53%), while African American caregivers reported (42%). Those caring for a parent/parent-in-law (63%) or spouse/partner (59%) are more likely than those caring for other relatives (44%) or non-relatives (33%) to continue in the role.

Key Concepts in the Caregiving Literature

Stress and Burden. Lazarus and Folkman (1984) described stress as an association between the individual and the environment considered by the individual as demanding or exceeding his or her resources and threatening the individual's well-being. Research has shown a significant link between stress and adverse physical and psychological health outcomes for caregivers (Cothran et al., 2015; Pharr et al., 2014).

The effects of chronic stress on African Americans' physiological and psychological health are extensively documented in the literature (B. G. Knight & Sayegh, 2010). However, exposure to stressors is differentially distributed by race/ethnicity with minority groups (older African Americans and foreign-born Hispanics) who reported a higher stress burden than non-Hispanic Whites (L. L. Brown et al., 2018). According to the researchers, exposure to a higher number of ongoing chronic stressors for the non-Hispanic group was concluded for this finding (L. L. Brown et al., 2018). Given the growing need for family caregivers and the caregiver role's enduring demands, it was theorized that minority caregivers would experience more significant adverse health outcomes, morbidity, and mortality from chronic stress (Pharr et al., 2014).

Stress. In a study led by researchers B. G. Knight et al. (2000), caregiving appraisal as stressful was considerably lower among African American caregivers and was related to lower levels of emotional distress. The study also found African American caregivers to be in poorer health and used more emotion-focused coping strategies, leading to higher emotional distress levels. B. R. Hansen et al. (2019) explored African American caregivers' perspectives on aggressive behavior in dementia family members as a primary stressor. The study sample (*n* = 13) consisted of a small percentage of male caregivers (8%). Their study's findings showed that the family member's aggressive behaviors exacerbated the caregivers' internal conflict. Additionally, the carers reported difficulties adjusting to their caregiving strategies to accommodate their new realities as caregivers.

To better understand the relationship between the adverse effects of caregiver strain and stroke risks, Haley et al. (2010) studied the relationship between caregiving strain and each of the component variables that comprise the stroke risk score. The findings showed that the risk was highest for “highly stressed” caregiving husbands, with “highly stressed” African American caregiving husbands, which identified particularly elevated Framingham Stroke Risk Score scores. The covariate-adjusted stroke risk score (26.95%) was 10 points higher than for any other race-sex group. The study showed that caregivers of advanced age, male sex, African American race, less education, and greater depressive symptoms were associated with higher stroke risk scores. Of mention, male spousal caregivers self-reported higher strain than wife caregivers in their caregiving roles.

The mistrust of healthcare providers or stigma faced by African American families and caregivers is postulated to pose another level of stress and burden in this population (Dilworth-Anderson et al., 2007; Nardecchia, 2015; Pharr et al., 2014). For example, according to previous research, African American caregivers used formal services much less than non-Hispanic White caregivers due to the lack of trust in health service (Dilworth-Anderson et al., 2005). Institutional discrimination leads to lower access to care, and cultural racism can combine with institutional processes to produce more reduced quality care for stigmatized racial populations (D. R. Williams & Mohammed, 2013). Gross (2013) study also described the effects of stigmatization and problems with medical staff in finding the experiences of gay male caregivers. The adverse consequences of racism and discrimination affecting caregivers’ health can be reduced through legislation that maximizes medical care supports health promotion (Nardecchia, 2015). Moreover, when social factors are addressed (i.e., stigma) that initiate and sustain risk behaviors, individuals and communities are more empowered to integrate self-care principles for their lives and health (D. R. Williams & Mohammed, 2013).

In contrast, Trantham et al.'s (2015) study showed great trust in physicians by cancer survivors and their families. This study was undertaken to explore cancer clinical research perceptions in African American male cancer survivors (*N* = 14) and their caregivers or significant others (*n* = 16) to gain their insight and help participants feel more comfortable in the focus group setting. The majority of the participants (cancer survivors and caregivers) were male (70%). A key finding in their research indicated a great trust in their physicians, as did the results in Neufeld and Kushner's (2009) study of male spouses and sons of dementia family members. Specifically, the carers cited dedication, respect, and competence in the care provision of healthcare professionals. The issue of trust was similarly a finding in Munro and Edward (2010), which showed the caregivers placed "hope and faith" in their medical care. Other results in the Trantham et al. (2015) study was reported as (a) social norms including generational and gender barriers remain problematic—participants often reported that men in the community do not talk about health issues, (b) pervasive misperception that placebos remain a major source of distrust and concern regarding clinical research, and (c) common terminology used to describe clinical trials often has a different meaning to cancer patients and their caregivers. The findings indicated the need for necessary information and education about clinical trials, including population-specific terminology and informational materials distribution to dispel placebo-related fears.

Burden**.** Race and culture can affect caregiver burden and outcomes (Bekhet, 2015; Black et al., 2018; Geiger et al., 2015; Mercer, 2017; Powers & Whitlatch, 2016; Wennberg et al., 2015; L. A. Williams et al., 2017). As an indicator of caregiver health, caregiver burden is associated with the pressure that caregivers commonly experience from their caregiving responsibilities (Lopez-Anuarbe & Kohli, 2019; Saffari et al., 2018). Previous studies have suggested that caregivers, in general, had poorer health and increased depression and anxiety as a result of their caregiver burden (Badana et al., 2019; Bekhet, 2015). Durkin's (2010) dissertation study on African American and non-Hispanic White caregivers showed that caregivers who reported a higher quality of pre-illness relationship with the care recipient reported less anxiety, depressive symptoms, and resentment demonstrated better self-perceived health. Bekhet's (2015) study showed non-Hispanic White caregivers reported greater burden (t= -3.68, p < .001), more anxiety ($t = -2.66$, $p < .01$), and depression ($t = -2.21$, $p < .05$) than African American caregivers. Studies that have focused on caregiver burden have yielded mixed findings in the literature. For instance, some caregivers described "frustration" and "loneliness" (Mayo et al., 2020) and feeling "sad" or "pissed" (Lindauer et al., 2016), while other caregivers have reported the use of positive cognitions and resourcefulness, such as social support (Bekhet, 2015); a familial sense of obligation, commitment, duty, and filial affection (Mars et al., 2017; McDonnell & Ryan, 2014; Mercer, 2017; Powers & Whitlatch, 2016; Simpson et al., 2018). Contrary to some prior research, Scott et al. (2020) led a study on caregiver burden for dementia care recipients showed no significant difference in caregiver burden between African American and non-Hispanic White family caregivers; as suggested that African American caregivers are less burdened than their non-Hispanic White caregiver peers (Bekhet, 2015; Powers & Whitlatch, 2016).

Caring for older adults with complex needs has been linked to a considerable burden on informal caregivers that have resulted in distress or the perception that caring demands exceeded the caregivers' resources (Lazarus & Folkman, 1984). The manifestations of burden have been related to gender, age, health status, ethnic and cultural affiliation, lack of social support, coping style, and the stressors associated with a chronic illness, such as mental disorder (Black et al., 2018; Geiger et al., 2015; Shah et al., 2010). Caregivers who reported poorer self-reported health, engaged in fewer self-care actions, and reported lower life satisfaction; faced high levels of burden (Lopez et al., 2012; Lopez-Anuarbe & Kohli, 2019; B. G. Knight et al., 2000).

In a literature review conducted by L. A. Williams et al. (2017) on caregivers of family members with end-stage renal disease (ESRD), the primary findings showed that patient comorbidities and the caregiver's health condition substantially increased burden in this population of caregivers. The findings also indicated that the family member's increased functional and cognitive impairments, which impeded ESRD patients' ability to care for themselves, were directly correlated with the experience of caregiver burden. The synthesis also revealed that the burden was compounded by anxiety, fatigue, deterioration of family relationships, and social isolation. Moreover, the review showed that caregivers reported the intense demands and responsibilities of caring for their family members caused tremendous strain, leading to resentment feelings. In summary, the researchers cited that male caregivers of persons with ESRD may be at increased risk of death (L. A. Williams et al., 2017).

Durkin (2010) presented findings on the impact of social isolation on African American and non-Hispanic White caregivers. In this study, activity restrictions that led to social isolation were a significant predictor of emotional well-being, but not heath. These findings indicated that caregivers who reported more social isolation reported more anger, anxiety, depressive symptoms, and resentment. Similarly, Munro and Edward's (2010) study of male partner caregivers of HIV/AIDS patients in Australia also reported social isolation due to caregiving responsibilities. The men said the physical signs (body image) and stigma associated with the diagnosis and deteriorating conditions increased isolation. The burden of grief and remembrance, financial and time strains of losing a loved one during the process and afterward created increase stress for the caregivers and resulted in carer lack of self-care, "exhausted and neglected" to ensure the best care for their partners. In C. S. Taylor's (2010) male caregiver dissertation study of older non-Hispanic White (*n* = 12) and one African American experience of caregiving yielded consistent findings reported in other male caregiver research (Cothran et al., 2015; Dilworth-Anderson et al., 2007; Henry-Edwards, 2013; Munro & Edward, 2010). This experience included reciprocity, resentment, frustration, social isolation, belief (faith), and strong support systems. The caregivers also reported their caregiving responsibilities could be better supported if they were more informed on the death and bereavement process, received education on the illness process, financial management, and the acquisition of skills to manage the caregiver role.

When exploring the mental health differences between male and female caregivers, researchers Edwards et al. (2017) used data from a secondary analysis of the Behavioral Risk Factors Surveillance System (2009) study to examine differences between male and female caregivers by demographics, health-related quality of life (HRQOL), and the effect of social support on HRQOL. Most caregivers were non-Hispanic White females (67.5%) and averaged 47 years in age. The male caregivers were younger (*M* = 45.9, 95% CI = 45.5–46.3 versus *M* = 48.0, 95% CI = 47.8–48.3) with slightly less education than the female carers. The male and female caregiver groups were married or living with a partner (66.7% and 65.1%, respectively). Additionally, there were no gender differences in self-reported general health or life satisfaction. The study's significant findings showed that men caregivers reported substantially fewer mentally and physically unhealthy days than women, and the buffering effects of social support were stronger in women. As reported by the researchers, this outcome was possibly attributed to female caregivers' larger social networks. In contrast, male caregivers reported lower social support findings for the study. This finding was congruent with other studies that have reported male caregivers who face caregiving burden, have weak support networks, and are less likely to seek out programs that increase their caregiving capabilities and help them cope with this burden (Lopez-Anuarbe & Kohli, 2019). Durkin (2010) showed that caregivers who reported greater social support reported less depressed effects and resentment in the caregiver burden. Neufeld and Kushner (2009) further investigated male carers' experiences of non-supportive interactions. Results revealed the complexity and variation in male caregivers' experiences of non-supportive interactions.

Social Support. Support of family, friends, or communities is associated with the caregivers' ability to cope with their caregiving experience. African Americans have a broader informal family and social support network that allows them to use collective rather than individualistic approaches (Black et al., 2018; Mercer, 2017; R. J. Taylor et al., 2016; Unson et al., 2020). To illustrate this point, Mercer (2017) reported the male caregivers in her study utilized solicited and unsolicited assistance from family members, church members, and friends. They also engaged in conversations with individuals who may or may not have had similar experiences. These actions are seen as effective ways of coping, decreasing social isolation, and reinforcing the need for supportive networks.

As reported in previous African American caregiver studies on dementia family caregiving, greater use of formal services (i.e., respite, financial assistance, or transportation access) was used by the caregivers (Badana et al., 2019; Simpson et al., 2018). It was reported that in this population, caregiver support and the use of formal resources are influenced by prior knowledge and reputation of services as culturally appropriate (Apesoa-Varano et al., 2015; Black et al., 2018). Although study findings are mixed, men often reported fewer formal sources of assistance and support (Geiger et al., 2015; Milligan & Morbey, 2016; Mott et al., 2019; Robinson et al., 2014; Wennberg et al., 2015). According to Simpson et al. (2018), African American caregivers seldomly used formal support services unless a crisis emerged. This low usage was due to the lack of confidence in formal support services. Furthermore, this study of all non-Hispanic

White older male caregivers (*n* = 6) revealed that male caregivers needed other men's support and company in similar caregiving situations. The poor services provided by the Veterans Health Administration and the extended amount of time it took to access the resources that could support family involvement in supportive activities were reported as a barrier (Epps et al., 2016). Samson et al.'s (2016) caregiver study showed that legal and financial planning support services were frequently delayed because African American caregivers reported "going against the grain to interfere in an elder's affairs" (p. 497). Apesoa-Varano et al. (2015) further indicated that African American caregiving involved complex primary, secondary, and tertiary structures. Within this support, the network consists of kin and faith-based connections (Apesoa-Varano et al., 2015). According to Cho et al. (2016), African American caregivers focused more on the frequency of support from family (kin), friends, and neighbors, while non-Hispanic White caregivers focused more on the quality of support. In Asian and Vietnamese American cultures, Ta Park et al. (2018) indicated that caregivers preferred to use social support networks, familial ties, indigenous healers, and religious/spiritual outlets rather than seeking professional help. To summarize, the degree to which individuals use social relations (i.e., informal support) depends on the caregivers' engagement with each other and extends to a level of involvement and concern beyond the surface level (Pearlin et al., 1981).

D. L. Cooper et al. (2013) conducted a quantitative study to explore the type of social support and the levels of strain reported by cancer caregivers (African American (*n* = 45); White (*n* = 4); Hispanic (*n* = 2); and Other (*n* = 1). The majority of study participants (89%) were female. As reported by Hamilton and Sandelowski (2004), as cited by D. L. Cooper et al. (2013), “African Americans have social support preferences that are culturally different from Whites and Asians” (p. 2720). The findings showed that most of the caregivers (67%) reported instrumental support such as transportation, household chores, or daily care was the most reported type of support needed. Delivery of emotional (42 %) and spiritual (20 %) support, at times in tandem, was a common way the caregivers helped their loved ones through the cancer experience. The summary scores for the Caregiver Strain Index suggested that the caregivers fell into either low strain (mean CSI score of 2.4, range 0–6) and high strain (mean 9.6, range 7–13). Thirty-eight percent of the caregivers were considered as having high caregiver strain, while 62 % had low levels of strain. The findings suggested that the caregivers were overwhelmed by demands on their time for the high-strain caregivers and required them to adjust their work, family, and social life activities.

Lopez et al. (2012) explored the specific needs and support required for male caregivers of breast and gynecologic cancer patients. The researchers used an exploratory longitudinal qualitative descriptive design using face-to-face interviews of 15 spouses/partners. The overall findings revealed a range of physical, emotional, and cognitive difficulties in their caregiving role alongside satisfaction when providing care for their wives/partners. In this study, the majority of the male caregivers reported challenges in finding support for themselves compounded further by limiting social contacts following their wives/partners’ diagnoses. This unsatisfaction linkage to support services was also described in Neufeld and Kushner’s (2009) study as an unanticipated change in or withdrawal of support services that lacked follow-through. In the Lopez et al. (2012) study, the caregivers also reported difficulty expressing their concerns to other people, especially to another male friend. This lack of communication was contrary to men's supportive relationships in studies conducted by Black et al.'s (2018) or Solli et al.'s (2018) studies. Additional findings that resulted in the Lopez et al. (2012) study showed that although the caregivers experienced physical and psychological problems, they focused more on caring and protecting the wife/partner by instilling positive thoughts, working together, and putting them first before themselves.

Unson et al.'s (2020) study of African American caregivers to a parent or grandparent explored caregiver perspectives, sources of uncertainty, internal sources of strength and external support, and their coping modes with the caregiver role transition. Inclusions included the engagement in caregiving duties for more than 5 hours per week. The participants were primarily unmarried, the average age was 52 (*SD* = 19; ages ranged from 24 to 82 years), and the care recipients' average age was 84 (*SD* = 9). The findings indicated that family members predominantly provided social support, and its absence resulted in conflict among siblings and caregiver stress. The most common coping strategies included religiosity, expectations of reciprocity, and coming to terms with the uncertainty, as reported by the caregivers in Lopez et al. (2012) studying male caregivers of breast cancer survivors. Moreover, institutional support was rarely mentioned in the narratives of the participants. As noted by the researchers, the small sample size was seen as a limitation, acknowledging the need for further research in this area of caregiver research.

Coping. Coping strategies are employed to lessen the effect of stress. As a mediating resource, coping strategies related to stressors attempt to modify the specific situation that created the stressful event or circumstance; seeks to alter the meaning of the problem to reduce the threat; while trying to control the stress symptom (Pearlin et al., 1981). These strategies have included resourcefulness and spirituality to manage caregiver burden (Epps, Brewster, et al., 2019; Samson et al., 2016; Zauszniewski et al., 2018). In B. R. Hansen et al.'s (2019) study, though primarily female, the carers described effective coping strategies such as "sitting on the porch to get myself calm" or "do laundry." The caregivers' significant point to minimize stress was seen as "picking your battles," which led the caregivers to reframe care recipient behaviors. This action is seen as cognitive and behavioral strategies for preventing and managing aggressive behavior, often seen in dementia patients (B. R. Hansen et al., 2019). Male caregivers tend to engage in coping strategies within the framework of problem-focused and emotion-focused coping (Black et al., 2018; Calasanti & King, 2007; Smith et al., 2014). Problem-focused coping refers to efforts to directly address problems created by the care recipient's illness (i.e., gaining knowledge, problem-solving). In contrast, emotion-focused coping refers to strategies to regulate affective responses, such as prayer, relaxation (Morano & King, 2010); seeking social support (i.e., adult daycare), engaging in self-care or avoidance-focused coping (i.e., substance use, denial) when examining caregiver burden (Geiger et al., 2015; Calasanti & King, 2007; Robinson et al., 2014).

***Spirituality/Religiosity*.** These paired constructs conceptually overlap and are often used interchangeably in context and provide a sense of guidance, security, and meaning (Epps, Brewster, et al., 2019). Spirituality is related to the morality and values of the human being. Religiosity is seen as the commitment to religion's traditions, going to church, or reading the Bible (Epps, 2015). Many caregivers use religiosity to cope with stressors in their lives, and those who reported a higher level of spiritual well-being were less likely to experience caregiving burden (Black et al., 2018; Epps et al., 2016; Nagpal et al., 2015).

For many African American caregivers, their reliance on religion and spirituality serves as coping strategies to support them during the trials and struggles in the role. Dilworth-Anderson et al. (2002) assert that African Americans tend to cope with the difficulties of caregiving using prayer, faith in God (Epps et al., 2016), and religion and emotional support from the church, such as advice and encouragement (Dilworth-Anderson et al., 2007). In this study, the researchers reported that religiosity served as a moderator for caregiving burden and influence caregiving's positive perception. This study sample comprised a mixed group of male (*n* = 90) and female (*n* = 213) caregivers. The majority were unmarried (57%), high school education (55%), with an annual personal income of less than $15,000. The most dominant themes from the study consisted of a) strength (i.e., support and guidance); duty/reciprocity (i.e., Christian values, help, reciprocity); c) faith (i.e., faith, prayer, Christ motivates); and d) gratification (i.e., "positive feeling," "no words can express gratitude"). The study findings indicated that between 7 and 22% of caregivers reported receiving help from their churches or worship places. This low source of support may indicate that African American caregivers need outside help from formal services to assist them in providing care to help reduce caregiving's physical impact. However, study participants (78% to 86%) indicated that their spiritual beliefs supported their caregiver abilities. Overall, adding to existing findings, the study showed that religiosity and spirituality have a powerful presence among African Americans. The strong belief in God, prayer, and faith were further exemplified in responses such as "God will take care of you as long you 'do the best in life'" (Epps et al., 2016, p. 283).

Epps (2015) conducted a mixed racial caregiver study (three equal groups of 23 African Americans, Hispanics, and non-Hispanic White caregivers) to explore religiosity and caregiving reward dimensions. The results posed challenges to many previous findings from other researchers (i.e., Dilworth-Anderson et al., 2007) regarding prayer and meditation as mediators in the caregiving experience. The results suggested the motivation for caring associated with religiosity elicited feelings that were burdensome to the caregiver (Epps, 2015).

Other studies have highlighted both the positive and negative effects of spirituality or religiosity on the caregiver's well-being. Having a religious faith in God or the church served as coping strategies to support caregivers (Epps, Brewster, et al., 2019; Epps, Rose, & Lopez, 2019; Mars et al., 2017; Nagpal et al., 2015; Powers & Whitlatch, 2016). For many African American caregivers, the church is a place of refuge, resources, and social support (Black et al., 2018; Epps, Brewster, et al., 2019). Study findings for Rathier et al. (2015) showed moderate-to-strong associations with "working with God" and other types of religious coping, praying frequency, and importance of spirituality ($\rho = .32 – .57$; $p < .01$). In contrast, religious coping that centered on working through God (i.e., passive deferral, pleading for direct intercession) showed small associations with higher levels of depressive symptoms and burden ($\rho = .20$; $p < .01$). Specific to male caregivers, religious coping indicated "working with God" ($p = .884$) and "working through God" ($p = .953$). Another study reported that caregivers assimilated the aggressive behaviors of dementia individuals with biblical scriptures that were seen as "ungodly," leaving the impression that the family member "would not be saved" (Aaron, 2016, p. 6).

Heo and Koeske (2011) used a modified version of the stress and coping model to examine religious coping pathways to depression. Religious coping was described as a distinct resource, a personal, psychological trait, and a set of implied behaviors and/or cognitions that acted to reduce the adverse effects of stress. A sample of caregiver/care recipient dyads ($N = 642$) participated in the study: African American ($n = 211$), 220 non-Hispanic White ($n = 220$), and Hispanic ($n = 211$) caregivers. Demographic characteristics consisted of the following: majority female (79%), mean age = 62.3 years, an average level of education (12.6), and average personal income ranged from $20,000 to $29,000. Sixty-two percent of the caregivers reported good, very good, or excellent physical health conditions. Significant outcomes related to the African American caregivers were reported as (a) highest level of religious coping and the lowest level of caregiver burden appraisal of the group, (b) African American caregivers were most likely to report greater attendance at religious services and more practice of prayer/ meditation than the other caregiver groups, (c) religious coping was most commonly used by African American caregivers, and the theoretical model of religious coping worked better for African American caregivers than non-Hispanic White and Hispanic caregivers, and (d) in racial group comparisons African American and Hispanic caregivers perceived their health to be significantly worse than non-Hispanic White caregivers.

Culture. Pharr et al. (2014) examined culture, caregiving, and health on the family caregiver experience to understand the cultural differences in family caregiving experiences related to perceived caregiving expectations. An interpretative, phenomenological research design was chosen to highlight caregiver experiences from different ethnic groups. The researchers used cross-sectional, semi-structured focus groups. Descriptions of the research questions included: (a) “Did you grow up an elder being taken care of by your family, or did a neighbor you knew to take care of an elder?”; (b) “What are the common stresses in giving care to your elder?”; and (c) “How do you cope?” The findings of the study indicated significant differences in cultural values and norms. The results were grouped into three categories: (a) cultural embeddedness of caregiving, (b) cultural determinants of caregiving responsibilities, and (c) cultural values and norms. As presented in the findings, cultural values and norms were the key influencers on caregiving experiences. The researchers associated the data analysis with the key variables (operationalized in the study) within the model and how the path analysis demonstrated the caregiver’s effects and, ultimately, their outcomes.

Powers and Whitlatch (2016) examined the psychometric properties of the Cultural Justifications for Caregiving Scale (CJCS) to evaluate the differences in cultural values and demographic variables among African Americans (*n* = 71) and non-Hispanic White (*n* = 131) caregivers. After IRB approval, data were collected on 202 adult caregivers for an older relative with memory loss. Most of the caregivers were female (79%) and spouses (56%). On average, caregivers reported caregiving duration (38 months) and 74 hours of care per week. Mean ages were (non-Hispanic White = 66.96 years) and (African American = 60.63 years). Overall, there was little difference between racial groups in the amount of time spent in the caregiving role. Using exploratory factor analysis (EFA), the findings revealed two underlying factors relating to “Duty” and “Reciprocity” with high levels of reliability. The two factors showed different correlational patterns with other caregiving experience measures (caregiver demographics and well-being). African American caregivers who expressed stronger feelings of duty were more likely to be adult children (e.g., daughter, son, grandchild) or other family members (e.g., cousin, sister) who experienced higher levels of strain their finances and dyadic relationship and reported higher levels of depression. This group was more likely to be female, unmarried, and an adult child. Non-Hispanic White caregivers had higher education levels, were spouses, and were significantly older than African American caregivers. Both groups expressed higher agreement with reciprocity and duty (cultural) as their motivation for caregiving. According to the researchers, African American caregivers may not have interpreted religious beliefs surrounding the decision to provide care as a negative aspect of “duty” but instead used it as a positive coping strategy to reframe the burdens associated with care.

Goins et al. (2010) conducted a study that explored American Indian culture’s role in the caregiving context. The authors recognized the contributions of prior studies regarding the influence of culture on caregiving among Whites, African Americans, and

Hispanics; however, the extent to which cultural factors influenced caregiving behavior in American Indian communities was unknown (Goins et al., 2010). Specifically, the study sought to (a) estimate the prevalence of adult caregiving, (b) present a demographic and cultural profile of caregivers, and (c) examine the association between cultural factors and being a caregiver. Consistent with the principles of the SSCM, the results highlighted the relevance of cultural factors in the caregiving context. Specifically, the researchers found that attendance and participation in Native events and engagement in traditional healing practices were associated with increased caregiving odds. Further, the findings indicated some heterogeneity in cultural factors and sex with caregiving status, which reinforced the idea that individuals in a given racial/ethnic group do not necessarily share the same attributes. Finally, this research supports the belief that familial obligations and interdependence are integral tribal values related to caregiving. Future research and interventions for American Indians should be attentive to the dynamics of culture and caregiving.

In another study, Evans et al. (2017) explored Mexican Americans’ caregiving experiences from an ethnic and cultural perspective. Based on the dearth of research that involved this group of both understudied and poorly served caregivers, their characteristics and needs were reported as under-represented in the caregiver literature (Evans et al., 2017), similar to African American caregiver studies. This quantitative study described the caregivers’ health disparities and social factors, such as immigration, acculturation, and specific cultural guidelines, and their caregiving trajectory as complicated. Twenty-two of the study participants were male (*n* = 4). Most participants were married (70%), and approximately 60% earned annual incomes of less than $40,000. Nearly 50% of the caregivers remained actively employed, and another 45% were unemployed or retired. In sum, the caregivers were younger, less educated, and had lower socioeconomic status, congruent with African American caregivers, as seen in previous studies (i.e., Cothran et al., 2015). The study's findings indicated that 16 of the 22 caregivers (73%) reported that "their lives changed dramatically when they began to provide care." Nine of the 22 caregivers (41%) said they had "become chained to their care recipients." Five participants reported weight management, hypertension, diabetes mellitus, or joint issues, but none connected them to caregiving. In the study, one male caregiver described his experience as, "*It's been a positive change, and it's been a negative. I mean, more positive. I'll tell you the truth; I wouldn't recommend it to nobody. I couldn't say I wouldn't recommend it; I'd say, be prepared*." Another male participant that described the positive effects of caregiving gave the statement, "*I'm doing this because I love and honor her. I really don't owe her nothing; it was her duty to be a parent and take care of me.*" This caring exemplified his view of honor and reciprocity for care. Like the plight of other ethnic minorities, the increasing numbers of older Mexican Americans living longer with chronic illness and their families who care for them at home for extended periods will create a greater demand for family caregivers due to the projected population growth (Pharr et al., 2014). Achieving a better understanding of these understudied, culturally, and ethnically diverse caregivers will offer advancements in caregiving's overall expansion from a minority, racial/ethnic lens.

Researchers Njai et al. (2014) studied different characteristics of sociocultural-specific models to emphasize the role of cultural resilience, such as racial and ethnic identity, in the face of racialized stress among the Caribbean- and African Americans. The researchers concluded that racial and ethnic identities were unique sociocultural resources that African Americans potentially used to modify detrimental lifetime exposure to racially attributed discrimination. These resources were illustrated by the use of increased adaptive coping methods. Specifically, the researchers asserted that ethnic attitudes directly affected African Americans' depressive symptoms and relevant coping. The findings revealed that racial identity for African Americans (racial centrality, private, and public regard) was identified as direct mediators related to a reduction in depressive symptoms in the context of discrimination and coping. In sum, Njai et al. asserted that ethnic identity relates to direct effects on depressive symptoms for African Americans. Accordingly, the study's direct implications included the need to be more conscious of intraracial heterogeneity when conducting research and developing interventions specific to African Americans. The results supported the need to consider racial and ethnic identity differences when conceptualizing mechanisms and pathways by which racialized stressors impact various ethnic groups' health within the African American racial category.

Health Outcomes. As the U.S. continues to see escalating population growth trends in every sector of the country, the need for family caregivers and caregiving effects will continue to increase. Caring for older adults with debilitating illnesses has demonstrated adverse consequences on the caregiver's health (Black et al., 2018; del-

Pino-Casado et al., 2018). These consequences are most often related to depression and anxiety, the adverse health outcomes that result from the demands and stressors caused by the caregiving activities, and the caregiver's appraisal of the caregiving situation (del-Pino-Casado et al., 2018). For some caregiver groups, such as dementia caregivers, exposure to care-related stressors posed increased risks of adverse psychological and physical health outcomes (Fauth et al., 2012), illustrating how the stress-process model depicts the pathway of background or contextual factors to mediators/moderators that manifest into the health effects of caregiving.

In the current study, the outcomes domain will be determined by the association between caregiver background or contextual factors, stressors, and mediating factors. The unique socio-cultural experiences among African American male caregivers pose major concerns for their health and wellness and the care recipient's enduring needs in community-dwelling settings. The following subsections will present major health outcomes that affect caregivers, particularly regarding African American caregivers, where the researcher's detailed results were presented in the findings of this literature review.

Physiological Health Effects. Over the last two decades, sociocultural models of stress and coping have gradually increased in the ongoing caregiver literature, especially concerning African Americans' health. In a longitudinal caregiver study, Dilworth-Anderson et al.'s (2004) study made several contributions to the caregiver literature regarding caregiving's physical health effects among African Americans. By including cultural justifications for caregiving in the analyses of health outcomes during a study, the researchers determined the role culture had in predicting health outcomes. That is, how African American cultural beliefs and values affected the study's findings. The researchers also found that higher levels of mastery were associated with poor health outcomes for African American caregivers in the study (*N* = 107), which were suggested to be attributed to African American culture and/or socialization. The researchers used a measure of psychosocial and functional health was used in this study. Psychosocial health provided information on subjective views from caregivers about how they evaluated their health. In contrast, physical functioning provided a more objective view of the caregiving's ability to function in their role. Overall, the findings showed that combinations of caregiver background characteristics, stressors, and resources were significant in predicting specific African American health outcomes for a three-wave data collection period of 3 years.

Psychological Health Effects. Many caregivers face severe psychological distress (Bailey et al., 2011; Epps, Brewster, et al., 2019; Epps, Rose, & Lopez, 2019; Geiger et al., 2015; Moon & Dilworth-Anderson, 2015; Mott et al., 2019; Semenova & Stadtlander, 2016; D. R. Williams et al., 2007). The anticipation of an adverse care recipients' outcome or emotional distress from watching a family member or significant other suffer through a debilitated state of health can create feelings of guilt, resentment, and disappointment, causing a profound impact on caregivers' mental health (Semenova & Stadtlander, 2016).

Depression. Research has reported that the course and trajectory of mental illness (i.e., depression) may be more chronic for African Americans than non-Hispanic Whites

(D. R. Williams et al., 2007); and once diagnosed, this chronically or persistently depressed population has more severe, persistent, and disabling depressive episodes, higher levels of impairment (Bailey et al., 2011), and do not receive treatment (D. R. Williams, 2018). Despite the benefits of formal mental health services, African Americans are less likely to seek formal mental health providers' assistance to manage psychological problems (S. L. Williams & Cabrera-Nguyen, 2016). Moreover, depression, strain, burden, and hypertension are commonly reported physical illnesses that affect African American caregivers' (Black et al., 2018; Epps, Brewster, et al., 2019; Epps, Rose, & Lopez, 2019; Geiger et al., 2015; Moon & Dilworth-Anderson, 2015; Mott et al., 2019) health outcomes related to the demands of the role. Among spousal caregivers, limited understanding of caregiving stressors and depressive symptoms demonstrates a gap in knowledge (M. H. Kim et al., 2017). In other studies, caregivers reported reduced social activity (Calasanti & King, 2007; Moon & Dilworth-Anderson, 2015) and avoidance-focused coping (Calasanti & King, 2007; Geiger et al., 2015), which was viewed as harmful and increased depressive symptoms (i.e., guilt and grief).

In a recent study, Gayman et al. (2018) studied the risk and protective factors for depressive symptoms in African American men (*n* = 248) using the stress-process framework for understanding their psychological well-being. Demographic data consisted of a) median income = $32,868, average number of chronic stressors was 3.31 (*SD* = 4.21, range = 0–26) and recent life events was 1.05 (*SD* = 1.53, range 0–9). Friend and family support fell between "moderately" and "very" supportive (3.36 and 3.63). The caregivers' self-esteem was scored 2.88 (*SD* = 0.92, range = 0.29–4.00), and mastery was

3.76 (*SD* = 0.42, range = 1.67–4.00 Overall, the men reported a mean depressive symptom score of 7.89, with 11% reporting 16 or more symptoms, a cutoff that is often used to estimate clinical-level depression. The authors concluded that social stress and psychosocial resources played a key role in understanding depressive symptoms among African American men within the study.

Ta Park et al.'s (2018) qualitative study explored the mental health needs of Vietnamese American dementia caregivers (males = 25%). The study aimed to gain insights into the development of a culturally tailored intervention to meet this caregiver group's health needs. Significant to the study, thematic themes that resulted from their research included: (a) the traditional values and beliefs as caregivers; caregivers' perceptions of mental health, help-seeking, and mental health services/support; and caregivers' unique needs, such as their holistic health issues (mental, physical, social) and effects of their Vietnam War experiences. Overall, for an intervention program to be acceptable and successful, it needs to consider all aspects of health and incorporate spirituality and Vietnamese cultural values and beliefs for this population. Regarding the contributions to racial and ethnic research, these findings exemplify how cultural values are internalized in racial/ethnic groups, and the significance of exploring the impact in nursing research is crucial. For example, social support was seen as a protective factor in Vietnam. Over time, immigration and acculturation as Vietnamese Americans, social isolation, and immigration status were purported to hinder help-seeking actions.

The review of the literature identified several studies that highlighted interventions for the management of depression included strategies such as counseling and/or cognitive behavior therapy, pleasant events training, or relaxation exercises (Easom et al., 2018; Schulz et al., 2017; Wennberg et al., 2015; Whitlatch & Orsulic-Jeras, 2018). Health promotion activities that contributed to caregiver overall physical health consisted of (a) adherence to medical appointments and prescribed orders, (b) adequate rest and sleep, and (c) engagement in stimulating physical activity (Epps et al., 2016; Mott et al., 2019). Wennberg et al. (2015) purported that few caregiver interventions have considered the cultural differences in burden, coping, and support between racial or ethnic groups. Hence, specific responses from African American caregivers suggested self-care strategies, more disease-specific education, and access to local resources, including African American providers (Samson et al., 2016).

Anxiety. Anxiety has been referred to as the most common negative effect among older dependents (del-Pino-Casado et al., 2014). Anxiety is a typical emotional response to a perceived threat and is often accompanied by feelings of tension, worried thoughts, and physical changes such as increased blood pressure (Moss et al., 2019); fearfulness, dread, and uncertainty (Cukor et al., 2013; Lopez et al., 2012; Mayo et al., 2020); as well as nervousness, that can lead to massive weight loss (Calasanti & King, 2007), or weight gain due to lack of exercise (L. A. Williams et al., 2017). The research literature postulated the distinction between anxiety and depression could pose difficulties in distinguishing between the two because of the overlap of signs and symptoms (e.g., poor concentration, insomnia, restlessness, and loss of appetite), and they frequently coexist (Moss et al., 2019). The occurrence of anxiety in caregivers has been described as the stress related to chronic illness and care obligations or role demands (i.e., “24/7”) (Boltz et al., 2016).

In 2016, Semenova and Stadtlander conducted a study to examine if death anxiety would be a significant predictor of depression and coping in a sample of adult family caregivers (*n* = 46) of adults. The male sample represented 10.9% (*n* = 5) and African Americans represented 9% (*n* = 1). The researchers used social media (Internet websites) and SurveyMonkey to conduct the study of noteworthy mention. Therefore, the sample of participants was not geographically specific. For example, the counties represented were Belgium, Mexico, the Russian Federation, and the U.S., which represented 91.3 of the participants surveyed. The major findings were: (1) the most frequent patient diagnosis was cancer, (2) the largest percentage of caregiver duration was 2-5 years, (3) 87% of caregivers were aware of diagnosis and prognosis, (4) 63% if caregivers were concerned that they would suffer from the same condition, and (5) 65% of caregivers did not have previous caregiving experience. Overall, caregivers with higher death anxiety scores had lower scores in depression. This finding was suggested by the researchers possibly related to a) duration of caregiving; allowing the opportunity to access resources to manage depression; b) use of coping strategies, such as problem-solving; c) death anxiety and coping (e.g., normal scores for depression, but coping difficulty with caregiving duties).

C. Cooper et al. (2007) conducted a systematic review of the literature on the inclusion and validity of studies (*n* = 33) that reported (a) the prevalence, predictors, and covariates of anxiety disorders or anxiety caseness (clinical case), and (b) covariates and predictors of the level of anxiety symptoms. Findings indicated that the caregiver's coping style might have been more associated with anxiety than depression. Neither care recipient cognition, ADL impairment, caregiver age, or caregiving duration was associated with caregiver anxiety levels. The researchers concluded that dysfunctional coping (i.e., confrontative and escape avoidance coping), caregiver burden, and poorer caregiver physical health were the only factors associated with higher anxiety levels, whereby reliable findings concluded.

Fauth et al. (2012) engaged a population-based sample of 234 care dyads (caregivers/care recipients) into their Dementia Progression Study (DPS), based on a national longitudinal epidemiological study from 1995 to 2007. A fourth of the caregivers were male adult offspring (*n* = 22) and male spouses (*n* = 34). The authors presented evidence that showed the higher closeness of the relationship, conceptualized as the quality of the emotional bond between the caregiver and the care recipient, was associated with less depression initially but increased depression as the disease progresses further. In sum, the authors presented implications for their findings: (a) the study supported that both current closeness (after dementia onset) and changes in closeness from the pre-dementia relationship is essential to assess when predicting caregiver outcome; and (b) the findings suggested that taking a purely cross-sectional view of these associations is misleading since closeness is related to better caregiver outcomes cross-sectionally, but worse outcomes longitudinally. These findings were postulated based on a process by which caregivers withdrew from the emotional bonds in the relationship (detachment) and took a more objective stance when managing care-related tasks. Overall, the findings showed that closeness predicted both beneficial and adverse caregiver outcomes.

Positive Effects (Gains). The positive aspect of caregiving has gained increased awareness in the research literature and clinical applications (Bekhet, 2015; Calasanti & King, 2007; Epps, 2015; Lindauer et al., 2016; Roth et al., 2015; Sullivan & Miller, 2015; Unson et al., 2020; Zarit, 2012). The positive effects of the caregiving experience, such as gratification, increased morale (Lloyd et al., 2016), encouragement from others, and positive recognition (Calasanti & King, 2007), have been reported to enhance the caregivers' physical and emotional health. To illustrate this point, respondents reported encouraging statements such as, "you know, you have a lot of courage. You don't find too many men doing what you are doing" (Calasanti & King, 2007). This type of positive reinforcement served as a means for the caregivers to manage their frustration and cushioned them from feeling bad and poorly performed tasks (Calasanti & King, 2007). Zarit (2012) reported that while caregiver outcomes have remained primarily focused on stressors, their consequences, and their management, examining the positive dimensions of caregiving is an area for further exploration.

National researchers reported nearly two out of three caregivers rated their caregiving experiences as mostly positive; describing benefits such as feeling closer to the care recipient and assurance that the recipient received high-quality care (Population Reference Bureau, 2017). Many caregivers have reported positive effects in the role (CDC, 2019a; Penkunas et al., 2018). The impact of positive aspects of caregiving has been associated with caregivers' well-being, mental and physical health, burden reduction, and role actualization (Carbonneau et al., 2010). These positive effects include a sense of fulfillment, need and usefulness, and the development of extended social networks or friendship support groups (CDC, 2019a). Others have reported caring for a family member with a disabling condition elicited gratification, meaning, joy, and a sense of purpose in life (Bekhet, 2015; Lindauer et al., 2016; Unson et al., 2020); in addition to reported deep satisfaction as family members were drawn closer together (Sullivan & Miller, 2015). Caregivers have reported feeling “honored” or “blessed” and reported a “positive attitude toward life” (Roth et al., 2015) and family closeness (Epps, Rose, & Lopez, 2019; Samson et al., 2016). African American caregivers reported more positive experiences and psychological well-being than non-Hispanic White caregivers (Bekhet, 2015; Epps, Rose, & Lopez, 2019; Powers & Whitlatch, 2016; Roth et al., 2015); particularly with supportive family and social support networks (Cho et al., 2016; Epps, Rose, & Lopez, 2019). The positive appraisal by African American caregivers can be attributed to their culture of greater participation in a broader extended family context and its influence on family member roles and perceived obligations (Epps, 2014). It has also been reported that African American caregivers use more positive reappraisal, such as reframing to minimize the negative impact, consider self-care or behavioral problems as less stressful than non-Hispanic White caregivers (Epps, Rose, & Lopez, 2019).

Roth et al.’s (2015) study (*n* = 642 dyads) explored the experiences of diverse caregiver groups’ (Hispanic, African American, non-Hispanic White) experiences on the positive aspects of caregiving. All racial groups were equally represented in the study. Both the Hispanic and African American caregivers reported significantly more positive aspects of caregiving than non-Hispanic White caregivers. The data analyses indicated that African Americans and Hispanics reported more positive caregiving experiences on items that were not sensitive to cultural differences. Also, the African American group responded disproportionately to two questions that spoke more directly to them—feeling “enabled” to “appreciate life” and to “develop a positive attitude toward life.” It was concluded that those particular survey items might have stimulated a long-standing tradition in the African American community cultivated in early life through racial socialization and maintained in adulthood and later life through spiritual and cultural beliefs that support positive attitudes about life. According to these researchers, the present findings reinforce previous recommendations to conduct more research that captures cultural beliefs and attitudes that will further understand the long-term effects of active coping, resilience, and positive attitudes on life among African American caregivers (Roth et al., 2015). When examining the caregiver experience’s positive and negative aspects, Lynch et al. (2018) conducted a study of compassion satisfaction and compassion fatigue as caregiving outcomes using the SPM. The researchers used a cross-sectional descriptive survey design with a convenience sample (n = 168) of family caregivers of individuals with chronic illness. Most of the participants (71%) reported high levels of caregiver burden, moderate to low levels of the compassion fatigue concepts of burnout (59.5%) and secondary traumatic stress (STS) (50%), and moderate levels of compassion satisfaction (82.7%). Data analyses showed that caregiver burden, time caregiving, coping, social support, and caregiving demands explained a total variance of 57.1%, F(11,119) = 14.398, $p < .00$ in burnout and a total variance of 56%, F(11, 119) = 13.64, *p* < .00 in STS. Study concepts that impacted the caregiving outcomes were derived from the model and included background context factors, caregiving demands as stressors, caregiver burden as an appraisal of stress, social support, coping as mediators, compassion fatigue, and compassion satisfaction. Overall, study findings showed that despite high levels of burden and compassion fatigue, family caregivers find satisfaction in the role (Lynch et al., 2018).

African American Caregiving. As the population ages and grows more slowly in the coming decades, the U.S. is projected to continue becoming a more racially and ethnically diverse society (Vespa et al., 2018). African Americans constitute a higher proportion of caregivers (20.3%) compared to non-Hispanic Whites (16.9%) and have worse physical health and fewer resources for caregiving (National Alliance for Caregiving [NAC], 2015). African American older adults have a greater risk of developing a chronic illness, such as dementia, than non-Hispanic White individuals (Epps et al., 2016; Graham-Phillips et al., 2016; Mars et al., 2017). In this population, most caregiving support is provided at home by family members (Mars et al., 2017; Roth et al., 2015); generally, it falls to women in the African American community (Samson et al., 2016). Since 2015, African American carers for an adult relative have increased significantly, showing an increase from (77%) to 88% in 2020 (AARP/NAC, 2020), and this carer group, more often, are the sole unpaid caregiver (55%) for their recipient. This single-caregiver group is contrasted to non-Hispanic whites (44%) or Asian American (43%) caregivers. Currently, the primary activities performed by these caregivers have also shown a marked increase since 2015: (a) monitoring recipient’s condition (74% vs.

62%), (b) communicating with care professionals (71% vs. 56%), and (c) advocating (62% vs. 47%) (AARP/NAC, 2020). Regarding the overall health of family caregivers, groups rated themselves as non-Hispanic White caregivers (45%, excellent or very good), compared to African Americans (34%) or Hispanic (35%) (AARP/NAC, 2020). African Americans also reported more adverse financial impacts than Asian Americans or non-Hispanic White caregivers due to providing care. Additionally, non-Hispanic whites reported more use of paid family leave than they did in 2015 (35% vs. 28%), while African Americans reported the use of paid sick days (70% vs. 53%) in 2015 (AARP/NAC, 2020).

Previous studies demonstrated that African American families had a strong sense of commitment and familial obligations that involved a sense of repayment to a loved one (Epps, Rose, & Lopez, 2019; Mars et al., 2017; Samson et al., 2016). Making the care recipient their “utmost priority,” caregivers reported the importance of rearranging all activities (B. R. Hansen et al., 2019, p. 3044), which consisted of informing their employers of the caregiver responsibilities. Hence, taking a person-centered approach to caregiving was expressed through narratives reported as “it’s the disease … not the person” (B. R. Hansen et al., 2019, p. 3041); or reference the “other” person versus the “real” person when connecting their loved one with the illness. Other studies have related African American family values of caregiving to the oppression of slavery (Pollard, 1981, as cited in Lindauer et al., 2016). The influence of ancestral African values of respect for the elders and the adverse effect of oppression, as a result of ancestral slavery, was postulated as a possible contributing factor to Lindauer et al.’s (2016) study findings.

African Americans have also been found to have stronger beliefs about filial and religious obligations to care for elderly family members than non-Hispanic whites, according to (Dilworth-Anderson et al., 2005). Epps, Rose, and Lopez’s (2019) qualitative study of African American caregiving showed that this group’s networks were held together by a strong sense of familism based on cultural beliefs and upbringings. Familism was also a substantial aesthetic value reported in Weinland (2009) and D. L. Cooper et al. (2013). For African American families, caregiving was considered a normal expectation rather than a disruption (Epps, Rose, & Lopez, 2019). Because of the priority placed on familism in African American and ethnic minority groups, they tend to receive more support from relatives, friends, and neighbors than non-Hispanic Whites. Epps, Rose, and Lopez’s (2019) study also showed that African Americans’ complex family system comprises numerous people, including spouses, children, siblings, and non-blood relatives, and demonstrated strong bonds and support systems were strengthened by familism, obligation, and religiosity. Notably, some relationships were weak or broken by divorce, disagreements, or drug addiction.

In one study, Badana et al. (2019) examined differences between non-Hispanic White (n = 697) and African American caregivers (n = 190) in strain, health, and service use in a population-based sample of informal caregivers for older adults. The findings showed higher physical strain was reported for African American caregivers when compared to non-Hispanic White caregivers (M (*SE*) = 2.55 (.27) and 2.58 (.12), respectively. Additionally, African American caregivers provided higher levels of ADL/IADL assistance and greater hours of care than non-Hispanic White caregivers.

Other secondary stressors are related to economic or financial strains (L. L. Brown et al., 2018; Epps et al., 2016), and intrapsychic strains, seen as dimensions of self-concepts (i.e., self-esteem or mastery); and positive gain as a caregiver (Badana et al., 2019).

Watkins et al. (2012) conducted a pilot study in one urban African American community to explore the relationship between trust in physicians and end-of-life (EOL) treatment decisions made by African American caregivers of family members with dementia ($n = 68$). Specifically, the researchers explored the caregivers' EOL treatment decisions regarding cardiopulmonary resuscitation, mechanical ventilation, and tube feeding. The findings indicated that those with more education exhibited higher trust ($p = .035$) in physicians than those who were less educated. Caregivers who were more trusting of their physicians were more likely to use mechanical ventilation ($p = .0005$) than caregivers with less trust in providers. Conversely, more trusting caregivers were less likely to use tube feeding ($p = .022$). The study's outcomes suggested that relationships exist among trust in physicians, demographics, and end-of-life treatment decisions. Thus, healthcare providers should consider African American caregivers' perceived trust in physicians when counseling about dementia and end-of-life treatment choices.

Dilworth-Anderson et al. (2007) reported outcomes for their study on African American caregivers' religious and spiritual coping values and beliefs ($n = 303$). Most of the caregivers were middle-aged females (average 56 years) and were primarily daughters. The average duration in the role was estimated at 8.7 years. The study showed that while two-thirds of the study participants attended church, most caregivers reported a lack of tangible support from the church, a similar finding in Epps et al. (2016). However, other results from the study revealed the impact of spirituality in the coping process, gave the caregivers strength to perform their day-to-day duties, gratification, and fulfillment in the caregiving duties to assume a higher spiritual meaning.

Another study, Pierval et al. (2019) was a qualitative secondary analysis that explored the role and influence of family caregivers as reported by cancer survivors. The researchers recruited a mixed-gender group of Black (African-Born, Caribbean-Born, Native-Born) caregivers (*n* = 32) who were identified chiefly as spouses (14) and adult children (*n* = 10). Other caregivers were identified as medical providers, siblings, spouse, and child dyad. Adult children were reported to fill the role of researchers of information seeking related to treatment side effects and support during treatment. The spouses were identified as the drivers and extensive supporters. This reference meant that they were the drivers of sustained behavior modification, and they provided support across the continuum from diagnosis to survivorship. Findings also indicated that caregivers could serve as effective community advocates for increased education on prostate cancer and screening in the Black community.

Twenty-six family members were recruited in a descriptive, qualitative study by McDonnell et al. (2019) to identify factors associated with receptivity and preferences for lifestyle behavior change among family members of survivors of African American survivors of lung cancer. In terms of family relationship type, there were equal numbers of spouses, siblings, and daughters. Five participants (19%) were male and included two spouses, one brother, one son, and one close friend, who lived in the same household as their associated survivor. Family members' mean age was 54 years, and nearly half (*n* = 12, 46%) were married. Most participants were high school graduates who had completed some college coursework (*n* = 16, 62%). Almost half (*n* = 12, 46%) were employed, and nearly a third were retired (*n* = 8, 31%). A majority (*n* = 19, 73%) reported a household income of less than $50,000. Of the 26 participants, 21 (81%) described their health as good to excellent. Four major themes emerged from the study: (a) family members and survivors both resisted the caregiver role; (b) dramatic changes induced by the diagnosis of lung cancer were facilitators and barriers to lifestyle choices; (c) reliance on faith in God was the primary source of support; and (d) these families live with a constant threat of multiple cancers. Overall, the finding highlighted the desire for family members to improve their health behaviors in support of the survivors; caregiving led to social isolation and a lack of guidance about health behaviors that negatively impacted family members' confidence that they could change. Findings emphasized the importance of meaningful discussions regarding the stressors and addressing family members' unique needs by healthcare professionals with survivors and family members. These needs included basic education, skills training, and support for lung cancer diagnosis, treatment, and recovery.

Male Caregiver Literature

As the demographics of the population changes, men are assuming increasingly important roles as caregivers (AARP/NAC, 2020; Baker et al., 2010; Sharma et al., 2016), despite caregiving, often being perceived as a feminine activity or commonly perceived to be a part of "women's work" in societies throughout the world (Revenson et al., 2016). Male caregivers have been called “hidden” caregivers (Black et al., 2018). An estimated 40% of all informal caregivers, or about 16 million, are men (Lopez-Anuarbe & Kohli, 2019; Mott et al., 2019), and 63% identified as primary caregivers. Male caregivers are more often younger (42%; 18 to 49 years) than middle-aged men (35%; 50 to 64 years). They provide care more often to kin or relative (92%) than women (88%). Male caregivers are more often employed while caregiving (67% vs. 58 % women), and, on average, they work more hours per week (38.7) than do women caregivers who are employed (33.5). The carers often maintain salaried job positions (45% vs. 34% women caregivers), while women caregivers more often work hourly (58% vs. 49% men caregivers).

On average, male caregivers provided care for nearly 4 years (spouses for 5 years), and 52% thought they would care for someone in the next 5 years (Accius, 2017). 49% were assisting an aging parent/in-law and 13% a spouse; 59% were White, 13% black, 7% Asian American, and 19% Hispanic. Regarding income, 44% of households were below $50,000 even though they were more likely than female caregivers to work outside the home (AARP/NAC, 2020), and 56% were married, while 11% identified as gay, bisexual, or transgender.

As reported by Collins (2014), men viewed their relationship with older parents as “filial” or “egalitarian” and, therefore, often waited until assistance in daily living was requested of them by their parents. Additionally, they are portrayed as “care managers” or “managerial” and “task-oriented” in their form of support as caregivers (Calasanti & King, 2007; Geiger et al., 2015; Robinson et al., 2014; Schwartz & McInnis-Dittrich, 2015). Male caregivers were also reported to prefer opportunities to “problem-solve” and “gather information,” as well as serve as the expert” to other caregivers (Schwartz & McInnis-Dittrich, 2015). Concerningly, these men were less likely to open up to others when they felt stressed or overwhelmed by their caregiving responsibilities (Ianzito, 2017; Lopez et al., 2012).

Some researchers have reported male caregivers are at risk of facing gender role conflict, which may pose psychological stress experienced by men during the caregiving process (Baker et al., 2010). To date, most studies of male (or men’s) caregiving have focused on the experiences of male spouses or have been included in mixed samples of men that included only small samples of other male figures (i.e., sons, partners, brothers, fictive kin) (Grigorovich et al., 2016; Robinson et al., 2014). This limited research or gap in knowledge proposes a barrier to understanding this male cohort group’s different experiences and support needs. Therefore, the aim of this focus of male caregivers will include a synthesis of relevant and current state-of-the-science on male caregivers, spousal, sons, and African American male caregivers.

Geiger et al. (2015) conducted a study of male Alzheimer’s disease (AD) caregivers to identify their likelihood of utilizing task, emotion, or avoidance-focused coping strategies to examine the caregiving burden’s effects. Data were collected from 138 male AD caregivers in the Southern region of the U.S. The majority of the sample was non-Hispanic White caregivers (61.3%), while nearly 36% were African Americans. Over half (58%) of the sample reported as married. The plurality of the sample (41.5%) reported being the care recipient’s child, while approximately 27% reported as the spouse. The researchers consulted an external researcher with expertise in working with this often-underserved caregiver population. The researchers used standardized measures in this study to measure coping strategies, which included the coping inventory for task stressors (CITS), the Zarit Burden Interview (ZBI) together with Revised Memory and Behavior Problems Checklist (RMBPC) to measure caregiving burden. Consistent with previous research, this study found that male AD caregivers were more likely to utilize task-focused coping rather than emotion-focused coping or avoidance-focused coping. Additionally, the results showed that emotion-focused coping is associated with increased depression and anxiety in the general population. The study also showed that participants who used emotion-focused coping were more likely to experience a higher caregiving burden and the increased use of avoidance-focused coping and increased caregiver burden levels. This study's implications for healthcare professionals are the need to assess male Alzheimer's caregivers for maladaptive coping strategies.

Research on the experiences of African American elder male caregivers (*n* = 13) was conducted by Black et al. (2018) using a narrative inquiry qualitative approach to explore their concrete and nonmaterial aspects of giving care to an impaired loved one. The male caregivers were described as over 60 years of age, most in long marriages, and have provided care in their homes for at least 5 years and as long as 25 years. The narratives described by the male caregivers were congruent with other major concepts/themes in the caregiver literature; however, they unfolded unique experiences in the rich descriptive stories told by these men. The major themes that derived from the study included: (a) what is caregiving? (b) stress, (c) role attainment/primary caregiver,

(d) health effects (adverse/positive), (e) duties/roles, (f) support systems, (g) coping, and (h) spirituality/religion. The findings depicted in the narrative responses represented responses such as (a) caregiving was described as “part of the marriage contract,” [for sons caring for mothers] “just natural; she took care of me when I couldn’t care for myself;” “unless somebody’s got a good heart, it’s hard to really understand what being a caregiver mean” “part of life” and that most interpersonal experiences that involved love also involved suffering and resulted in growth; (b) Stress or stressors were threaded throughout the narrative stories. In addition to physical, psychosocial, and financial stress factors, the emotional stress of managing the caregiving roles was illustrative in the statement “wondering what is in the mind of a wife or mother who “doesn’t talk anymore” or “doesn’t recognize you”; (c) Role, attainment/primary caregiver, was noted with statements such as “Uphold a promise” “wife requested that he [spouse] take care of her; she did not want “outside people coming in,” and “No one else” “I was the only one. I didn’t have siblings; she was widowed, and ahh, I did what I had to do”; (d) Health effects revealed positive and adverse manifestations such as “satisfaction,” “gratification,” compassion,” “honor,” and “fortunate.” Some of the men described “depressive feelings,” “sadness,” “melancholy,” and “suffering”; (e) Consistent with other male caregivers, the men in this study described the most onerous duty as dealing with the elimination and incontinence issues of caring for their spouses. Most of the men assumed caregiving’s task willingly and felt supported by someone close to them; (f) Supportive networks, both formal and informal, were reported by the caregivers: this included family, friends, neighbors, or fellow church members. The supportive relationship of other men’s friendship offered significant value and resources for the caregivers and was seen as functional, affective, and emotional; (g) Coping was identified through channels of work-life, reliance on others, setting goals, sharing family stories, faith, and spirituality/religiosity; and (h) The belief systems upheld by these caregivers yielded mixed findings. Different connotations regarding spirituality or religion (religiosity) persisted. For example, a few of the responses submitted by the men were reported as “a resource for finding strength within the precariousness of the caregiving situation, for stability during the progression of the care recipient’s illness or impairment, and comfort during the end stage,” “spirituality was a lived experience,” and “works” (i.e., accomplishing works of mercy—the practical and spiritual tasks that one person does for those in need). Most of the respondents had internalized childhood religious beliefs, which remained the lens through which they prayed, worshipped, and developed a self-and worldview (Black et al., 2018).

In 2012, Lopez et al. explored the specific needs and support required for male caregivers of breast and gynecologic cancer patients from a large specialist oncology center in the United Kingdom. The researchers used an exploratory longitudinal qualitative descriptive design using face-to-face interviews of 15 spouses/partners. Ten of the participants were spouses, whereas the remaining were partners or fiancé’s, with 13 participants living in the same house with their wives/partners. The interrelated cognitive, physical, psychosocial/ emotional, and gender-related impacts of caregiving experienced by the male caregivers extended over 12 months. Findings showed predominant categories that were identified as (a) breaking bad news, (b) tiredness, pain, loss of sleep,

(c) searching for information and alternative treatment, (d) unpreparedness for female work, (e) fear of losing partner, (f) fear of the unknown, uncertainty, (g) lack of support and limited social contact, (h) financial concerns, and (i) difficulty expressing emotions. The male caregivers reported challenges in finding support for themselves and were compounded further by limiting social contacts following their wives/partners' diagnoses. This finding was seen as significant in the effective use of limited resources by directly targeting the provision of care and support needs. As carers and protectors of their partners, the implied obligation as male caregivers provided both instrumental and emotional support to their loved ones, consistent with other studies (Epps, Rose, & Lopez, 2019; Mars et al., 2017; Powers & Whitlatch, 2016; Samson et al., 2016; Simpson et al., 2018).

Green (2020) took a qualitative phenomenological approach to examine the lived experience of different ethnicity male caregivers (*n* = 10) for an aging family member (i.e., parents, spouses, relative siblings). The general themes extrapolated from the data analysis identified (a) initial stress experience, (b) lives put on hold, (c) shifting focus due to caregiving, (d) feelings of selfishness, (e) feeling overwhelmed, (f) relationships with others, (g) time, and (h) caring in the future were all found to be a common concern of the participants. Major findings showed that all participants experienced some form of stress that manifested into mental and physical symptoms, such as nervousness, preoccupation with thoughts of caregiving, headaches, sleep issues, and changes in diet.

Solli et al. (2018) used a qualitative design with semi-structured in-depth interviews to explore how Norwegian male partners (*n* = 6) described their experiences of being caregivers of women with cervical cancer during and after the illness. Three analytical themes emerged from the data analysis: loneliness, an altered sexual relationship, and shared feelings of vulnerability. The implications of the study findings indicated that the male caregivers described a form of interdependence in the relationship with the women; however, the bonds were severely altered, notably, in the intimacy or sexuality realm. Based on these authors' empirical findings, the norms of being a man and the values of care and emotion, in the context of severe illness and care, form entwined connections. Further, the researchers suggested that healthcare professionals must increase their awareness of the complexity of the issues regarding physical intimacy and sexuality in this area of study and refer couples to psychologists and/or mental health therapists specializing in sex therapy to help them restore their sexual intimacy.

Husbands and sons differ in many of their caregiving experiences. Figueiredo et al.'s (2016) exploratory qualitative study of 12 male caregivers (husbands = 7, sons = 5) in Portugal highlighted the commonalities and differences of these carers of chronic obstructive pulmonary disease (COPD) family members. The majority of caregiver/care recipient dyads co-resided (*n* = 10), married (*n* = 10), and duration in the role (> 4 years; *n* = 8). Most of the husbands were retired (*n* = 5), and all sons had full-time employment. The key themes that derived from the study were described as (a) Meaning; an extension of marital role (husbands) and fulfilling a sense of duty (sons); (b) Challenges and constraints; household tasks (husbands) vs. conciliating personal and profession life (sons); (c) Fears; losing the life partner (husbands) vs. becoming sill and unable to provide care (sons); (d) Needs; practical skills (husbands) vs. education and self-confidence (sons); and (e) Positive aspects; wives' self-confidence and emotional strength (husbands) vs. opportunity for personal growth (sons). The general findings identified competent and dedicated caregivers with differing experiences based on their relationship type and possibly generational differences. Consistent with the caregiver literature (Lopez-Anuarbe & Kohli, 2019; Sanders & Power, 2009), this study reported a strong sense of commitment, filial obligation, work challenges, intimate/personal care tasks difficulties, and positive aspects (i.e., gratification, "*labor of love*") in the caregiving experiences.

Spousal Caregivers

Male spousal caregivers perform a crucial role in the increasingly complex long-standing care of community-dwelling older adults (Pierce et al., 2019; Reinhard et al., 2014). Spouses tend to be the first choice of primary caregiver for care recipients when help is needed. These men take on the primary caregiver role if they are capable of doing the necessary tasks, and they assume the provision of care even if the care recipient is severely impaired or if their health is poor (Black et al., 2018; Neufeld & Kushner, 2009; Pierce et al., 2019). These caregivers have been reported to minimize difficult situations, deny problems, and are persistent in a task-focused, problem-solving style when managing caregiving circumstances. Older spousal caregivers provide more extensive and comprehensive care (i.e., daily care/household duties, therapy/medication schedules) (Pierce et al., 2019). Men have been reported to maintain the caregiving role longer, experience more severe adjustment demands on lifestyle, and report greater burden, personal strain, and physical stress (Lopez-Anuarbe & Kohli, 2019) than younger spouses or other caregivers (Wittenberg-Lyles et al., 2014). The older spousal caregiver has been shown to experience distinct aging-related stress during caregiving (Wittenberg-Lyles et al., 2014). For example, in Wittenberg-Lyles et al.'s (2014) study, caregivers conveyed worry that their aging would impede their ability to provide quality care. Although caregiving spouses are willing and committed to helping each other, they often demonstrate adverse outcomes that represent depressive symptoms, anxiety, stress, and physical impairment (E. E. Brown & Jackson, 2004). Caregivers in Pierce et al.'s (2019) study reported "feeling physically, mentally, and emotionally exhausted" and feeling "run down," "pulled something in my back," and "feels like I'm on an emotional roller coaster." Spouses in caregiving situations may be at advanced ages with limited physical and stamina for the tasks of caregiving and sole responsibility of performing household tasks and home maintenance that were previously shared. This group of male carers has reported self-doubt, worry, perceived most caregiving activities as "feminine" (i.e., cooking, cleaning, personal care), and reported emotional and physical exhaustion (Milligan & Morbey, 2016).

Coe and Neufeld (1999) studied male caregivers of dementia, Alzheimer's disease, or cognitive impaired care recipients. The sample mainly consisted of husbands (*n* = 17), sons (*n* = 3), and kin/friend (*n* = 4). The majority of the caregivers were over 60 years of age and retired (*n* = 19). The primary care recipient were wives (*n* = 17). Annual income ranged from less than $20 000 to more than $40,000. The duration in the role varied from less than 2 years to more than 11 years. The study participants expressed both positive and negative feelings regarding their experiences as caregivers in seeking support. According to the researchers, the caregivers also reported frustration, helplessness, uncertainty, displeasure, desperation, and shame. The study findings revealed that personal barriers deterred male caregivers from getting assistance and that men were isolated and reluctant to disclose their situation. It was only when men faced a crisis that they accepted formal care, and their interaction with the health care system and individual members had both enabling and disabling effects.

A qualitative study led by Sanders and Power (2009) investigated changes in the roles, responsibilities, and relationships of all non-Hispanic White spouses (*n* = 17) in the caregiving role to wives suffering from memory loss and other chronic conditions. All caregivers had received or were receiving some form of formal or informal assistance, i.e., adult daycare facilities, in-home personal care assistance, chore, laundry services. Two main themes emerged from their findings. The first theme pertained to the adaptation of old marital roles and new caregiving responsibilities. The categories that emerged from the study included: (a) self-esteem, dignity, and personhood; (b) provider of personal care; (c) activity planner and socialization; and (d) home maintenance and keeper. The second theme is related to the changes within the relationship between the dyad due to the onset and progression of memory loss and the other chronic health condition. Four categories emerged within this area: (a) developing a new type of intimacy and closeness, (b) adjusting to the personality changes associated with chronic illness, (c) learning to cope with the unexpected, and (d) recognizing the finality of the relationship. Overall, their findings suggested that husbands adapted to their new role as caregivers and learned to form new relationships with their wives.

Son Caregivers

Minimal research exists that explores male caregivers’ roles, specifically sons, as caregivers to parents (Weinland, 2009). With an aging cohort of community-dwelling older adults, men can no longer be considered bystanders as caregivers to their aging parents (Collins, 2014). Of the one out of three male caregivers, an estimated 30% of these male caregivers are sons (AARP/NAC, 2020). Due to a changing landscape of the family structure, such as geographic distanced or family members, personal health issues (i.e., daughters), sons as an only child (Grigorovich et al., 2016), sons have assumed a more active role in the provision of care (Collins, 2014). Compared to male spousal caregivers, sons demonstrated higher emotional and financial strain in the role (Lopez-Anuarbe & Kohli, 2019). This same study showed that son participants reported less personal time from their 2011 to 2015 longitudinal study results (57%, 52%, respectively). The possibility of adverse mental and physical health may be due to a lack of personal time. While daughters continue to emerge as the principal primary care providers for aging parents, there is a significant trend describing sons’ caregiving roles, although limited in the scientific research realm.

Grigorovich et al.’s (2016) study of sons (n = 20) caring for a parent with dementia, using a qualitative descriptive approach. Based on the findings that approximately 40% of dementia caregivers are husbands (McDonnell & Ryan, 2014; Robinson et al., 2014), the researchers used a qualitative descriptive approach to explore the roles and coping strategies of son caregivers in a parent with dementia. The themes that were developed from this study included (a) coming to care, (b) managing the care,

(c) the impact of providing care on sons, and (d) coping with the role. The finding revealed that many of the caregivers gradually assumed the role under the conditions such as previously held (or shared) power of attorney for their parent or managed their parent's finances before the parent's diagnosis and gradually expanded these duties or no sibling available to provide care. The men described both positive and adverse effects, such as "satisfaction or personal growth" and "developing a closer relationship with their parent and with other family members." One example of an adverse effect was reported as the difficulty maintaining participation in valued activities (e.g., employment, leisure, exercise) and social relations with their own family and friends. The caregivers expressed coping with "setting boundaries," and they employed "self-care" strategies. The caregivers also maintained participation in leisure activities and their valued interests. Finally, supportive networks were identified through the use of other family members, formal and informal support (i.e., aides, nurses; community day programs), psychoeducation support and services (in-person support group, educational sessions, counseling); and the use of technology, such as cameras, baby monitors, or Skype options to foster communication and to monitor for problem behaviors (i.e., wandering).

McDonnell and Ryan (2014) explored the caregiving experiences of sons (*n* = 13) for a parent in Ireland. Consistent with prior studies (Black et al., 2018; Epps, Rose, & Lopez, 2019; Mars et al., 2017; Samson et al., 2016), commitment and a strong sense of duty were reported by the caregivers. Positive effects of caregiving were expressed with narratives such as "giving something back to their parents," "it's payback time," and satisfaction based on the belief that they [sons] were "doing the best" in the provision of care. The son caregivers referred to the role as ‘binding’ and found it difficult to detach themselves. The sons also described the role as “engrossing” and “consuming.” Regarding social life, one caregiver shared, “Your social life and your work have to stop … even relationships … telling a person that you are caring for your mother … they look at you as if to say … that’s not a job for a man” (McDonnell & Ryan, 2014, p. 794). As a result of the stress and strain, caregiving’s adverse effects were mediated by coping factors, illustrated as “inner strength and courage” and “will power and determination.”

African American Male Caregiver Literature

Although the non-referred literature is abundant with findings regarding the increasing role of male caregivers in our aging society, the contributions of African American caregivers have been underrepresented in peer-reviewed publications (Collins, 2014; Cothran et al., 2020; Mott et al., 2019), or male caregivers in general (Simpson et al., 2018). Research and literature on African American older males as informal, primary caregivers of disabled or impaired family members, particularly spouses, are negligible (Black et al., 2018). These caregivers’ gendered experiences remain marginalized, as seen by low participant rates for African American male caregivers with obscure or underreported (Simpson et al., 2018). While other works have supported the dearth of research on male caregivers, gaps also exist due to the lack of African American male caregivers’ averseness as a family caregiver. Male caregivers in the Black et al. (2018) study on elderly spousal caregiving responded “no” to the caregiver label’s inquiry. Instead, they described themselves as “just a loving husband” or “devoted son” and “doing what I’m supposed to do.” When examining the intersection of African American male caregiving experiences with care of dependent, chronically ill family members, the benefits, challenges, and interventions are limited due to a lack of distinct and empirical research studies.

Health Status

The significance of understanding the underlying health issues of African American men, in general, is because this group exhibits the highest mortality rate and the worse health profile compared to other racial/ethnic groups of men (Thorpe & Whitfield, 2018). Given the multi-dimensional and complex role of caregiving, combined with the physical, psychosocial, physiological, and financial factors that African American men face in the role, their health behaviors and health outcomes are significant areas of study. Yet, there is a paucity of research focused on the impact of these factors on African American men’s health and well-being (Thorpe & Whitfield, 2018).

Weinland’s (2009) study has been repeatedly referenced in the caregiver literature on the minimal available research on African American male caregivers. In her phenomenological study that described the lived experiences of this population of male caregivers (n=10), Weinland’s findings produced commonly seen themes in this area of study for male caregivers, in general: commitment (Mars et al., 2017; Powers & Whitlatch, 2016; Simpson et al., 2018), supportive networks, spirituality (Dilworth-Anderson et al., 2002; Epps, Brewster, et al., 2019; Rathier et al., 2015; Samson et al., 2016; Zauszniewski et al., 2018), stress (Boltz et al., 2016; Epps, Rose, & Lopez, 2019; Geiger et al., 2015; Wittenberg-Lyles et al., 2014), as well as, time and financial strain (L. L. Brown et al., 2018; Lopez et al., 2012). Specific to this research, a few of the men reported “role reversal” with the role assumption or “use of humor” in the care of a female recipient, which improved the caregiver’s comfort level. Most of the caregivers were unable to pay for formal or informal services. A few (*n* = 3) were hesitant to have support (i.e., home health aides, transportation assistance, or medically required therapy support. However, a strong sense of family support was reported by the caregivers (*n* = 7). Concurrent with other studies (Boltz et al., 2016; Epps, Rose, & Lopez, 2019; Mars et al., 2017; Powers & Whitlatch, 2016; Simpson et al., 2018), a familial obligation was also a significant finding. Interestingly, highly educated African American male caregivers (mostly sons) had lower scores regarding filial and religious obligations than African-American female caregivers and those with less education (Dilworth-Anderson et al., 2005).

L. A. Williams (2015) researched the phenomenon of male caregiving experiences of persons with end-stage renal disease (ESRD) as a dissertation study. The researcher used the stress process model (SPM) as the theoretical framework. Twenty-nine male caregivers were recruited for the quantitative cross-sectional study. The findings provided descriptive demographic data of the sample and the caregivers’ objective and subjective levels of burden, depressive symptoms, and perceived health status. The majority of study participants were African American (79.3%), married (65.5%), and unemployed (51.7%). The average age was 57.1 ± 16.4 years, and the majority co-resided with the care recipient (82.7%), who were mostly females (89.6%). The results also showed that the vast majority of caregivers (93%) experienced moderate to high levels of objective burden (28.8 ± 4.4). The subjective burden was scored as ‘moderate’ and ranged from 13 to 65 (average = 47.7 ± 9.2). More than half (58%) of caregivers reported mild to severe depressive symptoms. Regarding health status, most caregivers rated their health as ‘good’; however, one-third rated their health status as fair or poor, and 14% reported their health had worsened since assuming the caregiver role. The relationship among burden, depressive symptoms, and self-rated health was reported as follows: objective burden was significantly and positively correlated with the subjective burden (*r* = 0.48; *p* = 0.01; 95% CI [.07, .13]. Weakly positive relationships were reported between objective burden and depressive symptoms and objective burden and health status. However, a significantly positive correlation was reported between caregiver subjective burden and depressive symptoms, *r* = 0.36; *p* = 0.05; 95% CI [.64, .01]. In sum, the findings were consistent with prior research and supported previously tested interventions in female ESRD caregivers; however, future studies that addressed the specific needs of male caregivers of persons with ESRD are needed (L. A. Williams, 2015).

Another qualitative study that explored the perceptions of caregiving by African American male caregivers of persons with Alzheimer’s disease (AD) was conducted by Henry-Edwards (2013) as a dissertation study that used the stress/adaptation theoretical framework. The purposeful sample of men (*n* = 6) were age 47 to 69 years, married (*n* = 3), sole caregiver (*n* = 4), and religious affiliation (e.g., Baptist, Methodist, Christian, Seventh-Day Adventist) (*n* = 6). Most of the participants had (*n* = 5) had college-level education, employed (*n* = 3), retired (*n* = 3); annual personal income (greater than 100K = 3; 50 to 75K = 2; 0 to 25K = 1). The duration of the caregiving ranged from 18 months to 8 years. Care recipients ranged in age from 76 to 93. The five research questions for the study centered around (a) role as caregiver, (b) major stressors, (c) support networks, (d) decision to become a caregiver, and (e) impact of the role in caregiver lives. In this study, spouse caregivers revealed the themes of obligation, resignation, enduring, need for specialized resources, loss, and household manager. Son caregivers and the one paid caregiver revealed the themes of obligation, loss, emotional detachment, behavioral symptoms of dementia, role conflict, church family, reciprocity, and reflection. Their overall response to the caregiver role was positive. Responses included statements like: “I feel good; I’m glad; I’m happy; I don’t regret it; I would do it again; I feel very well about it.” Overall, the findings from both the spouse and son caregivers of the study were congruent with prior studies on male caregivers (Henry-Edwards, 2013). Moreover, the author suggested that differences, based on race, will require in-depth studies with larger samples, including variables of income, education, age or caregiver, stage of victim disease, and environmental support.

As a dissertation research study, J. F. Moore (2010) conducted a qualitative survey of African American male caregivers (*n* = 20) in the South-central region of the U.S. The self-identified male carers provided care to care recipients over the age of 50 and were related to the caregiver as their mother, father, stepmother, aunt, companion, brother, and fictive kin. The major themes that were presented from this research were (a) personal choice as a caregiver, (b) non-traditional caregiver roles, (c) skill malfit, and (d) range of duties as a caregiver. Twenty-five percent of participants reported informal training, while 31% stated formal caregiving training. Nearly 45% provided care between

20 and 50 hours a week. Consistent with other studies, the men assisted with ADLs, personal hygiene duties, and transportation duties. Seventy-five percent provided some form of medical care and 70% prepared meals. Other duties consisted of grooming, financial management, and shopping. Many men did not plan to take on the caregiver role but did not want to place their loved ones in a nursing home and “age in place.” The men in this study demonstrated a strong commitment to providing care. The caregivers also reported challenges, worry, and stress. Stress relief activities included physical exercise, relaxing, and resting. Other ways of coping consisted of “church,” “hang out with friends,” “short trips,” “tie out to the lake to kind of rejuvenate my spirit.” A significant challenge presented as described in the lack of home management and nursing skills to perform the role—or skill malfit. Consistent with most male caregiving studies, the participants in this study expressed significant discomfort in performing personal hygiene tasks. The narratives reported by many of the men reflected a strong support network, which included help from spouses, partner, family members, friends, or significant others.

Gaps in the Literature

As the older adult population becomes more diverse and more than 50% of Americans are estimated to identify as a member of a minority group by 2044 (Colby & Ortman, 2015), it is imperative to address the lack of empirical research that focuses specifically on African American male caregivers. This same group of elderly Americans (age 65 and older) is projected to nearly double from 49 million in 2016 to 95 million by 2060 (U.S. Census Bureau, 2020); with the 85 years and older group expected to double from 6.5 million (2020) to 11.8 million (2030) and triple to 19 million by 2060. Simultaneously, the number of older adults with some chronic, debilitating condition is expected to increase. To illustrate this point, the progressively debilitating effects of dementia are a chronic illness that, at some point, will cause mild to total dependency on others. African Americans are a high-risk group for developing this particular condition. Caregivers of people with dementia exhibit more symptoms of anxiety and depression than non-caregivers (Joling et al., 2015) and experience stress, burden, and sleep disturbances (Chiu et al., 2014). The need to consider the escalating rise in African American elders means the number of elderly persons with chronic health conditions may require support services and informal caregiving by family and friends to remain community-dwelling residents.

As this review on the current state of caregiving has demonstrated, men have assumed increased roles and duties as family caregivers (AARP/NAC, 2020; Baker et al., 2010; Sharma et al., 2016). These husbands, brothers, sons, sons-in-law, partners, friends, and neighbors play a significant part in the league of family caregivers providing care across the country (Accius, 2019). This review has identified the reluctance of many male caregivers seeking advice and assistance with the complex issues that occur in the caregiving process. Difficulty accessing services, mistrust of healthcare providers, or social injustices served as the basis for the men seeking help. Concerningly, these caregivers are less likely to disclose to others when they feel stressed or overwhelmed by caregiving responsibilities (Ianzito, 2017), thereby increasing their caregiver burden. Furthermore, what this review has shown is that stress and burden may lead to adverse health outcomes such as psychological effects (i.e., depression, anxiety), physical effects (i.e., hypertension), or social isolation (Black et al., 2018; Green, 2020).

Lack of Empirical Research

Research on African American men's caregiver experiences is substantially underrepresented in current empirical research studies (Collins, 2014; McDonnell & Ryan, 2014; Mott et al., 2019; Robinson et al., 2014; Thorpe & Whitfield, 2018). Regarding the dearth of research on male caregivers, L. A. Williams et al. (2017) reported that few studies documented the experiences of male caregivers of persons with chronic illness. Before her research, no reviews were found on ESRD caregivers. Henry-Edwards (2013) and Houde's (2002) studies reported the lack of adequate male caregiver participants in health care research; thereby, generalizing findings from mixed studies or other racial/ethnic groups is seen as a limitation. Specifically, Mott et al. (2019) purported that there has been almost no research on improving quality of life, decreasing depression, or increasing hope for men caring for cancer patients.

Cultural-Focused Research

Peggye Dilworth-Anderson, a scholar and content expert in caregiving research, has published numerous studies on the necessity of including the impact of culture in the study of African American caregiving (Dilworth-Anderson et al., 2004). Health outcomes in African American caregivers have been linked with cultural beliefs and values. The literature has presented substantial data on the cultural values and norms for deciding to be a caregiver. Many African American caregivers continue to take on this responsibility based on cultural justifications at a point of deep sacrifice and burden. Given this familism-type of caring for a dependent loved one, amidst financial strain and the array of psychosocial, physiological, and psychological stressors, what makes men, especially African American men, committed to the role needs further exploration. Understanding the stress and burden on caregivers is a particularly crucial time in caregiving research where our society's current state is living with the weight of the COVID-19 pandemic.

Minimal Access to Formal and Informal Support

The lack of formal and informal use of available services to support caregivers, and subsequently, the care recipients were seen as a challenge for many male caregivers. As stated previously, these challenges were attributed to multiple reasons (i.e., unawareness of services, preference to manage care independently, mistrust issues, etc.). Other factors identified included unwillingness to accept help based on cultural norms and values, leading to social isolation issues, a major theme shared in the study participants' responses across many of the studies. The literature supported the access gap in supportive networks (Black et al., 2018; McDonnell & Ryan, 2014; Simpson et al., 2018; Weinland, 2009), where findings showed that the inability to have social relations with family and friends, church, employment, etc., was often related to the failure to access supportive networks.

Education

Throughout the literature review, many studies revealed an education deficit related to a lack of access to informational resources to support caregivers' ability to manage the role. Family caregivers are likely to receive little to no training on providing care, contributing to the potential for adverse outcomes, such as depression symptoms, anxiety, stress, and emotional difficulties (Schulz & Eden, 2016). The results of this synthesis revealed several gaps in what is needed to support male caregivers. Specific gaps were identified, such as understanding the disease process and management of chronic illnesses, such as dementia (Black et al., 2018; B. R. Hansen et al., 2019) and ESRD (L. A. Williams et al., 2017), in African American male caregivers. The caregivers' educational levels were widespread, with most of the participants self-reported high-school to advanced degrees acquired. To better understand what constitutes the deficits in educational needs (i.e., resources, skill training) requires further exploration.

Marginalization and Stigma

The effects of being marginalized compounded with the stigma of being a male caregiver, African American male caregiver, or a gay/partner male caregiver has produced adverse emotions and outcomes in caregivers and their families. A knowledge gap is perceived in this area related to the lack of understanding of disease trajectory or chronic health illness progression (i.e., mental illness or advanced disruptive behaviors of dementia) on behalf of the caregiver, families, and communities. Many men expressed a sense of shame associated with the carer role, whether seen as the averseness to self-identifying as a caregiver or the relatedness of the diagnosis (i.e., HIV/AIDS, schizophrenia). A few of the studies cited healthcare providers' slow uptick in recognizing the male caregiver's role in caregiver/care receiver dyad or the perception that disruptive behaviors associated with advanced mental illness states were attributed to a judgment of punishment (i.e., sin).

Intimacy/Sexuality

Surprisingly, the topic of intimacy and sexuality was seldomly mentioned in most of the studies in this review. Possibly this was because many of the studies involved older adult caregivers, and affection was demonstrated in other non-sexual ways. The studies that included minimal discussion were related to the men's descriptions of the adverse effects in the relationship associated with cancer-type illnesses (breast or gynecological cancers, HIV/AIDS). Whether this is an unspoken topic due to the intimate details of sexuality will be an important area to be attentive to in this study.

Addressing Gaps in the Literature for the Dissertation Study

One of the most critical approaches to addressing the numerous gaps identified in this review of the literature can be addressed by advancing empirical research studies that include all family caregivers, particularly African American male caregivers. The accessibility of current, state-of-the-science on male caregivers, with a narrow focus on African American males, demonstrates an insufficiency of published academic research in the caregiver literature. As discussed previously, the researcher found minimal studies that focused primarily on African American male caregivers. Expanding the scope to include all male caregivers still yielded negligible results. Many studies that were close fits were significantly outdated; therefore, requiring the need to examine the historical perspectives and seminal findings by content experts, such as researcher Peggye Dilworth-Anderson or Jo-Ann Weinland. Although the insights and expertise are well-received, times have changed, so have people, technology, and science. New research, gender-specific research, and ethnic research must occur to meet the needs for tailored interventions and strategies. This review has emphasized the cultural values and familism in African American caregivers. Empirical research is needed to see how these values and beliefs resonate with African American male caregivers.

Conclusion

Projections for a growing aging population and epidemiologic trends of aging with more significant chronic disease burden, informal family caregivers will likely reach epidemic rates in future decades. Despite the extensive literature on family caregiving, much remains to be understood about why people take on strenuous caregiving duties, how they approach their caregiving responsibilities, and the consequences of taking up a caregiver’s role. From an African American male perspective, a more accurate understanding of the caregiving context, which includes gender, familial relationship, and cultural background of the caregiver, is necessary to gain insight into caregiving experiences. The caregiving and aging research would benefit from the ideas to address the knowledge gap in this research area to support African American men’s health and the enduring societal and family demands of family caregivers.

This synthesis of the current state of the science aimed to provide a perspective of the breadth and depth undertaken to demonstrate the need for ongoing and enhanced research on male caregivers. Where African American male caregivers have been included in empirical studies, their experiences have been negligible in scholarly publications or buried in the number of studies that present male and female findings. To the point with this dissertation, what has been demonstrated from this literature review are the challenges when investigating peer-reviewed or academic research to understand the plight of African American male caregivers in their commitment to caregiving roles and how they do this impact them psychologically, physiologically, and socially. It is not the researcher's intended criticism to misrepresent African American men's inclusion or understudy in these types of studies but rather to highlight their accomplishments, contributions, and struggles. This underrepresentation in academic publications does not mean that these male carers' narratives are not being told. If they exist, they are not readily accessible or have not been accepted or disseminated in peer-reviewed journals. This lack of peer-reviewed sources is evidenced by the number of unpublished dissertations that have supported this review of the literature. This void in dissemination limits the findings that can add to the existing research on caregiving, inform the attention of policymakers, legislators, health care providers, and administrators, and clinical nurses. The stated interest in understanding and exploring African American male caregivers' experiences for this dissertation study contributes to the lack of existing literature on racial/ethnic caregiver research. This study's contributions can expand the scope of empirical research findings that support caregivers in health promotion and health disparities.

CHAPTER III

METHODOLOGY

Purpose of the Study

This chapter describes the research methodology selected to address the research problem: the need to understand African American male caregivers' experiences caring for a dependent family member with a chronic illness during a pandemic. The current study used a qualitative descriptive approach to answer the research questions. The purpose of the study was two-fold. The first objective was to describe the experiences of African American male caregivers who are (or were) the primary family caregiver to a dependent, chronically ill family member and explore how caregiving affected their health-related quality of life using the Revised Sociocultural Stress and Coping Model (SSCM) to guide the study. The second objective was to understand the psychological, physiological, psychosocial, and financial outcomes on the health and well-being of African American male caregivers related to their caregiving experience during a COVID-19 pandemic. By applying a qualitative descriptive approach (Sandelowski, 2000), the researcher extrapolated themes from the rich descriptions provided by this group of caregivers. The study used the Revised SSCM adapted by B. G. Knight and Sayegh (2010) as the conceptual framework to explain how the study participants' experiences are represented in the model and how their associated pathways impact the male's health outcomes caregiver.

A comprehensive literature review was undertaken using various literary and research sources that provided insights into the issues that caregivers face, in general, and a more distinct focus on male caregivers, specifically, African American male caregivers. This examination of the literature identified numerous gaps that demand an enhanced awareness or an ‘awakening’ of the health inequities affecting the male caregivers’ population. As previously mentioned, the gaps that exist in the literature are numerous; a few of these gaps are seen as (a) prior research primarily focused on female caregivers or non-Hispanic White caregivers; (b) the underrepresentation or omission of African American caregivers in empirical studies; (c) methodological issues, particularly with sampling design; (d) lack of, or minimal, interventions that are tailored to the ethnic and cultural differences of specific groups, such as African American male caregivers; and (e) application of SSCM for African American male caregivers during a global pandemic.

This qualitative study fills this gap in knowledge about male caregivers’ experiences and issues. This chapter describes the methods used to investigate the proposed research questions, the research design, target population, and the selected sample. This section also includes details of the procedures, such as participant selection, protection of the participants, data collection and analysis, informed by the Sociocultural Stress and Coping Model (SSCM) as the conceptual framework to guide this study. The model is a theoretically based conceptual framework for understanding caregiver stress and coping processes across diverse cultural groups (B. G. Knight & Sayegh, 2010). The revised model recognizes that differences exist among diverse cultural groups built around a shared common core model in which caregiver stressors lead to the appraisal of caregiving as burdensome and thus to poor health outcomes (B. G. Knight & Sayegh, 2010; Losada-Baltar, 2015). The last section of Chapter III summarizes the chapter.

Research Questions

The proposed research sought to answer the following research questions to gain a more comprehensive understanding of the caregiving experiences from African American male caregivers' perspectives.

RQ1: How do African American male caregivers describe their decision to become caregivers?

RQ2: How do African American male caregivers perceive their caregiver role?

RQ3: What coping strategies and support systems do African American caregivers use?

RQ4: "What has been the impact of the COVID-19 pandemic on the lives of African American male caregivers?"

RQ5: "What are significant stressors described by African American male caregivers before, during, or after the pandemic?"

Research Design

Qualitative descriptive research is an appropriate study designed to gain insight and understanding of African American male caregivers' experiences as carers of dependent, chronically ill adult family members. Using the qualitative descriptive approach in this study provided a framework to explore, describe, and understand African American male caregivers' experiences—whether a son, step-son, son-in-law, adopted son, brother, father, uncle, male spouse, or male partner. Qualitative research is applicable in studies when researchers aim to share individual stories of participants, use a literary or flexible writing style, and understand the context or setting of issues (Colorafi & Evans, 2016). The processes for quantitative and qualitative are similar; however, qualitative methods rely on text and image data, have unique steps in data analysis, and draw on diverse designs (Creswell & Creswell, 2018). Kim, Sefcik, and Bradway (2017) performed a systematic review of qualitative descriptive studies' characteristics. Their findings justified that many scholars used qualitative description in their study designs and subsequent publications. As purported by these same researchers, qualitative descriptive as a scholarly approach allows flexibility as research questions and study findings change during an investigation. The conclusions from this research coincide with Polit and Beck's (2017) position that research designs demonstrated a significant increase in the use of a qualitative descriptive approach, supporting this approach's relevance and significance in nursing research and possibly other scholarly disciplines. Several assumptions regarding the qualitative description research approach are discussed. Philosophical perspectives dictate what constitutes knowledge and how phenomena should be studied (Bradshaw et al., 2017). Conforming to Bradshaw et al. (2017), within this approach, philosophical underpinnings of qualitative description consist of: (a) an inductive process, (b) subjectivity, (c) a specified approach to understand and describe phenomenon (d) researcher role in the phenomenon of study, (e) an emic stance), and (f) naturalistic data collection setting. Ontological assumptions consider reality as subjective and vary among people. Here, the senses and consciousness engage in producing multiple realities. The epistemological assumption views the approach based on real-world phenomena, or subjectivism. Subjectivism accepts all objects' reality and relies on a person's subjective awareness of the truth, and considers the researcher's role and contribution during the study (Bradshaw et al., 2017).

According to Sandelowski (2000), the qualitative descriptive approach presents the phenomenon of interest "in everyday terms of those events" (Sandelowski, 2000, p. 336). These studies are interested in discovering the "who," "what," "where," and "why" of events or experiences (Bradshaw et al., 2017). The researcher aims to provide a rich (or thick) description of the study participants' experiences in easily understood language (Grigorovich et al., 2016). This approach's key characteristic is the term "data-near" (Sandelowski, 2010), meaning that the study's findings are close to the data. This study captured the 'rich data' through the experiences of these male caregivers; and provides a more explicit understanding and meaning to their emotions, needs, struggles, or gratifications, from their perspectives—with their narratives. In turn, this knowledge can lead to strategies and interventions that may offer supportive networks to these caregivers to ease their caregiver burden and continue in the caregiving role to their loved ones.

Sample

This study examined the experiences of African American male family members of significant others, who are primary caregivers of dependent, chronically ill family members. A purposive sample of African American men who self-report as caregivers was included in the current study. According to Bradshaw et al. (2017), purposive sampling selection is based on accessibility to the participants and the researcher's ability to select participants whose qualities or experiences. Purposive sampling aims to generate insight and an in-depth understanding of the topic of interest while choosing participants based on their basis to provide data-rich information for analysis (Braun & Clarke, 2013).

Sample Size

In qualitative studies, the sample size should be based on informational needs—generally, to generate enough in-depth data to illuminate the patterns, categories, and dimensions of the studied phenomenon (Polit & Beck, 2017). The sample size may refer to the numbers of participants or numbers of interviews and observations conducted and the numbers of events sampled (Sandelowski, 1995, p. 180). Data saturation is generally the accepted standard to determine sample size in qualitative research when additional data fails to generate new information (Braun & Clarke, 2013; Polit & Beck, 2017; Sandelowski, 1995). According to Braun and Clarke (2013), interviews require an adequate sample size between 15 and 30. For this study, it was expected that a sample of 15 to 20 participants would be used; or until data saturation occurs. The anticipated sample of participants was based on previous studies with similar sizes in this area of research. Grigorovich et al. (2016) used an exploratory qualitative descriptive approach in a study conducted with 20 son caregivers of a parent with dementia. McDonnell and Ryan (2014) used a purposive sample of son caregivers (N =13), who were the primary carers of a parent with dementia. Lopez et al. (2012) explored male spouses'/partners' experience of caring for their wives/partners with breast and gynecologic cancer. Using an exploratory longitudinal qualitative descriptive design, the researchers used face-to-face interviews of 15 spouses/partners in the study. This study required 13 participants to reach data saturation.

Recruitment

Researching family caregivers of chronically ill family members has many challenges, such as identifying and accessing family caregivers (D. Hansen et al., 2017), as well as finding caregivers with time to participate, despite their caregiving responsibilities (Horrell et al., 2015; Morrison et al., 2016). In the current study, recruitment of research participants occurred via recruitment flyers posted in public areas, such as barbershops, adult daycare senior centers, African American churches, and a caregiver book promotion WebEx. The researcher also enlisted the assistance of one local adult daycare program social worker who served as the liaison between the program's male caregivers and the researcher. The social worker was instrumental in sending all study materials to a select group of caregivers via email, who agreed to review the study details. The social worker also posted hardcopy flyers in the designated patient care areas around the facility. The flyer detailed the essential eligibility requirements and instructed the men to call or email the researcher.

Social media recruitment for research studies has increased. A potential advantage in using this form of recruitment is the researchers' possibility to reach hard-to-reach individuals (Allsworth, 2015; Waltz et al., 2017). It is also cost-effective (Allsworth, 2015), and it allows individuals to share specific interests and characteristics, attitudes, values, beliefs, and problems about an issue (Waltz et al., 2017). Social media networking has been integrated into many Americans' daily lives and has become an important means for public communication. These forms of interactions are an important aspect of modern society and can potentially affect family caregivers' health (D. Hansen et al., 2017). Dissemination and collection of cutting-edge geriatrics-focused research are essential for academic geriatrics researchers, clinicians, older adults, and their caregivers (Lindquist & Ramirez-Zohfeld, 2019). In 2016, about one-third of older adults utilized at least one social media site, such as Facebook or LinkedIn. Facebook remained the most commonly used social media site in this age group (S. Greenwood et al., 2016). The previously mentioned social media forums provide a means of quickly reaching a wide range of users. Therefore, the social media platforms Facebook and LinkedIn were also used to recruit the men who self-reported as primary caregivers to a dependent family member. This was accomplished by the researcher’s contact with friends, colleagues, and church members who agreed to place the social media flyer on their social media platforms. The social media flyer was approved by the researcher’s dissertation committee and University’s IRB.

Recruitment Process

The process of recruiting the male participants used a paper flyer for self-referrals or social media recruitment flyer (identical to the paper flyer) containing the same information (see Appendix A: “Recruitment Flyer”). Both forms of communication directed the potential participant to contact the researcher, from which the eligibility to participate is determined by the researcher. Either form of recruitment can elicit more potential participants through word-of-mouth or snowball sampling, thereby promoting early eligible participants to refer to other people who meet the eligibility criteria (Polit & Beck, 2017). For the social media recruitment process, the flyer was sent to nurse colleagues and personal friends, who then placed the flyer on their respective social media networks (i.e., Facebook, LinkedIn). Once the flyer was accessed, the study information and criteria to participate were available for the potential participant caregiver to assess their ability to participate. The flyer information contained the inclusion criteria, the researcher and dissertation chair names, and contact information.

If the caregiver believed that he qualified to participate, he was directed through the written or email correspondence to contact the researcher for the next steps. The participant was rescreened after contacting the researcher to validate that he met the study's inclusion criteria. If the participant qualified for inclusion, the following steps were followed: the recruitment letter (see Appendix B) and the IRB Information Sheet (see Appendix C) were sent via the caregiver's email address by the researcher. After the potential caregiver read these documents, the researcher confirmed understanding of the content and answered any potential caregiver's questions. Upon confirmation of the caregivers' qualification of the study's inclusion criteria, the scheduled date and time to conduct the interview was determined between the caregiver and the researcher at the caregiver's convenience. If a potential participant contacted the researcher but did not meet the study criteria, the researcher thanked him for taking the time to consider participation in the study. The caregiver was not accepted as a study participant. However, the researcher inquired if he could or would like to refer another potential participant. Finally, for any caregiver that participated in the study, the researcher communicated the opportunity to contact national caregiver support services during the interview. The information was available upon his request via the caregivers' email address. Participants who enrolled and completed the research study were offered a $25 gift card via postal mail or an electronic transaction as an incentive to participate.

Procedures

The procedures for conducting this qualitative descriptive study include the following sections: (a) participant selection, (b) protection of the participants/ethical considerations, (c) instrumentation, (d) data collection, and (e) data analysis. Before beginning the interviews, the researcher reviewed the caregiver literature to establish a baseline understanding of male caregivers as primary caregivers in caregiving's broader context. Based on the phenomenon of the study—African American male caregivers, a specific focus to develop an interview guide specific to male caregivers while developing guiding questions that would answer the research questions was undertaken. Therefore, a demographic survey was devised (see Appendix D) and the researcher-designed interview guide (see Appendix E) based on the caregiver literature in this area of study.

Participant Inclusion/Exclusion Criteria

The inclusion criteria for male caregiver participants in the study included (a) African American men over the age of 18 years of an adult family member with the chronic illness; (b) self-report as the primary caregiver for at least six months or within 2 years of the caregiving experience; (c) English-speaking; (d) able to understand the purpose of the study and agree to participate voluntarily; and (e) willingness to participate in an interview for 45 minutes to one hour, via telephone or mobile phone, or a form of social media (i.e., Zoom). Exclusion criteria were if the male caregiver functions in a secondary caregiver role.

The decision to use the specified timeframes for the caregiver experiences “six months as a primary caregiver and within two years of the caregiving experience” was based on the following rationales. The informal family caregiver is not professionally trained to be a care provider in most instances. The researcher recognizes that paid healthcare professionals are also family caregivers; however, they are not the target population of this study. While there are no empirical data to support a specified timeframe when a caregiver begins to manifest symptoms of caregiver stress or burden, to my knowledge, six months in the caregiver role seems to be a sufficient amount of time to assume the role demands and possibly feel the effects of caregiving to a dependent family member. This researcher’s clinical judgment that any time sooner than the six months may find the caregiver in the novice or honeymoon phase of caregiving. This judgment is perceived to be similar to Level 1 (Novice) to Level 2 (Advanced beginner) of Benner’s From Novice to Expert model for nurses (Benner, 1982). The rationale for using the “within two years of the caregiver experience” was based on the researcher’s perception of Sandelowski’s “data-near” concept (Sandelowski, 2010). Therefore, it is supposed that if a caregiver is farther from the ‘experience’ of caregiving, the likelihood of recall or intensity of the role demands and positive or adverse effects on the physical or emotional well-being of the caregiver may be diminished.

Setting

The location, date, and time for the internet or phone interviews were scheduled for convenience and availability between the researcher and the participant. Participants were requested to participate in the interview in a private location in their own setting.

Protection of Participants/Ethical Considerations

Human Subject Protection

Ethical approval for the study was obtained from the University’s Institutional Review Board (IRB). Ethical considerations included uncoerced, informed, voluntary consent, honest representation of the study’s purpose, and accurate citations. Other protections consisted of (a) identifying potential risks and benefits, (b) ability to withdrawal from the study at any time, (c) confidentiality throughout the study by using coding procedures to disguise identities, (d) protection of data, and (e) destroying audio recordings after transcription.

Risks

This study posed minimal risks to study participants. These risks included unanticipated side effects, such as physical discomfort, fatigue, or boredom. Emotional distress may present from self-disclosure, introspection, fear of repercussions, anger, or embarrassment at research questions.

Protection

Study participants received the required information regarding the research, state understanding of the study, and voluntarily consent to be in the study. Participants could withdraw from the study at any point during the process. The informed consent process included the participant’s signing of the consent form and the researcher’s signature on the form. Both researcher and participant retained a copy of the consent forms.

Potential Benefits

The benefits that study participants stand to gain from participation in research studies are apparent in numerous ways. Firstly, access to intervention and strategies can improve living conditions, and secondly, the contributions of information to enriching the lives of others in similar situations. The incentive for participation in this study was a $25 gift card for each participant, available upon completion of the interview.

Data and Safety Monitoring

The UNCG IRB reviewed the data safety plan for the appropriateness of risk levels in the study. All study forms are in complete control of the researcher. Individual paper forms of demographic questionnaire forms contain de-identified information. They were placed in separate envelopes and stored in a locked cabinet in the researcher's home until data was transferred to a password-protected (multi-level authentication) location. After validating transmitted data, copies were destroyed via shredding and placed in a locked sensitive documents bin. No participant data can be accessed in public venues, where risks of viewing by unauthorized personnel or unsecured servers exist. Data was only accessed through a secure VPN connection. Faculty had restricted access to study data via the university's BOX system (a secure lock system). Data analysis occurred on a designated computer with password and firewall protection. The data will be securely stored for 5 years and then deleted from the computer hard drive and UNCG Box files.

Instrumentation

Different methods to collect the data are used in qualitative research. The most common are personal interviews, focus group discussions, observational techniques, and document analysis. The instruments are used to collect data on various concepts ranging from physical functioning to psychosocial well-being. In qualitative research studies, discussion groups, in-depth interviews, case studies, and focus groups are used most often.

For this study, the researcher used an interview method that incorporated: (a) a semi-structured interview guide (see Appendix E), (b) a demographic questionnaire survey (see Appendix D), and (c) observation as the instrumentation in the current study. The semi-structured interview guide contained questions related to the interview phenomenon covered in the interview (Polit & Beck, 2017). For the current study, nine high-level topics (major areas of focus) were relevant to answering the research questions and encompass the interview guide. The researcher also used supportive questions within the major areas to engage the participant in more essential details about their experiences. Further, the researcher's probe questions were used, when needed, to elicit more detailed responses to critical questions. The semi-structured interview guide major categories are identified as follows:

1. What would you say it means to you, as a male caregiver (CG *) taking care of your (*insert CG title)?*
2. What is it like for you to care for someone with a chronic illness or disability on a day-to-day basis?
3. Some people, even though they provide a lot of care to another person, do not consider themselves as a "caregiver."
   - Why do you think that is?
   - Do you think of yourself as a caregiver?
   - Do others (i.e., family members/significant others (S.O.) think of you as a caregiver? Please explain.
   - Can you share something about how you came to take on the caregiver role for your loved one or care recipient (CR) (*insert CR title)?*

4. What types of benefits do you receive from being a caregiver?
5. Please share any difficulties you may have experienced since you began caring for your family member.
    - Please describe what makes you feel stressed in your caregiver role.
    - Will you describe your experience of the excess burden since you began caring for your family member?
6. How do you cope with the stress or burden of caregiving or being a caregiver?
7. Tell me how being a CG during COVID-19 has:
    - affected you personally (i.e., socially, physically, emotionally, or financially).
    - Affected your ability to provide the same level of care to your loved one?
8. Tell me about how caring for your (*CR title)* has changed your relationship with family or SO.
    - Tell me about the kind of support you get from your family or SO.
    - Tell me about any support you get within the community (i.e., church, support groups, etc.).
    - There are many services available to support caregivers in the community.
9. Thank you for taking the time to tell me about your caregiving experiences. Is there anything else you think I should know?

The semi-structured, open-ended question interview guide used for this study was pretested for content validity with the caregiver during a directed research study in 2019 (*n* = 4) that studied African American son caregivers. Modifications to the guide were made for the dissertation study due to the broader scope of African American male caregivers added to the inclusion criteria.

The interview questions were not developed to be read verbatim or in order; but rather as a guide, when needed, to focus on the research questions. Additionally, the researcher can add more questions about an unexpected but relevant area that emerges, and sections of the pre-determined guide that does not apply to the participant are not used (S. Knight, 2013). The use of motivational probes (i.e., conversation continuers) allows the researcher to gain more detail, encourage the participant to elaborate more, or provide more clarity about an issue or help the research more fully understand some process (Polit & Beck, 2017). During the interview, a question that arose from one caregiver posed explicitly as a possible line of inquiry for other caregivers was, “Ask other men, are they happy.” The researcher proceeded to ask the next participant this specific question. The response seemed to elicit a sense of aggravation and was therefore not used in further inquiries. The researcher did not need to pose any additional questions beyond the pre-determined guide and probe questions to answer the research questions. The interviews occurred using technology resources (i.e., phone, Zoom video conference) due to the COVID pandemic.

The demographic questionnaire allowed the researcher to gain background information on the participants and the care recipients. The questionnaire collected data such as age, education, employment status, the current state of health, chronic illness types, and other essential background characteristics critical to the study to analyze their data better.

Observation is a systematic data collection approach, where researchers use all of their senses to examine people in natural settings or naturally occurring situations (Cohen & Crabtree, 2006). This requires the researcher to become fully engaged in the participant’s environment while also taking objective notes about what is going on. The researcher used observations during the participant interviews combined with the interview guide to corroborate research findings. For the current study, the researcher documented contextual information. This observation included the participants’ visible, spoken, and unspoken communication cues and body language. The researcher recorded this data as field notes during the inquiry. Similar to the face-to-face interview process, the telephone or zoom interview was audio-recorded. Using this process to collect participant data was less costly and more efficient than in-person interviews. The participant nor the researcher had to travel or take time away from work or other caregiver duties.

Data Collection

*Field Testing Research Question*s

It is suggested that the interview guide questionnaire be piloted to determine if the research questions are sound, or the interview survey performs the way it is intended to work (Braun & Clarke, 2013). Following Waltz et al. (2017), the researcher asked three clinical nurse specialists who were content experts in gerontology with a strong research background and one male caregiver to review the guide for the current study. As suggested by leading researchers, the enlisted persons were asked to complete the survey and comment on the instructions' clarity, the wording (i.e., understandable terms), and ordering of questions, design, and layout (Braun & Clarke, 2013; Waltz et al., 2017). The researcher did not find the need to modify the interview guide based on the content reviewers' feedback.

Interview

Whether the participant contacted the researcher from the posted flyer or social media access, the participant interview occurred the same way. The following steps describe the process used before conducting the official research interview:

> The researcher received a phone call, text, or email from a potential participant.
>
> The researcher provided a return response (either text, phone call, or email) to decide upon an agreed-upon time to have an introductory ‘meet and greet’ via telephone.
>
> During the introductory meeting, key discussions included a review of eligibility to participate, verification of email and phone contact information, and the scheduling date and time for the official interview.
>
> The participant determined the decision to participate either via phone or Zoom.
>
> The participants were emailed a copy of the IRB information sheet and a copy of the recruitment letter. For those who are willing to interview using Zoom, the interview link was sent at this time. The participants were asked permission to send a reminder email or text regarding the scheduled interview.
>
> The demographic questionnaire was completed on the day of the official interview before setting the timer and starting the interview.

Data collection occurred via telephone (mobile or landline) or social media technology (i.e., Zoom). In this study, the researcher used a semi-structured interview guide. The use of interviews enabled the researcher to explore issues with participants by encouraging depth and rigor, facilitating new concepts or issues (Bradshaw et al., 2017). The length of the interviews for the telephone interviews lasted between 34 minutes to 48 minutes. The Zoom interviews lasted from 49 minutes to 99 minutes. Two audio recorders, in addition to Zoom-based recording, were on hand for recording the interview. The researcher transcribed the interviews in a texted format. The expected and actual timeframe for data collection was 8 weeks.

Zoom Video Communications

Zoom is a collaborative, cloud-based videoconferencing service offering features including online meetings, group messaging services, and secure recording of sessions (Zoom Video Communications Inc., 2021). Zoom provides the ability to communicate in real-time with geographically dispersed individuals via computer, tablet, or mobile device. Zoom's key advantage is its ability to record and store sessions without recourse to third-party software securely. This feature is particularly important in research where the protection of highly sensitive data is required. Other critical security features include user-specific authentication, real-time encryption of meetings, and the ability to backup recordings to online remote server networks ("the cloud") or local drives, which can then be shared securely for collaboration (Zoom Video Communications Inc., 2021). Essential information that must be included in the report to participants included:

1. All interviews will be audio- and video-recorded, and participants must reaffirm consent verbally before the interviews.

2. Unique identifiers for each participant (for reference purposes and to protect confidentiality).

3. Demographic survey data will be entered using Microsoft Excel software to calculate the sample's descriptive statistics.

4. Study participants can request access to a copy of the data that Zoom is holding, asking for correction or supplementation of existing data, or requesting restrictions on further processing of data and deleting existing records.

5. Participants can object to collecting and using their data, if appropriate, and may withdraw their consent after data are collected (Zoom Video Communications Inc., 2021).

Qualitative researchers Archibald et al. (2019) conducted a study as part of a broader longitudinal frailty study that included nurses (*n* = 16) working in general practice settings to participate in two to four focus groups be held either in-person or virtually. Due to insufficient recruitment, the researchers sought online communication technology (Zoom) to retain the previously recruited nurses in the longitudinal study. The study results indicated that both researchers and participants found using Zoom technology a useful method for conducting qualitative interviews. The majority of participants (69%) identified Zoom as a preferred method compared to in-person interviews, telephone, or other videoconferencing platforms. Other key advantages of using Zoom for qualitative interviewing reflected impersonal, technical, and logistical considerations: (a) rapport (69%), (b) convenience, and (c) simplicity (56%), and user-friendliness (56%). The ability to see the researcher and respond to nonverbal communication is regarded as an important aspect of establishing rapport, building interpersonal connection, or adding “a personal touch” (Archibald et al., 2019). According to the researchers, the ability to respond to nonverbal cues such as facial expressions and gestures was important in facilitating engagement, building trust, and promoting natural, relaxed conversation. It was concluded that the ability to see the caller and respond to body language facilitated lively and engaging discussion, which allowed for rich data to be collected.

An ideal state for qualitative researchers might be to guide the interview in the traditional face-to-face mode. However, given the current state of society and the impact of the COVID-19 pandemic, the telephone and Zoom web-based options were very appropriate alternatives to conduct the interviews. A seemingly disadvantage to telephone interviews is the risk of miscommunication or visual communication between the participant and researcher. The use of nonverbal communication has the potential to strengthen critical points. Although nearly half of the participants chose this option, the researcher believes that the intended message demonstrated through the change in tone, pitch, and participant responses such as "you know what I mean?" was spoken, emphasizing their perceptions. In short, while the researcher could not visualize the men, their voices conveyed their emotions.

Regarding the Zoom video-based interviews, a significant advantage was seeing the respondent and the unspoken communication. Overall, the researcher found responses of the caregiving men using the phone mode as meaningful and productive in answering the research questions compared to the Zoom-based interviews. A challenge within the current study regarding Zoom technology consisted of issues associated with establishing call connection and audio/video reliability and quality.

Data Analysis

The Revised SSCM guided the data analysis for this study. When conducting data analysis, the researcher became the instrument for analysis, making judgments about coding, theming, decontextualizing, and recontextualizing the data. The method to analyze the research data for this qualitative descriptive study used a qualitative content analysis process, a systematic approach for analyzing written, verbal, or visual communication data. And different concepts of credibility can be chosen in the discussion of trustworthiness (Bengtsson, 2016). The qualitative content analysis approach is appropriate for studies that seek to describe and quantify phenomena and analyze documents (Elo & Kyngäs, 2007); therefore, it is applicable for qualitative studies.

In contrast to qualitative research methods, qualitative content analysis is not linked to any particular science, thereby minimizing philosophical concepts and discussions (Bengtsson, 2016). Also, content analysis is a research method for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use to provide knowledge, new insights, a representation of facts, and a practical guide to action (Krippendorff, 1980, 2004, as cited in Elo & Kyngäs, 2007). Because African American male caregivers' knowledge is not adequately presented or lacking or fragmented in the literature, the researcher took an inductive approach in the current study.

With the qualitative content analysis approach, the analysis process reduced the volume of text collected, identified and grouped categories together, and sought to understand it. The aim was to "stay true" to the text and to achieve trustworthiness. Following the Elo and Kyngäs approach, the three main phases that made up the process consisted of: (a) preparation phase, (b) organizing phase, and (c) reporting phase.

In the preparation phase, the unit of analysis was selected. A unit of meaning can consist of more than one sentence and contain several meanings. Based on the research question, the unit of analysis can also be a letter, word, sentence, portion of pages or words, the number of participants in the discussion, or the time used for discussion. When starting the analysis, the researcher decided whether to analyze only the latent content’s manifest content. The latent content includes the awareness of silence, sighs, laughter, posture, etc. During the analytic process, the researcher strove to make sense of the data and understand the entire shared experiences. The goal was to become immersed in the data. In the current study, the researcher became familiar with the data or “immersed in the data’” by way of the “live” interview (face-to-face, phone, Zoom) and replay of the audio recorded interview, textual data (transcripts), and field notes as vital steps in the analysis process. Researchers must immerse themselves with the data to familiarize themselves with the content’s depth and breadth (Braun & Clarke, 2013). Repeatedly listening to each interview and reviewing field notes indicated prolonged engagement with the data (Nowell et al., 2017) and helped the research conceptualize an idea about the data. The researcher used a diary to document thoughts and reflections, telephone, or other communication forms with the study participants in the current study. All data-making methods helped add meaning and clarity to the transcripts; and, ultimately, to the findings’ trustworthiness. After audio-recorded interviews were completed and transcribed, the narrative texts were organized into a manuscript or data spreadsheet (i.e., Excel). The researcher next began to consider potential codes and themes.

During the organizing phase, open coding, creating categories, and abstraction occur. Each identified meaning unit was labeled with a code that should be understood concerning the context (Bengtsson, 2016; Elo & Kyngäs, 2007). The categories provided a means of describing the phenomenon, increasing understanding, and generating knowledge. During the abstraction process, the concepts are created (Elo et al., 2014). Within this process, the researcher used an inductive approach to evaluate the data.

When generating initial codes, the researcher used reflexive journaling and developed a coding framework or codebook for the current study. Using keywords or phrases that were bolded or highlighted eased creating a visual and contextual interpretation. The development of themes was a process that was built from abstract codes to patterns, categories, and themes from the ‘bottom-up’ (Creswell & Creswell, 2018). This process means working back and forth between the themes and the database until a comprehensive set of themes emerged. This process allowed the data analysis to remain ‘true’ to participants’ accounts and contributes to ensuring the researcher’s interpretations are transparent (Bradshaw et al., 2017). Analyzing and synthesizing codes into themes was completed based on the research objectives.

In the reporting phase, results are described by the content of the categories describing the phenomenon using a selected approach (either deductive or inductive). In this phase, the researcher considered how the results would be reported—systematically or logically, and the connections between the data and the results. The transferability of the results was also determined and detailed. These results included the inclusion of the data, sampling method, and the participants were described in a detailed manner. In this study, the researcher used thick descriptive language that included direct quotes and scientific language in conveying the results. The researcher demonstrated Lincoln and Guba’s (1985) trustworthiness criteria in the documentation throughout the study’s research process.

Trustworthiness and Rigor

To ensure a thorough examination of qualitative analysis, the researcher outlined a practical and useful procedure for conducting content analysis that meets the trustworthiness criteria outlined by Lincoln and Guba (1985). For a study to be acknowledged as trustworthy, qualitative researchers must demonstrate that data analysis has been conducted in a detailed, consistent, and comprehensive manner through recording, structuring, and disclosing the methods of analysis with sufficient detail to enable the reader to determine whether the process is credible (Nowell et al., 2017). Lincoln and Guba (1985) set forth the quality criteria of the concept of trustworthiness as a significant criterion for judging whether a qualitative research study is "rigorous." According to Lincoln and Guba, trustworthiness addresses the qualitative researcher's ability to convince the research user that the findings of a study are essential (Lincoln & Guba, 1985). These standards integrated throughout the research process consist of credibility, dependability, transferability, and confirmability.

Based on the Lincoln and Guba (1985) criteria, credibility is the extent to which the findings of a qualitative research study are internally valid. This criterion refers to confidence in the truth of the data and interpretation (Polit & Beck, 2017). Readers can ascertain a researcher's credibility through (a) prolonged engagement, (b) persistent observation, (c) triangulation, (d) peer debriefings, and (e) member checks. In the current study, the researcher demonstrated credibility through member checking, ongoing debriefing with the dissertation chair, establishing an environment that supported honesty among the caregivers, and prolonged engagement. The researcher engaged in member checking to enhance confidence in the accuracy of the caregivers' narrative responses. Conducted in real-time, the researcher reiterated key points of clarity throughout the interview. Member checking also included asking selected participants to read sections of the transcribed manuscript in which they provided dialogues. In the follow-up email to the selected participants, the emphasis was on the accuracy of the transcribed narratives to text and if the caregiver's intentions were accurate. Of note, one participant wanted to clarify the selective text further.

The ongoing debriefing with the researcher's dissertation chair was another opportunity to ensure the credibility of the study's findings. These debriefings included how the researcher coded, categorized, and developed the themes derived from the transcribed texts. The recordings and narrative texts were available and reviewed by the dissertation chair.

To promote honesty, participants were informed of their right to discontinue participation or withdraw from the study at any point. This would ensure that the study only included caregivers who willingly wanted to participate and provide their experiences freely. After the demographic questionnaire and before the first interview questions, the caregivers were encouraged to be honest and frank, as the researcher aimed to establish a rapport with the participant.

In the prolonged engagement process, the researcher spends adequate time learning the participants' culture and social environment. The researcher acknowledges that the current study consisted of a single scheduled interview with each study participant, with an agreement for follow-up, as needed. Before the scheduled interview, the researcher spent between ten to twenty minutes speaking with each potential participant to ensure that the male caregiver met the study criteria and establishing a trusting relationship. During these dialogues, the researcher was able to begin the data collection process. As expected with qualitative research, numerous hours were spent engaging in the audio recordings and countless hours self-transcribing the recordings to text. The minimal time transcribing the recordings lasted between six to eight hours, with a maximum time for several recordings approximated at fourteen hours. A final point of interest, with several participants, upon conclusion of the interview, the caregivers reengaged the researcher into further dialogue for an extended period. These discussions added to the researcher's collection of field notes.

The dependability criterion in the Lincoln and Guba (1985) framework refers to data stability over time and conditions (Polit & Beck, 2017). To address the dependability of the study's findings, the processes within the study are reported in detail, thereby allowing future researchers to repeat the work that occurred in the current study. This included an accurate account of the research design and how the researcher implemented the study. For example, data accuracy of the telephone and Zoom web-based interview recordings were transcribed to narrative text and subsequently read and re-read to ensure accuracy before undergoing the data analysis process. The researcher also used a reflexive journal to document reflections of values, interests, and insights about self during the interviews. For instance, one caregiver described the lack of church members' visitations with his mother before the pandemic restrictions. Another reflection involved the interruption of a caregiver's mother twice during the interview. This disruption led to his comment of her being "nosy," which led to additional complaints about her behaviors. Subsequently, the researcher inferred frustration or agitation as the interview continued. The researcher also recorded the participants' behavior and other factors that may contribute to bias. For example, many times, participants via Zoom "leaned in" as if whispering a response to the interviewer. Many of the participants used hand gestures and colloquialisms indicative of African American culture. By utilizing the reflexive journal, the researcher maintained a documented firsthand account of any interviewer bias or presumptions and variations in the interviewer's handling of interviews throughout the study.

Transferability refers to the generalizability of the inquiry. Transferability allows a researcher who seeks to transfer the findings from a study to conclude whether the transfer can be considered a possibility within their research (Lincoln & Guba, 1985). A detailed description of the participants, setting, and circumstances of the study demonstrated these criteria. This study reported, in detail, the use of “thick description” and used direct quotes given by the study participants. In this study, transferability involved describing the extent to which the findings of this study would be true of other African American male caregivers in different settings or geographical locations. The researcher detailed methods for conducting the study, with the inclusion and exclusion criteria of the sample, the recruitment process, and the condition of the COVID-19 pandemic. The use of thick descriptions of the caregivers' experiences helped convey the actual situations and contexts surrounding these experiences. These descriptions are illustrated by the numerous verbatim quotes that support the study's findings. The researcher also used purposive sampling to represent the phenomenon of interest—African American male caregivers.

According to Lincoln and Guba (1985), confirmability is established when credibility, transferability, and dependability are achieved, and the researcher’s interpretations and findings are derived from the data. To establish the confirmability of the findings, the researcher made every attempt to ensure that the findings represent the experiences of the caregiver participants. Confirmability was achieved through the objectivity of the data's accuracy and meaning, demonstrated by how the researcher provided detailed methodological descriptions, which included accurate records of contacts and transcription of interviews. This process allows the ability to create an audit trail. The audit trail provides readers with evidence of the researcher’s decisions and choices regarding theoretical and methodological issues throughout the study, and clear rationales support the conclusions. In this study, the researcher maintained accurate field notes, transcripts, and a reflexive journal to aid the researcher's ability to synthesize and cross-reference data.

Role of the Researcher

For any researcher, the beginning steps of conducting a research study must be an awareness and articulation of his or her research perspective and world view; the explicit acknowledgment of one’s position, biases, and assumptions, so that readers can better understand the researcher (Austin & Sutton, 2014). Thus, ontological and epistemological perspective shapes how research questions are raised and framed, methods selected, data collected and analyzed, and results reported (Polit & Beck, 2017). Reflexivity is understood as how researchers reflect on their role in the study; background, culture, and experiences hold potential for shaping their interpretations (i.e., themes) and the meaning they attribute to the data (Creswell & Creswell, 2018). Reflexivity calls into question the notion of "detached objectivity." One way to maintain detached objectivity during the study is for the researcher to use reflexivity and consider his or her own underlying biases and assumptions. This concept reflects the researcher's interest in researching this phenomenon, identifying personal biases, 'bracket' the researcher's assumptions, or whether external influences exist that will shape my views and expectations as a researcher. The researcher should explicitly identify biases, values, and personal background reflexively to assure that the interpretations and findings formed during the study reflect the participant's experiences (Creswell & Creswell, 2018).

The current study researcher is a middle-aged, African American female registered nurse with extensive medical/surgical and geriatric background. The researcher's shared cultural, ethnic, and social history provided a sense of 'relatedness' to the participants. To this point, the researcher's spouse is an African American son caregiver, and the researcher is a geographically distanced informal caregiver to an aging parent with multiple chronic illnesses. The researcher was also a previous informal caregiver to aged parents-in-laws, who are now deceased. Based on the researcher's female gender and, all study participants were men, measures were taken to bracket biases and only sought to understand these caregivers' experiences. However, in recognizing the need to remain objective and unbiased, without preconceived ideas regarding the study, the data were audio-recorded and transcribed verbatim. It is hoped that these actions eliminated the opportunity for misinterpretation or bias in the findings. The researcher believes that the results and interpretations accurately reflect the narratives of the study participants.

Summary

This research study used a qualitative descriptive approach to explore African American male caregivers' experiences who are caregivers to a dependent family member with chronic illness. Application of the Revised Sociocultural Stress and Coping Model (SSCM) guided this study's research processes. A purposeful sample of participants was recruited through innovative strategies such as personal and referred contacts of religious leaders and church member referrals, caregiver book promotion WebEx, barbershop flyers, senior or adult center, and through parish nurse contacts. This method of recruitment, which included snowball sampling, provided most of the participants. The researcher hoped to recruit participants using the social media network (i.e., Facebook, LinkedIn); however, few contacts were received, and only one was eligible for inclusion in the study. The participants shared their experiences during their semi-structured interviews to collate rich and thick descriptions of their narratives. This chapter presented a synopsis of the research methods, the research design, the methods used in collecting data, analysis procedures, the assessment of trustworthiness, and rigor. Chapter 4 presents information for more specific details about the data collection and the data analysis results. Chapter 5 discusses the research study results and provides future research recommendations.

CHAPTER IV

FINDINGS

Introduction

The purpose of this qualitative descriptive research study was twofold. The first aim was to describe the experiences of African American male caregivers who are (or were) the primary family caregiver to a dependent, chronically ill family member and explore how caregiving affected their health-related quality of life using the Revised Sociocultural Stress and Coping Model (SSCM) to guide the study. The second aim was to understand the psychological, physiological, psychosocial, and financial outcomes on the health and well-being of African American male caregivers related to their caregiving experience during a COVID-19 pandemic. There were five specific research questions. In support of the first aim, the researcher asked the following research questions:

> RQ1: How do African American male caregivers describe their decision to become caregivers?
>
> RQ2: How do African American male caregivers perceive their caregiver role?
>
> RQ3: What coping strategies and support systems do African American caregivers use?

The researcher developed two research questions to support the second aim of the study:

> RQ4: "What has been the impact of the COVID-19 pandemic on the lives of African American male caregivers?"

RQ5: “What are significant stressors described by African American male caregivers before, during, or after the pandemic?”

Thirteen male caregivers participated in the study. In several cases, participants provided care to more than one recipient simultaneously. All thirteen individuals participated in a semi-structured interview. This chapter presents the study findings organized into the following subsections: description of the sample (participant and care recipient demographics), research methodology applied to data analysis, presentation of the data, and findings of the data analysis.

Participants’ Demographics

As stated above, there were thirteen participants in this study. All participants were African American men who were past or present primary caregivers to their spouse, parents, or sibling. The semi-structured interviews were conducted in two ways: (a) via telephone with two mini-digital recorders, or (b) through Zoom Communications, Inc.; video telephony and online chat service. The interviewer used the Zoom recording feature with at least one mini-digital recorder for backup. The audio-recorded telephone interviews (n = 6) ranged from 33:59 to 48:24 minutes, with a mean interview length of 42:04 minutes and a median of 42:40 minutes. The Zoom semi-structured interviews lasted from 49:24 minutes to 98:46 minutes with a mean length of 74 minutes.

The participants’ ages ranged from 38 to 77 years, with a mean age of 58.9 years. The amount of time spent in the caregiver role ranged from less than one year (n = 2) to 24 years (n = 1); 11 to 15 years (n = 4), and two to 6 years (n = 6). All care recipients in the study were African American. The care recipients were mothers (n = 9), fathers (n =

2); both parents (*n* = 2); and parents and brother (*n* = 3). The average age of the female care recipients was 82.1 years. Male care recipients averaged 78.4 years in age (Table 1).

Table 1

Participant Age, Years of Caregiving, Care Recipient Age[*]

	N	**Min**	**Max**	***M***	***SD***
Caregiver Age	13	38	77	58.9	9.132
Years of caregiver experience	13	1	24	7.46	6.826
Care Recipient Age[*]	16	58	100	81	11.91
Female	12	59	100	82.1	12.14
Male	4	58	89	78.4	12.30

Note. [*]Multiple care recipients for some participants.

Six of the 13 participants were married; seven were either divorced or never married. Three participants had dependent children, two of whom were in the sandwich generation. The others either had adult-dependent children or had no dependents. Nine of the 13 participants were primary caregivers to a mother, three to a father, and one to a grandmother-in-law. One provided care to both parents, while another provided care to both parents and an adult sibling, and two were caregivers to spouses. The majority of caregivers co-resided with the care recipients (*n* = 12), except for one whose parent lives independently (Table 2).

Table 2

Demographic Characteristics of Caregivers (N = 13)/Care Recipients (N = 16)

	n	%
Marital Status		
Married	6	46
Unmarried/Divorced	7	54
Care Recipient Relationship		
Spouse	2	13
Mother	9	56
Father	3	19
Sibling (brother)	1	6
Other (grandmother)	1	6
Co-reside with the care recipient		
Yes	12	92
No	1	8

Regarding physical health, seven caregivers reported “good” health, while six stated they had “fair” health. The care recipients had a broad range of disabilities and co-morbidities (*N* = 32) that contributed to their dependency on family caregivers. These conditions comprised varied age-related chronic illness types, such as gait disturbance, visual deficits, and hearing loss. The caregivers also mentioned more severe illnesses, such as brain stroke, aneurysm, and diabetes. Dementia (*n* = 8) was the most frequently reported co-morbid state (Table 3).

Related to the weekly time spent in the caregiving role, responses consisted of the following: > 40 hours (*n* = 5), > 20 hours (*n* = 2), 12 hours (*n* = 1), and “varied, ongoing, or unable to approximate” (*n* = 5). Of mention, the caregiver that provided the 12 hours of care reported use of formal support services (home health care and adult daycare), did not co-reside with the parent and had personal health issues (dialysis). The majority of the caregivers had siblings, spousal, or significant other support, except for one participant. Of the 13 caregivers, two reported no assistance from family members.

Table 3

Health Ratings

	Ratings	*n*	%
Caregiver	*General Health*		
	Excellent	0	0
	Good	7	54
	Fair	6	46
	Poor	0	0
Care Recipient	*Major Disabilities/Dependency**		
	Dementia	8	26
	Impaired Mobility	7	22
	CAD	4	13
	Stroke	3	9
	Cancer	3	9
	Visual/Hearing Loss	3	9
	Brain aneurysm	2	6
	Diabetes	2	6

Note. * Care recipients (CR) chronic illnesses/disabilities (N=32). Percentages indicate the number of illnesses out of the total disabilities.

Twelve of the 13 participants said they were associated with some religious affiliation, while one caregiver responded: “no affiliation” to this inquiry. One of the participants attained a master’s degree level of education; six achieved a BS or a college-level degree; four reported “some college,” while two reported a “high school” degree. Out of the 13 participants, four were employed full-time and received compensation; three worked part-time with paid salaries, and three were retired. Two received payment from part-time employment (i.e., singer in a band and family business). Three of the caregivers were unemployed, one due to chronic disability. No caregiver reported decreased work hours or unemployment due to the pandemic. Two caregivers had annual household incomes less than $25,000; three reported less than $50,000, while six reported a yearly income greater than $50,000. Two of the caregivers declined to respond to this inquiry regarding annual income (Table 4). All participants were given a researcher-provided pseudonym when reporting study findings. See Appendix F for detailed caregiver descriptions.

Table 4

Sociodemographic Characteristics of Participants (N = 13)

	n	%
Religious Affiliation		
Yes	12	92
No	1	8
Education Level		
High School	2	15
Some College	4	31
BS/Degree Attained	6	46
Graduate Degree	1	8
Employment Status		
Full-time	4	31
Part-time	3	23
Retired	3	23
Unemployed	3	23
Income level		
<25,000	2	15
<50,000	3	23
>50,000	6	46
Declined response	2	15

Interview Questions

During the individual interviews, the 13 participants answered researcher-developed questions based on the semi-structured interview guide. The guide's final question asked the participants to offer subsequent responses or comments to support the study that the researcher may not have asked. If the question (s) or comments were seen as beneficial in understanding the individual caregiving experiences and could contribute to answering the research questions, they were incorporated into subsequent participant interviews, as appropriate. The following were the interview questions:

1. What would you say it means to you, as a male caregiver (CG), taking care of your (*insert CG title)?*
2. What is it like for you to care for someone with a chronic illness or disability on a day-to-day basis?
3. Some people, even though they provide a lot of care to another person, do not consider themselves as a "caregiver."
    a. Do you think of yourself (or others see you) as a caregiver? Please explain.
    b. Can you share how you came to take on the caregiver role? When did you start? What sort of care do you help with?
4. What types of benefits do (did) you receive from being a caregiver?
5. Please share any difficulties you may have experienced since you began caring for your family member. Describe what makes you feel stressed in your caregiver role. Describe any experience of an excess burden while caring for your family member.
6. How do (did) you cope with the stress or burden of caregiving or being a caregiver?
7. Tell me how being a caregiver during COVID-19 has a) affected you personally or b) affected your ability to provide the same level of care to your loved one.
8. Tell me about how caring for your (care recipient's title) has changed your relationship with family or significant other? What kinds of support do (did) you get from your family/S.O., or community (i.e., church, support groups, etc.)? What type of support services would you say you need to maintain your caregiver capabilities?

9. Is there anything else you think I should know (about your caregiver experiences) that I may not have asked or further comments you would like to share?

Presentation of Data and Results of the Analysis

To engage and set the context for the interview, the researcher started the semi-structured interview with the African American male participants asking the general question: “*What does it mean to you to be a male caregiver providing care to your (title inserted) or loved one?*” Five significant concepts derived from the inquiry: honor, commitment, reciprocity, sacrifice, and responsibility. These are detailed in the following sections:

Honor

Five of the participants used this expression to describe their feelings about being a caregiver. For example, Fred stated, “it meant to me that it was an honor for me too, first of all, be in the city that they’re living in, as they were aging and needing more help, and that I was available.” Griffin added, “I feel honored, I feel honored. I mean, because some folks look at you and say, uh … Wow, it’s a lot. It’s, it’s … I can never get back to her as much as she’s given me. While John shared, “… how do, I do it [provide care] in a way that I can honor [wife’s name], and I can, I can make sure I do the best for her?” Finally, Tony reiterated this expression by stating, “It was an honor for me to be a caregiver, I was compelled to do it because I felt like it was the right thing to do.

Commitment

This term or similar descriptions was threaded throughout the interviews in varied contexts. The researcher identified the specific use of the term in several direct quotes of the respondents. John stated, “It’s a … I consider it part of my commitment as a married Christian man. I did not spend a lot of time thinking about whether I should fulfill my commitment.” The researcher saw another example in Keyon’s statement, “I’m really coming to terms with … uh … being the person that is responsible for someone who was responsible for you at the time.” “And I believe in love. And so, if you love your parents, you’re gonna do … you know, whatever you need to do … you’re going to step up to the plate.” Wendell expressed his commitment with the following statement: “… it was something I needed to do. It made me feel that it was something that was necessary. It made me feel as though I was showing love and support to someone who needed it.”

Reciprocity

The researcher identified reciprocity as another expression in various forms of the narrative text. Specifically, Griffin acknowledged a sense of reciprocity with the following statement: “I can never, I can never repay, repay her what all she’s done for me.” Quinn contributed to the expression by stating: “You know, to be in home with your elders, you know, who have taken care of you, throughout your … uh …, you know, life and so you take care of them in the twilight of theirs.” Greg, on-the-other-hand stated,

> Well … It means validation. She took care of me, looked after me, took care of me whenever I needed to be there, time for me, whatever you will call it. And it’s my responsibility as a man … and as a son to make sure that she’s comfortable and taken care of the best that I can.

Keyon added the following statement:

> I’m really coming to terms with … uh … being the person that is responsible for someone who was responsible for you at the time. And I believe in love. And so, if you love your parents, you’re gonna do … you know, whatever you need to do … you’re going to step up to the plate.

Sacrifice

Five of the participants descriptively expressed the sacrifice of caregiving. To illustrate, Jordan described the positive benefits of being a caregiver to his wife’s grandmother, “the positive thing to know that you’re, you’re making a sacrifice, you’re making a difference in a person’s life.” While Jamel stated, “just putting things very selfishly aside … some of your things aside to make sure they’re in a mentally … a good point where they’re happy being there. It’s making sure that their mind … that they’re in a good state.” Wendell shared his feeling through the following expression:

> Loving your parents go way beyond just saying they’re your parents. It’s what are you doing for them? Are you making any sacrifices? I’m glad to have made those sacrifices; I’m glad to have been called to do that role. I’m glad it helps me to be a better person that helps me to understand that it ain’t always about me and what I want in my life.

Lastly, Tony imparted this statement:

> Think about how they (they) sacrificed for you when you were an infant and a baby … when you couldn’t take care of yourself. And you know, and you know, the roles are reversed. Think about your mortality, your end of life.

Responsibility (Duty)

While all of the participants related to some form of responsibility associated with the assumption of the caregiver role, a few statements that reiterated this expression were seen as Keyon stated: “I’m really coming to terms with … uh … being the person that is responsible for someone who was responsible for you at the time.” Meanwhile, Wendell expressed:

> I don’t know what would have happened to my mother if I did not take care of my mother. And … you need to have your vision of how you’re trying to do what you’re doing. It’s hard. And that’s where the satisfaction comes in, that you push through, even though it was hard, you make compromises, but you never let go of what your ‘true vision’ is.

Derrick offered the following statements:

> It all falls on me … on top of taking care of her, it’s like taking care of another child. Immediately, as soon as you have to become a caregiver, it immediately set you in a position of having to do things that you were not normally doing.

Clarence was very pointed with his description and verbal intonation:

> This job (*blows out-breath*) … Most men are not prepared for it. Most men, unless they’re old school. They may know how to cook and wash and do these things. But if you ain’t [got] no home training, you’re gonna be like a fish out of water.

The next major topic of inquiry addressed African American male caregivers and their perceptions on the use of the caregiver ‘title’ or ‘label.’ The researcher posed the following two questions to each participant: (a) “*What are your thoughts about the use of* *the term ‘caregiver’ or ‘title?’*” and (b) “*Do you see yourself as a caregiver?*” Eight of the 13 participants indicated that he identified with the role.

Clarence: I would say … cause that’s what I do (*increased voice pitch*). Basically, everybody say (caregiver’*s name*) is a caregiver for his mother.

Keyon: Oh, I see myself as a caregiver. Yeah, I mean, that’s, you know, I look at the term is if you’re taking care of someone then you are a caregiver.

Derrick: Yeah, I identify with it because that’s what I’m doing. I’m taking care of her … you know, so I don’t have any qualms about the label.

Griffin: I don’t have no problem with the title, cause, like I said, that’s how I got qualified for the grant. I don’t have a problem with it. Because either way it goes … that still my moms.

Tony: Yes, I do … right.

Jamel: think so, I really think so …

Quinn: I suppose I do identify with the term … caregiver. Yes, the word caregiver (*emphasized the word*) Yes, I, you know, take care of my mom, I give my mom care, you know, yes. But I welcome it; I embrace it. I try not to shy away from it. For as how I feel personally about the caregiver title, I just feel as though I am my mother’s son.

Fred: I considered myself a caregiver because I started as a nursing assistant. When I look at other people, I didn’t I don’t think about the male friends as being caregivers. Generally, hear, my mother’s son. I help take care of my parents; I’m their support.

In contrast, five participants had differing responses to how they viewed the concept of caregiver or caregiver title. The following are excerpts of their responses:

Greg: No, I think we do it. That’s my mama kind of deal … you know. I don’t see (I don’t see) myself as a caregiver; I’m not getting paid for it.

Wendell: I wouldn’t, most of the time, use that title. That title has just been put up, in my opinion, just to categorize, which is fine, but usually, you just taking care of your mother. I just thought that hey, whoever (is) has the most ability to (to) have their mother live with them, that’s what you did.

John: … I think we as a society have to have a bucket to put things in, and the caregiving bucket. It’s okay. It’s, it’s, it’s all right. But it gives that connotation … that … uh … the person can’t do for themselves.

Blake: A caregiver does give the full description of what I do. Uh … But it goes so much further than that. Uh … I think that people may find some offense to it or don’t care for it because it just sounds so commercial, I would like to say, or it doesn’t sound very … uh … family-oriented.

Jordan: I think that when (when) you say African American male, and you throw that caregiver on the side of it, I think most men think about it as a lessened role. I guess because … what you do … that … to me, that “caregiver” sounds too much like a profession (laughs) … I’ll just be honest with you. You know, I’m saying, but if when you are caring for Mama, caring for Auntie, caring for grandma, to me, it’s not a professional duty. So, I, me, I don’t look at myself as a caregiver. But oftentimes, I consider that more of a professional term in my own mind. Because what I’m saying is when I love you, when I take care of you, I don’t put myself in any category or anything. I just do it because I love you.

The following subsection contains the description of the four major themes that emerged from data analysis: (a) My Time to Take the Reins, (b) It’s a Male Thang, (c) Caring Amid a Pandemic, and (d) Effects on the Caregivers’ Journey.

Theme 1: My Time to Take the Reins

This first theme, “My Time to Take the Reins,” begins with the varied explanations each participant provided for taking on the caregiver role. For some, as the only family member available or willing to assume the role, a matter of choice in the role assumption was described as not an option or consideration, despite the hardships. The researcher determined the role assumption was also guided by what was described by many of the caregivers as love, respect, honor, and blessings. Being compelled to take on the role, whether by one’s spiritual belief or the coping benefit of religious affiliation or faith, also empowered the caregivers to endure the role. Based on these reasons, the researcher discusses three categories that comprise the “My Time to Take the Reins,” theme as: “Do What I Gotta Do,” “The Heart of Caring,” and “Spirituality/Religiosity.”

Do What I Gotta Do

These caregivers asserted that they needed to “Do What I Gotta Do” in providing the care required for the care recipient. The experiences that make up this category were based on the caregiver role—the roles and responsibilities. It also captured what decisions influenced the need or willingness to assume the role. Following are statements that illustrated this category:

> Blake: We were together when I was in (stated name), back where we’re from. We moved here, and my mother became sicker. You know she (she) got ill. So, I’m the only one here.
>
> Greg: brother doesn’t do a whole lot, and you don’t have any siblings …
>
> Clarence: And I could say, when I was young, if anything happened, I would always come back and take care of my mom and dad. I told my wife, I said, ‘look … I said, you … I said I’m going to take care of my mom and dad. You have a choice to do what you want to do. I mean, I’m not going to tie your hands, but I’m gonna do this.
>
> Keyon: You know, as we get older, you’re gonna be taking care of us, and you’re gonna have to take care of your brother after we pass on.
>
> Tony: So, how that came about is … it just played out that way, I guess. It was like no formal discussion between my sister and I … that … I

> would do this, and she would do that, you know. It just kind of came up, you know.
>
> Jordan: We knew that for her to get the quality of care, that we believed in our heart that God would want, and she would want, and we would want for her, we had to bring her down here.

Other caregivers who had a supportive network described their assumption of the role in the following ways:

> Wendell: I came to the realization that there wasn't anything that I wasn't going to do. I don't know why I can't explain how I came to that. But I've always given my mother a bath. I've always clipped her toenails and sanded the bottom of her feet. I've always helped get her dress; you know. So, it's in-depth, you have to do everything from cleaning to cooking to (to) translating to transporting. Uh, It's 24 hours a day.
>
> John: We were committed all the way through the process. Best case scenario, 'you're gonna have paralysis in the right side. And you're probably gonna lose some other functionality on that, on that side.' That was 24 years plus ago. And I still try to be her best cheerleader and her best critic along the way.

When probing further into the day-to-day care for his parents, Jamel and the researcher had the following exchange regarding personal care and hygiene:

> PI: You had to help her? And you don't have any problems with the personal hygiene?
>
> Jamel: um hum.
>
> PI: and … she's okay with that too?
>
> Jamel: Yeah … 'cause it has to be done.

Regarding his father, Jamel stated, “he has issues as well … he sometimes … he don’t make to the restroom, and so he can make a big mess as well in the bathroom. Or right in the track of his tracks.” Lastly, Greg shared these comments:

> I mean everything … except for giving her a bath, changing out her Depends, taking into the restroom, uh … any female issues along those lines … I don’t do; I don’t do the female stuff; that’s the only part I don’t do.

The Heart of Caring

The researcher chose this category, “The Heart of Caring,” based on the collective narratives that described the pulse of the study participants’ caregiving experiences. The following describes narrative excerpts of individual caregiver statements:

> Tony: When the parent becomes infirmed, or sick, or ill, then it’s up to the children to take care of the parent.
>
> Blake: To be a caregiver is truly an unselfish role. This is a role for the unselfish. It’s not just anyone can do this. … you have to be unselfish. And think of yourself less.
>
> Clarence: ‘cause she all I got … and basically, when I was a child, she took care of me. So, I figured, I can do the same for her.
>
> Derrick: So, I’ve promised her when I got together with her, then I would make sure she’s taken care of, and that’s what I’m doing.
>
> Greg: It’s my responsibility … it’s my responsible thing, for me to take care of my mom. She’s been taking care of people all her life, and I’m going to take care of her now.
>
> Griffin: The benefits of it [caregiving] … is to never have to look back and say that I wish I could have could have done this or done that. And to being able to feel good about … It ain’t always the leaning tree that falls. But right now, she’s the leaning tree.

John: I look at my challenges with my wife. If I stay in it long enough, I can take a rest, but I'm not gonna quit. So, when I'm done, I'm done.

Quinn: I've always been here with my mom always tell people that right about the time I was ready to leave the nest is when I found out I had to bring along with me.

Spirituality/Religiosity

Most of the male caregivers related a connection to some higher power or 'being' (*n* = 12). Whether as a coping strategy or as a sense of commitment, spirituality/ religiosity or faith was exemplified in the analysis. Religious affiliations were associated with religious practices such as 'Baptist/Nondenominational' 'Christian,' 'Methodist,' 'Believer,' and 'Spiritual/Archemic.' The findings of this study showed that many of the men used their dependency on their religion or spiritual belief as a coping strategy, as well as being instrumental in taking on the commitment of being a caregiver to their family member. Although a religious affiliation was provided, the caregivers' reliance on religion, spirituality, or faith was not perceived by the researcher in all narrative responses. For those who did reveal faith/spiritual-based responses, the following statements illustrated their connection to a higher power. For example, Blake stated, "But you know, he [GOD] says, "honor my mother, my father, honor thy father, though mother" as I have commanded." So, that was … that piece for me was not an option. It was a command from God." Wendell expressed, " I just feel as though the (the) reward comes from Lord letting him know that I did all I could do to the best of my ability." While Keyon shared, "My mom always said that me and God work well together. And I totally understand that. A few years back, I totally understand what she meant when you put your full trust, for me would be source for God.” Jordan shared, “And to know that being a Christian is a is a great example. I believe that God is pleased with what we’re doing.” Lastly, John offered these statements:

> God will help me through it. And that has kept me … those kinds of things keep me centered, just knowing where to go … and a no-quit attitude. … and I said, without God in my life, I would have made a different decision. But because of that commitment to God, and her at the same time, it made all the difference. And … those seeds … see, this is the reality when I … when I give testimony … that’s … I tell people, the God that I serve is the reason I do what I do.

Theme 2: “It’s a Male Thang”

This theme was represented by four categories: coping, cultural aspects, societal perspective, and support systems from the male caregivers’ point-of-view. All caregivers provided some response to how they coped with the stressors of caregivers. In general, cultural aspects regarding being a male caregiver yielded nine responses from the participants. Likewise, the caregivers’ individual views on how they perceived society, at large, viewed male caregivers are presented below.

Coping

Within this category, the researcher identified eight strategies that described how the caregivers reacted to or managed their stress levels. The strategies described were: (a) faith/spirituality/religion; (b) relaxation techniques; (c) exercise; (d) non-stress-related paid work; (e) “me-time;” (f) respite; (g) professional/informal emotional support; and (h) anger management. The following quotes illustrate these coping strategies:

(a) Faith/Spirituality/Religion was related to references to pray or prayer. Four of the caregivers described how this category supported them. For example, Jordan stated,

> I'll just put it in a nutshell, finding rest, finding peace, finding comfort, the ability to cope, I found it through messages and reading the Bible, and things like that would basically help bring me down to where I needed to be.

John offered this statement:

> And from a sermon that I heard many years ago, he (his) title was "Knowing where to go." And what he meant by that was when life is great when you've just overcome some challenges, or you heard something that really inspired you to keep you going … write those things down. When God answers a prayer, write those things down.

(b) Relaxation techniques were described as watching television, YouTube, listening to music, cooking, reading, or getting a massage.

(c) Exercise as a means of coping included taking walks, attending a gym, yoga, or bowling. As told by Blake, "I get outside of myself, you know, uh … That's what I do … is I busy myself, I move a muscle change a thought, to the best of my ability." Griffin, on the other hand, made this statement regarding the benefits of exercise and coping: "Workout also helps you relieve release and calms you, and I'm not doing it now. So, I know I've got to get back to it. Matter of fact, you got me motivated … I'm starting … I'm starting Monday" (laughter).

(d) Non-stress-related paid work included doing a fun thing that could be seen as a hobby and generated income that supported the family household. Three of the caregivers were self-reported musicians (i.e., DJ, drummer, and band singer). Jamel shared, "I'm so … a diehard in my music. That’s what keeps me going. This is what I know when I when I do music; it makes people happy people love it actually makes me happy.”

(e) “Me-time” captured the statements given by the caregivers such as “alone time,” “peace and quiet,” “fishing,” “you time,” “meditation,” and “long baths.” Three of the caregivers provided direct statements that underscore this category. Although, it is noteworthy that other responses could also fall within this category of coping.

(f) The respite coping strategy captured the time the caregivers attended to self-care needs or relaxed. This opportunity was provided when the care recipients participated in the adult day care center, paid out-of-pocket for sitters, or members of the family or friends relieved the caregiver. The majority of the caregivers (*n* = 8) described some form of taking time away.

Blake shared how his attempt to take away was interrupted due to the COVID pandemic, even though he expressed “guilty” the entire time he was planning for the trip:

> I don’t have much of a life for myself, but I could maybe take a trip. And I was on my way to Spain, in July, and I had to find … then COVID came, and I cancel … I was going for 19 days. I, uh … had someone in place to stay with my mother the whole time that I was going to be gone.

When explicitly asked about the term respite care, most caregivers (*n* = 9) had an awareness of the benefits or had used the services in some fashion. Derrick provided this response:

> Yeah … So, I go to the bowling alley on Tuesday. And she stays from, say, like six to 10. Okay, and pay her for that. But aside from that, see on Wednesdays, see my mom why goes to the daycare and my … I bowl at one o’clock.

Quinn also provided how respite has been a benefit to his family:

> Now, I am familiar with respite care. As a matter of fact, my wife and I, you know, had mom in respite with (respite center). I'd say the week before Thanksgiving because we were going on vacation. And we have used them for her for respite, say since about September of 2018. And they're (they're) actually great.

Two caregivers provided the following statements:

> Jordan: The respite, I think … is something that maybe … I just tell you, as, as an African American period, or male, I just don't know we (we) have been? I'ma see how to say this; I don't know if WE think about things like respite. You know what I'm saying?
>
> Keyon: Because I think, uh … that's one thing that isn't provided for, even though they call it respite, but I couldn't put all three in respite at the same time because it's … you have to have a certain type of insurance. Insurance is also a killer. If you don't have the right type of insurance or the money to (to) afford you … uh … the R and R, that you need, then that is a downfall.

(g) Professional/Informal emotional support strategy: Several caregivers discussed seeking professional help or leaned on others who were held in high regard as a previous caregiver.

> John: So, my coping mechanism was to listen to that (that) therapist who said (caregiver's name), you need to plan some time by yourself … for yourself … with things you enjoy.
>
> Blake: I talk with two of my friends. One is a psychiatrist, out of (university name). I have another one who is a therapist.

In contrast, one caregiver opposed the need for professional assistance. He gave this response:

> Greg: No professional, not (not) okay? I won't go unless I'm feeling a little something, something now. That's the only reason I will go. And it'll be for everybody else's safety … not mine. (laughter)

(h) Anger management was another coping strategy. Two of the men described anger-related emotions. How this emotion was related to coping can be seen in the responses of these caregivers:

> Wendell: But one of the important things that I learned was you can't stay mad. Staying mad is gonna mess up your communication, which is then going to mess up your relationship because you mad at something that y'all already got over.

While not describing a personal anger issue, Fred offered this statement:

> How do you handle your anger? Or, or … how can you … How can you help … especially, some of the men deal with those untapped emotions or (or) not understanding. My barber, I asked him how he's doing. And he's so angry about his father having dementia. We talked about it … and (and) I've given him a couple of examples of locally that he could go on and get some education on dementia. And I go in, I said, Did you do it? Oh, I forgot.

Cultural Aspects

The impact of how cultural values and norms influence the caregiver experiences is a continuous line of inquiry by researchers. Culture encompasses the social behaviors and norms of a group of people. It also embraces the knowledge, beliefs, and customs of the ethnic group. In this qualitative study, the researcher looked for specific cultural values or norms that provided insights concerning the influence of culture on these thirteen African American male caregivers’ caregiving.

For some of these African American caregivers, culture tended to define the reasoning for their sacrifices and their determination for assuming the caregiver role. For example, Jordan gave the remarks: “I was brought up, you know, to take care of your family.” And, “I did come up with, you know, the man being the leader, the head of the house.” Greg believed it was a son’s duty or a child’s duty to look after their parents. “So, it’s a dutiful; it’s a dutiful thing for me as well.”

As mentioned, these male caregivers’ coping strategies were abundant and incorporated multiple means of managing the stress or burden of caregiving. According to Jacobs (2021), African Americans may cope with caregiving better because their culture enables them to feel more positively about it. The caregivers described cultural aspects through the following statements:

Fred described a sense of generational bonding:

> to see how our children … because they were involved in visiting and (and) we help them understand the aging process and dementia and older people forgetting. When they [grandparents] died, my children didn’t have any regrets about how they had been involved in their life.

Jordan described what he perceived is needed for African American men to feel valued within their communities as caregivers: “they [caregivers] need to be elevated to a position of respect. And no one thinking less of you because you’re a caregiver.”

Notably, John offered the following statement regarding ‘stepping up’ to take care of a loved one:

> There needs to be some immediate awareness made that it’s okay to decide to do your best to take care of your loved one … from a male perspective. It doesn’t make you weak; it doesn’t make you less of a man.

An idiom that is repeatedly cited in the African American community is “it takes a village.” This saying can take on the practical sense in caregiving for African American families. Often, the caregiving task is shared among family members and beyond to extended family and community members, such as church families. Jamel provided the following illustration of the parents and adult children co-residing and sibling/church support:

> Well, first of all, I try to make it easier for my siblings. For them because my sister is there, ALL day (*raises voice*). When I’m at work, she, she cooks, whatever she does every need they want. I take her wherever she needs to go. I even pay her bills. Like, uh, a certain amount, certain time of the month.
>
> I try to make it as easier, as best for … I’m all about taking care of … trying to take care of them as well. I take that into consideration and how I prep for prep for him [brother] … so he’ll have less to do … because he has to literally get there and really go immediately … he runs out of time … sometimes, he runs out of time. Oh, I try to do everything to make it easier for him.
>
> She [mother] does so much herself … she gives out … she gives so much of herself—it comes back. So, it’s like they have a lot of love for people just really bringing them food … like a couple of weeks ago. I mean, the refrigerator it’s like … it just cannot breathe. It’s like that kind of love.
>
> I have another sister, and she lives in [city]. She does a lot of things as well. Go take … she goes to the doctor. She has a lot to do with the doctor … when they go to the doctor or something … you know, when I’m… while I’m here.

> And then my brother, I have a brother that lives in [state]. He does stuff around the house or what whatever he can do to make … you know, things they don't have to pay … anything he can financially, he tries to work around the house. He tries to get it done.
>
> If it wasn't for their church … that's why, I mean, they wouldn't have their house … I mean … they got … they gave them money to get that house.

For many African American male caregivers, stigmatization has been associated with Black and racial discrimination or the stigma of women's work. As a survival strategy, the African American population tends to remain unified as a culture or within their ethnic group. In this study, Keyon offered these statements:

> And I think, you know, the cultural aspect of being Black in America. And being a Black man in America, and the stereotypes around that, you know. How do I … like I said, I happen to be very lucky. Um, but I really don't talk to anybody.
> In our culture, it is a woman that does the work [of caregiving], it's, you know, you're gonna, you're … most of friends of mine, their wives take care of their mothers. I think that's got to change; we've got to open up, we've got to evolve in our culture.

Tony added to the stigma associated with women's work by making this statement: "I don't think that any man should be made them feel shame, or guilty, because they're basically taken over a role that traditionally women." Jordan added, "So, I just think with us, it's just a mindset of, we've always taken care of our own business even within family." Wendell stated,

> So, I'd already grew up in a father environment of caring. So, I already was in an environment of a male caregiving role because he was a single dad; where I grew up, most of the kids were raised by a mother. I already saw a male role figure. I already saw how a person, a male Black male, could take care of his three kids.

Lastly, Jamel communicated,

> … African Americans are not bad. A lot of them have hearts for caring. And all do not want to just kill and hurt. There are ones out there that have good hearts. And it just has been stigmatized, just because … we're just because … of who we are.

Reference to how caregiving was an expected part of life passed down through generations was also associated with cultural embeddedness. To illustrate this point, Quinn made the following statement:

> You know, like, it's, you know, for me to be an African American male caregiver for my mom … is … uh … slightly different, than, uh … the dynamics, we usually, you know, hear of here in the States. Whereas, elders of a family in most African or Middle Eastern families of Asian families, you know, they, we all have their elders, you know, with them. Like there is no tradition of sending the elders to nursing homes or convalescent homes, or retirement, or homes of that nature. It's, you know, to be in the home with your elders, you know, who have taken care of you, throughout your … uh … you know, life and so you take care of them in the twilight of theirs. So, I feel as though I'm doing a traditional—just motion here.

Keyon shared that cultural norms, such as sharing in the dying experience or "crossing over," has evolved:

> We (we) don't have our ancient ways of living, right indigenous ways of living, where the family was around you when you passed on. And the loved ones here are to transport the loved one that is transitioning into the world of the loved ones that are passing over or that are already on the other side.

African Americans characteristically wrote down important information in the family Bible. Fred contributed to this cultural aspect and value of historical norms, seen as “handing down traditions,” with this response: “We put together this book of all important information, you know, my favorite songs for the funeral and those kinds of things, and they didn’t want to hear those kinds of things.”

Societal Perspective

The decision to provide care—or not to—to assist a loved one is an individual decision made by the caregiver, regardless of gender. Historically, caregiving’s connotation as “women’s work” has often reflected society’s view of who have been the primary informal caregivers within families and an overview of role, responsibilities, and tasks. The findings in this study identified caregivers’ responses from this group of men, who often corroborated what has been found in the caregiver literature based on their experiences. Despite the increasing emergence of male caregivers, society has not considered this trend and maintains its caregivers’ tradition. The following narratives provide more profound details of these thirteen caregivers’ perceptions regarding societal views, as caregivers, specifically African American male caregivers.

Differences exist between personal care tasks, such as bathing, feeding, managing incontinence, and daily living management duties. In our society, women are more likely than men to assist with personal care tasks. “Most the time, women… you expect for women to be the caregiver. I think that’s what most folks expect, as uttered by Griffin. According to Keyon, “in this … today’s society, we have created a society where we are giving women a role to play and given men a role to play.” He also added,

> If you read the studies on girls and boys, boys are the most sensitive, which is why I think we’re taught to ‘man-up’ at a certain age, it’s the young boy that will

> go and hug their mom and go and hug their dad a little bit more than the young girl would, you know, do as children. So, men are compassionate … we're just taught not to be.

When approached by a social worker (SW) regarding his ability to manage an infant son and a 2-year-old toddler, John shared this response to the exchange:

> SW: You got these two little babies here, and you got this, you got that, you're not gonna be able to do it, you're just not gonna.
>
> John: This is not … these are societal norms. There's some … sometimes I think there are some societal or social pressures that … in considering why men are … they decide to be caregivers or not.

The caregiver's final comments regarding the SW's comment led to the following statements:

> They (healthcare providers) will gather from statistics and say, Well, you know, most, most men, and I don't know if they, they made this assumption, but, but based on the feedback that I got afterward, they're their assumptions … were probably correct. Society tries to shape how we move before we can make a decision because that covers their back.

Greg's thoughts and response to male-gendered caregiving and societal view generated this remark:

> I think people think because you're a dude, you don't know what's best for her because she's your mom, and they know more because they're older women. So, you know … and a lot of them (referring to women beliefs) just because men aren't naturally geared to take care of it (caregiver duties).

Keyon added to this point by adding this statement: “So why would you put that burden on your wife and really make men look at their role as the child and (and) you know, if there’s only men in that family if you weren’t married, what would you do?” whereas Jamel contributed this response regarding male versus female caregivers: “I think it’s the sickness, depending on the sickness … the level of the sickness.” Fred provided his perspective that seems to align with women’s work and how men place themselves into societal expectations:

> I think perception is that … and part of it may be true … that a lot of times males don’t want to face up to the aging part of their parents and having the responsibilities of cooking or washing clothes or things like that … uh … and that males tend to look at their wives to take on those responsibilities, even for their own parents.

As John stated,

> My perspective on [the societal perspective of caregiving] is you don’t know what you’re gonna do until you’re faced with it yourself. Because you don’t know the elements that went into the decisions that were made at that point in your life. So, society from the outside looking in, it’s a whole different story when it’s you (when it’s you). And if you (if you) take your cues strictly from society, you’re gonna miss what you were meant to get a great deal from.

Societal norms regarding stoicism and restricted emotional expression are areas that a few of the caregivers referenced. Jordan shared, “and then the perception may be… that if I avail myself to those services [formal support], how will I be looked at my family and other people?” Furthermore, he concluded,

> This is what I discerned, okay? I think it [caregiver] was looked at favorably, mainly because here is a male, hey, and an African American male, showing such gentleness and such kindness … which is contrary to how we are perceived. I’m not gonna go there. I’m a leave that alone. But you know where I’m going with that. I’m just saying, uh … how we are looked at.

Fred shared the following response of a conversation with another male caregiver and friend, who two days after her death made this statement: “Do you think I’m a punk … because I’m still hurting?” Tony added to this topic area by stating: “Society doesn’t support men expressing themselves.” He followed this statement with exemplars, such as “boys shouldn’t cry, should not talk about their feelings and emotions.” Furthermore, he stated, “Men suffer undue burden, and they need to know that it’s okay to show emotion, let loose without judgment. Men should move beyond holding their feelings.”

As has been stated elsewhere, African American men have been victims of stigmatization, as Jamel asserted, “because of who we are.” Wendell, on the other hand, made these statements:

> I think that, uh, part of our feeling is that society has not noticed what African American men do as caregivers because we’ve been labeled as deadbeat dads, don’t pay child support, have kids out of wedlock. So, there’s a lot of negativity around the Black male. There is not a lot of education or things to uplift the Black male in a caregiving role. I think society doesn’t recognize single fathers, but it does do a lot for single mothers. Because I think we’re in the background. So, I think that a lot of focuses on single women, which is, of course, the dominant factor of who’s raising the kids. But yet, and still, I don’t think there’s a lot that has been said about male caregivers, in general.

A final point on the topic of societal perspective and caregiving, Tony provided this response:

> I don’t really look at it from a societal point of view or how other people might think about it. I just look at it as … it’s just what we do in our families. When a family member is in need, and … we have to rise to the occasion, especially when it’s … uh … you know, end of life care, which is was with him.

Clarence gave these responses: “How society looks at … makes no difference to me … uh … somebody has to do it. I’ll do it. And, I hear the comment, ‘oh, a man who takes care of his mother, he’s really nice, he’s a good man. He’s sweet.’ But really … nobody really wants to be bothered.”

Support Systems

The researcher recognized an awareness of supportive services and networks as resources for the thirteen participants. However, within this group, two of the caregivers expressed their desire not to use formal or informal support networks. One participant, Blake, rationalized his mother’s severe medical diagnosis (leukemia) for his reluctance to accept support. Blake’s statements:

> They (extended family) ask, can they come and do things, but because of COVID, I don’t allow anyone in the house … because of my mother’s numbers … that is … I think she’s on like … five-tenths of her white blood cells.
>
> I don’t want anyone just touching my mother or doing for my mother. Because … I mean, of course, I feel like I do it better than anyone can do. But I know her … and she’s in my home.

Clarence’s reluctance for formal assistance was based on a lack of quality services. He stated:

> I’ve had ‘em … I’ve had them trying to tell me how to run the house. Tell me what to get. Tell me what to do. And I’m like, wait a minute. Excuse me; you got

> it wrong. So, me personally, If I had someone to come in and take care of my mom. I wouldn't want it because of what I've been through with caregivers. That's just being very honest.

The participant further described his response regarding informal support in the following manner:

> They (kin) live on the other side of town. They'll call and say, "you're doing a good job," or something like that. But just … we come by to give you an hour or time for yourself … Nah … I don't have that.
>
> Church … umph … you know, the church really bothers me. Because they always talk about calling, and gonna come see, and doing this and do that. And to be honest, they don't do anything.

Most of the male caregivers used both formal and informal support networks. These supportive networks were perceived to sustain the caregivers' endurance within the caregiving role. Given the length of caregiving years among these carers (less than one year to over 24 years), supportive networks were instrumental in survivorship. Based on the level of care recipient dependency and level of frailty, support needs varied. The findings in this analysis indicated formal services included home health professional services (i.e., registered nurses, certified nurse's aides/CNAs, physical therapists) (*n* =3), hospice care services (*n* = 3), and nutritional support services (i.e., "Meals on Wheels) (*n* = 3). Another formal care support was reported as a use of adult day care services (*n* =4); whereby two of the caregivers (Quinn and Greg) care recipients are enrolled in an "all-inclusive care program," or the elderly, that manages a broad range of medical (provider, nursing, social work, and respite) services, as needed.

Informal support was reported by 10 of the 13 participants and reflected various types of support received. The informal support network included: spouse (*n* = 4), sibling (s) (*n* = 6), caregiver dependents/children (*n* = 7) and other informal support (i.e., friends, church) (*n* = 6). The following statements exemplified the sources of support:

> John: (sharing how he eventually accepted help from his son's godparents): and just know that we're here to help you. And it's okay to ask for help. Because if you don't ask for help, and you burn out, who's gonna take care of your children, your wife and your … so, … you choose.
>
> Keyon: We have a younger cousin; he's my second cousin. So, he comes in and checks on him every now and then and helps him with the mechanical stuff.
>
> Greg: My daughter is a big help. If I call my daughter and say I need you to take (take) your mom for a little while, she usually does … no matter what she has to do. Grandchildren, the kids are old enough to be able to help her do those things.
>
> Wendell: So, my brother can come see my mother, cheer her up, he's happy, go-lucky … come and go. My sister … she was involved with her kids heavily. So, we would make plans to where she would go there for the holiday or (or) stay for a month or two to give me a break or things of that nature. So gradually, my sister participated.

Two of the participants described the use of professional therapists, while two others verbalized their reluctance through the following comments:

> Greg: I'm not into the group therapy thing … If I get to the point where I feel like I'm getting ready to snap … I will attend or go see a psychologist. But I'm not the group therapy thing because and this might be my negativity on the situation, but your problems can't solve my problem … you feel what I'm saying? I need to find someone who's got the solution. I don't need someone whose got more problems.

> Jamel: I think I have enough support between work and people here and my outside friends or whatever? I'ma … I have a lot of support. And I don't think I need it to where … Yeah, I mean, I have a lot of support at work. I don't think I'm to that point where I need it … like that.

Several of the caregivers commented on personal benefits from support groups; however, they did not attend a support group. Their comments are as follows:

> Jordan: I just tell you, as an African American period, or male, I just don't know we (we) have been … I'ma see how to say this; I don't know if WE think about things like respite. I was brought up, … you take care of your family.
>
> Derrick: I've been debating it, but I just haven't had time to do that right now. It probably would be good for me because I could hear from other people. But I don't know of any, and I haven't really tried to pay attention to it. I think there's some Alzheimer's groups around someplace.
>
> Jordan: I don't think we have in our mind that there are services available to us … And then the perception may be that if I avail myself to those services, how will I be looked at my family and other people?
>
> Clarence: Men support groups … I never thought about it. Not too many men, and I know, do caregiving … or even think about it.

Theme 3: Caring Amid a Pandemic

COVID-19

This category was specific to the participants involved in caregiving to their loved ones during the COVID-19 pandemic. Only one of the caregivers, Fred, did not meet this criterion due to caregiving's timeframe and the pandemic's onset. For the caregivers that met these criteria, the results are presented as follows.

Here, the findings describe 12 of the male caregivers' responses regarding caregiving insights during the COVID-19 pandemic. The researcher will present the narratives of the other 12 participants' perspectives on being a caregiver during the pandemic. This inquiry included: (a) if and to what extent was he and the care recipient affected, (b) the willingness to accept the vaccine for himself and/or for his loved one, and (c) pandemic-specific effects on his social interactions with others. Of mention, the willingness to take the FDA-approved COVID-19 vaccine became a point of inquiry once the vaccines became available across the country.

Caregiving Effects During the Pandemic

When queried on the experiences of the pandemic on the caregiver's ability to deliver the same quality and/or quantity of caregiving hours of care, as provided before the pandemic, the most significant responses are summarized as follows: (a) protection from acquiring the virus and giving to the loved one (safety precautions), and (b) changes in formal and informal support systems, and (c) changes in lifestyle.

Taking measures to safeguard their loved ones (and themselves) from acquiring the COVID-19 virus, the caregivers in this study shared what actions were taken to ensure appropriate safety precautions were in place:

> Blake: I have to be careful of COVID for myself, I have to be careful of COVID for my mother, I have to be careful of any germs for my mother.
>
> Derrick: I spend a lot of time with her here, anyway. The biggest thing that we've had a problem with is the masks, you know, because a lot of times, both of us get up, and we forget about putting our mask on when we get ready to go in someplace.

> Griffin: When I wash dishes, for example, I like I use I normally use hot, hot (hot) water and everything. But now, COVID, I also put some Clorox in the water because I want to make sure that that even if I'm washing dishes thoroughly, that they're thoroughly sanitized. We do (do) things to try to try to head off this COVID if it should happen to get around us.

As aforementioned, Griffin engages in the use of deep-breathing exercises and over-the-counter products to build up the immune system for himself and his mother.

> Jordan: She (CNA) comes with her mask; she puts a mask on; granny was putting hers on too. When stuff coming in, but I'm just saying my keys, my wallet, the doorknobs? I wipe the car down and all that I'm trying to do as best we can, you know, we keep wipes around in the house.
>
> Jamel: Yeah, they wear their masks, even my mommy my daddy sitting down, but he's got that. He's got that mask ready and whatever. The caregiver expressed concern that he could potentially give the virus to his parents due to his healthcare employment and being out around other individuals. Yeah, it crosses my mind … Uh, and if they get sick.
>
> John: And uh … so the impact of COVID has been for me, as a caregiver... adjusting in my head. We have not had a direct COVID impact. But it's been the periphery [that's] been felt. And it's (it's) hard to put a finger on what, what it was.

The caregiver recounted a hospital encounter when he was not allowed to stay with his disabled spouse (care recipient) due to the COVID restriction. He responded, "So, now I go to the hospital. And they tell me, I can't, I can't even stay with my wife. They tell me. And I gotta adjust to that?"

> Keyon: It's a, it's bad. When (when) my dad was here, we had to take him to the doctor, and I couldn't go in. And I'm like, "What do you mean, I can't go in? … I'm his caregiver and (and) healthcare proxy." "Well … we can only allow one person in at a time," … I said, "the man's got

dementia … so he's not going to be able to remember to tell you what's wrong with him."

Quinn: (Regarding the occasional visitors): you know, those who have visited … they've been, you know, far away from mom, and they are, you know, clean individuals.

Wendell: COVID-19, didn't really change that much … wore a mask around her.

Several of the caregivers shared direct changes in their formal and informal support systems due to the pandemic restrictions. Greg communicated this statement, "That's why I said, … this summer … this summer was rough with my mom. It really was … uh … no (adult center). The only company she was getting was her neighbors. And it was, it was (it was) something." Other responses included:

Quinn: I get a call saying that (*adult day center named*) is going to close participants indefinitely until further notice. At which point, it sort of put my wife and I in a state of contingency because we're like, Okay, what are we going to do? You still have to work, as do I. And then this is pretty much from March until July.

Blake: They ask, can they come and do things but because of COVID, I don't allow anyone in the house … because of my mother's numbers (care recipient has leukemia). Adding to this response, he stated: "I'm just afraid that, uh, somebody's coming in … they still have to go home to their lives. So, I don't allow anyone (*with emphasis*) in my home."

Jamel: Before this COVID happened … We had my niece or them or my dad or sister … they went … Well, not my dad or my sister … my sister (*not the sister who lives in the home*) or my brother … they were able to go with her (*medical appointments*). But since COVID, she has lately had to go by herself.

Tony: It affected him when he was in the rehab center when we couldn't visit him at one time because of the COVID-19.

Lifestyle changes yield mixed findings in the current study. While many people would undoubtedly acknowledge some changes as a result of the pandemic, two of the participants in this study conveyed minimal to no effects:

> Clarence: Basically, to me … none whatsoever. COVID (COVID) didn't make me change anything I did; we put on a mask.
>
> Quinn: But … it really didn't affect us as though we (we) work at (*place of employment*), and they actually manufactured and distribute items for military branches. So, they are pretty much considered to be an essential business. And so, we didn't have any loss of revenue. We didn't have any loss of income. We, unlike many others, were able to maintain. The only thing that I was unable to maintain during this pandemic was the DJing schedule.

COVID-19 Vaccine

At the time of this study, the availability of the COVID-19 vaccine was in the immediate phases of being available to the highest risk category of individuals. Following a phased approach according to the Advisory Committee on Immunization Practices (ACIP), those eligible in the first phase (Phase 1a) included healthcare personnel and long-term care facility residents (Dooling et al, 2021). The next phase of vaccine administration (Phase 1b) included persons ≥ 75 years of age and essential frontline workers by the end of data collection. It is necessary to mention that the researcher only asked the inquiry regarding the vaccine administration after it became public knowledge that the vaccine was available and ready for consumers (public) to receive the injections. Therefore, caregivers who were interviewed during vaccine availability were asked about their willingness to accept the medication. If the caregiver brought up the vaccine subject, that information was captured and presented in these findings. During this study, no caregivers or their care recipients received a vaccination due to the national administration guidelines.

When queried further about the willingness to accept the vaccine for himself or his loved one, three caregivers indicated that they would take the vaccine immediately when it became available. Two caregivers said they would accept the vaccine at a later date. Two other caregivers responded that they would not take the vaccine. Jordan**,** the caregiver to his 100-year-old wife's grandmother, shared that he would willingly accept the vaccine. The other two caregivers only responded that they would take the vaccine without further commentary. According to Jordan, "I trust that when they say it's ready (*COVID vaccine*), I'm ready. And so, I will be one that would take it … and Granny and (*wife's name*) whenever they do it." When faced with negative comments from others regarding taking the vaccine, he offered these comments: "We all have to be at peace with whatever decision we make. … I said that's fine … I say … I'll be in line when it's time to take the shot (laughter). And I'll tell you about; I'll talk to you later."

Consistent with the current literature on communities of color and their hesitancy in taking the vaccine, a few present study caregivers reported that they would delay administering the vaccine for themselves, once eligible, or refuse to accept the medication altogether. Two of this study's caregivers shared these responses:

> Clarence: And for myself, which I'm looking at, I'm watching the results of people taking the vaccine [*phone interruption*], and I'm trying to … I'm trying to … see really what's going on with the side effects from

> the vaccine. Give me … maybe three to six, maybe three to six months.
>
> John: And I’ll probably do it … but not after having some conversation, especially with our doctors in our community. So, at some point, I gotta trust us. We have some smart people in our community. And they’re going to do the research necessary to give us the right recommendation, our community just to survive through this. So, I (I) haven’t made a decision definite decision yet, but I’m leaning toward Yeah … I’d probably take the vaccine.

However, several of the study participants held to their convictions for not accepting the COVID-19 vaccine: According to Griffin: “But uh, as far as I’m concerned. I don’t take vaccines.” Keyon also expressed his opposition to the vaccine with this response: “And so, but the vaccine for COVID … no … it’s it [not] for me, it’s not. And I have friends that are doctors. And I have a lawyer that consult me and what’s really going on behind the scene? So, no … not yet.” From hesitancies to refusal regarding the vaccines, two caregivers gave these responses:

> Griffin: Yeah, yeah … we’ve (we’ve) been … our community has been experimented on so many times. And I’ll just talk about the Tuskegee is there’s other things in history as shown that, that that that that that we’ve been? We’ve been targeted at times.
>
> Keyon: So, I wouldn’t consider a vaccine that was created in a couple of months; that I feel is only geared towards people of color and poor White folks. I think we’re being used as test objects with that.

Concerning the care recipients receiving the vaccine, four care recipients were deceased, although two caregivers responded that their parents would willingly have accepted the vaccine. Three of the caregivers responded “yes” to the rest of the care recipient group, three of the caregivers responded “yes,” he would support his loved one receiving the vaccine, while zero said “no” to the vaccine being offered and administered to his loved one.

> John: [*wife’s name*] would be a good candidate for COVID vaccine. But [because] she’s really high risk.
>
> Wendell: Yes, I believe that if she was alive, that she would have already received her vaccine or vaccination shot, vaccine shot.
>
> Clarence: Right now, and my mom being 98 years old. Being that she don’t go out this house … uh … I ain’t too much worried about this vaccine right about that. I may be thinking about giving [the vaccine] my mom because it’ll be summertime, and people will be moving (moving) around again.
>
> Griffin: So, she’ll probably get the COVID (COVID) shot when it’s available. When it’s more easy to access because we’ve been tested twice, and everything’s good.

Social Interactions

The need to mitigate the effects of the COVID-19 virus and eliminate the coronavirus spread globally; individuals and families have had every sector of their lives impacted by the pandemic. This section describes direct pandemic-related social interactions for the participants in this study and/or the caregiver/care recipient dyad. While a few of the men denied being significantly impacted by the pandemic, the detrimental effects were sensed for most of the caregivers, based on their responses. For example, the pandemic’s impact on their social interactions (i.e., social life) led some of the men and care recipients to experience social isolation (i.e., no family visitations, decreased social functioning) and, for some of the men, reduced quality of sleep, reduced services for the care recipient, and increased anxiety due to severe COVID-19 restrictions. The following excerpts from the transcribed texts describe a few of the caregivers' perceptions of how their social interactions remained untouched or marginally affected by the pandemic.

> Jordan: We pretty much told our family; we'll see you when this thing gets under control. I'm just being honest with you—that ('s) how we're doing it. You know what I'm saying? And … (*states PI name*), it's like this, "I love you; you know, you love me that love will endure this COVID-19, believe me. So, for the social life … before COVID … it began to reduce (reduce)(reduce) to basically down to zero."
>
> Blake: I don't have a social life because; and I won't dare start to meet somebody because they're only going to get upset because I won't have time for them. It doesn't allow the … uh … social life … because of the pandemic.
>
> Griffin: I know people invite me to cookouts and stuff like that, right? With this COVID thing going on. I say, "not my thing." I don't, (I don't) (I don't) get around a lot of folks. Plus, I can't afford to bring anything back here to her.
>
> It makes you close your (close your) "circle the wagons." It makes you close your (your) interaction with people. It's closed to a certain (certain) group, okay? And then it closed my … closed mine even a little more. Because I can't (I can't) even … I can't (I can't) afford to bring some … or let someone bring something by here that does she don't need … doesn't need to get.
>
> Keyon: If you've got a father who's not tech-savvy, because they (they) are doing things online … meetings with the elderly and where they can gather online and talk to each other. That was a slow process in coming because they can't get out the house. And my father is a social kind of guy. So being home all day, not being able to go out, and not being able to go out to lunch with the boys was an issue.
>
> Wendell: [the pandemic] … but it kind of shortens the visits that she would make to the house, you know, or go out for doctor's appointments, because doctor's appointments were changed, wouldn't go out to eat after those

doctor’s appointments. She wanted to go on a trip or two, which we said “no” because the COVID slowed down the little bit of travel that she would do.

Greg: She’s got so many people that come by and visit and spend time with her. Keep her company, laugh with her and all. And, she goes to (*adult day center named*) three times a week. She’s happier now than she’s been in months. And then … because initially, it just stopped it altogether, when COVID first hit, she could not go at all?

Jamel: Immediate family still comes over; otherwise, no other interactions. If they come now (*church members*), they just come from the cars and leave; drops something off. So, there’s … everybody is wearing masks.

As pointed out, social isolation was identified in the lack of social connections due to separation from friends and family or limited exposure to social activities. Although the caregivers in this study are not alone physically, their responses suggest solitude in several cases. One caregiver, Derrick described the lack of engagement with his spouse due to her progressing Alzheimer’s: “One thing that gets me more than anything else with her is when I asked her something, or when I try to talk to her about something, or we … I’m trying to converse with her, she’s silent, doesn’t say anything.” The caregiver also expressed: “church things, activities, and things like that, if it’s not something that we do with our spouses or our families … would make it hard … tough for me to do. Because of the fact that I couldn’t leave her here by herself.” Blake’s very restrictive isolation was based on the severe health concerns for this mother: “With regards to the pandemic, and with regards to my mother, being who she is … the type of disease that she has, knowing that she can catch something … we’re both isolated, but we do have each other.”

Clarence described his lack of social engagement with others due to the virus in this manner:

> I don’t hang around a lot of people. My mom … uh … and my mom is not, you … we (we) not? You know, we’re not the type to keep running to different people’s houses. That’s not us. And when I go out, I’m out there and back. I don’t. I don’t lollygag Fuddy Duddy; fiddle-faddle … anything. No Flim Flam and (and) nothing.

John related the social isolation for his family as a result of the pandemic in this way:

> COVID has affected us in that we can’t go out and do the interactions. We can’t be at church every Sunday. We can’t … all of those things that we used to do, we can’t. And I don’t want to risk … because she has, she has respiratory issues.

Due to the unknown effects of the COVID-19 virus, severe restrictions were placed on social gatherings, visitation guidelines for hospitalized loved ones, curfews, among a long list of other conditions. For Tony, the ramifications of the pandemic led to this description of social isolation, more specifically for his father:

> Once he got out of the rehab center, you know, the state said that you couldn’t have … you had to limit, you know, like family gatherings and things like that. So, people were leery about coming to visit him. People either didn’t want to come because they didn’t know if he was a carrier or if they were a carrier and, you know, didn’t want to make them sick and stuff like that.

A prolonged decrease in social life activities or persistent caregiver social isolation can generate disengagement for caregivers. This detachment can cause symptoms, such as stress and anxiety, for caregivers managing numerous and often complex caregiving responsibilities. Social isolation can manifest as adverse effects of caregiving. Without a good social network, which includes formal and informal supporters and appropriate coping strategies, the likelihood that detrimental health outcome symptoms can emerge. The following section, Theme 4: “Effects of the Caregivers’ Journey,” denote the findings of the positive and adverse (negative) effects of caregiving on the male carers. Also, the distinct physiological (physical) and psychological (emotional) impacts on the participants’ health outcomes are presented.

Theme 4: Effects of the Caregivers’ Journey

This theme includes three categories that describe the caregivers’ journey (experiences) of caregiving. They include: (1) “Stressors—Positive and Negative Effects,” (2) “Physical/Emotional Adverse Health Outcomes,” and (3) “Benefits/Gains—Positive Health Outcomes.” The following sections present how each of these categories collectively describes the theme, “Effects of the Caregivers’ Journey.”

Stressors: Positive/Negative Effects

The experiences (journey) described by the male caregivers, seen as both positive (benefits) or adverse (negative) effects from experience, with the adversities and challenges. All participants (*n* =13) described both positive and negative effects encountered during their caregiving experiences. The researcher, thereby, categorized these experiences as positive effects and negative effects as described in Table 5.

Table 5

Positive and Negative Effects of the Caregiving Journey

Caregiver	Participant Quotes
	Positive Effects
Blake	When I sit with my mother … um … I tape her … I video chat, she doesn't know. And every time we talk, she just constantly tells me how much she loves me. What better gift is that?
Keyon	It's a reward, being a caregiver, and knowing that you, she never had to go into a nursing home, she didn't die in a hospital by herself.
Quinn	I still feel somewhat accomplished and, you know, thankful that I was able to … you know, keep her with me.
John	But I think about this sometimes. I say … what if I had walked away? What if I had made that other decision?
	Negative Effects
Jordan	I've had moments where I've been worn down and felt like even throwing my hands up in the air. And then, if you're not careful, if you're not careful, you can easily slip into a spirit of resentment.
Greg	I'm more impatient; I do know that. When it comes to dealing with my mom, I'm a lot more impatient because it gets repetitive.
Wendell	It puts a black cloud over the family. [caregiving] caregiving also puts stress on your family because the kids are expected to do certain things; you ask your spouse or mate to (to) pick up the slack and do certain things.

Caregiver	Participant Quotes
Tony	I guess another financial burden for me … was that my job … after a certain amount of time, only paid for … well, it hasn't happened yet, but it's gonna happen; I only get 65% of my pay.

Having a choice to undertake the caregiver role or allowing others to assume that responsibility was a personal decision for each individual. Through the positive and negative effects of caregiving, as aforementioned, the researcher perceived the spirit of caring was reflected in each of the narratives and stories conveyed during the interviews.

Following the caregiver literature, caregiver stressors accounted for the most significant physical and emotional stress for the current study caregivers. Risk factors include co-residing with the care recipient, social isolation, financial difficulties, increased duration and length of time spent caregiving, absence of coping skills, problem-solving challenges, and lack of choice in being a caregiver (Mayo Clinic Staff, 2020). An account of these male caregivers' experiences is reflected in these commonly recognized risk factors' narrative descriptions. The following sections will illustrate verbatim statements of how caregiver stress affected the caregivers, both physically and emotionally. Table 6 documents the psychological and physiological effects these male caregivers described.

Table 6

Physiological and Psychological Effects[*]

Characteristics of Symptoms	*n*
Psychological Adverse Effects	
Witnessing suffering (of care recipient), anticipatory grief	4
Emotionally draining, overwhelmed, defeated, frustration	5
Subclinical stress (self-reported stress)	2
Worry, fear, burden, vigilant demands	4
Dread, anxiety	4
Guilt	3
Feeling isolated or abandoned by others	1
Burden (financial)	6
Emotionally abusive	1
Physiological Adverse Effects	
Lack of sleep	5
Fatigue, tiredness, exhausting	3
Easily irritated or upset or angry (anger), tense, moody	2
Risk of illness, injury, mortality	3
Exacerbations of personal health issues	2
Weight gain	1

Note. [*] Caregiver report of symptoms in multiple categories. *n* = number of caregivers

As the caregivers shared their caregiving experiences, it became clear that their emotions and physical health were affected by their distinct caregiving journey. The physical and emotional characteristics presented in Table 6 are not projected to represent a position of rank about the self-reported stressors of caregiving. However, the caregiver reported symptoms that occurred during their caregiving roles indicated which stressor type (physical or emotional) was most predominant and the characteristics most prevalent.

The findings showed that most of the characteristics were in the psychological or emotional effects category (*n* = 9). Moreover, the data showed within this category, the participants identified with at least 30 adverse psychological conditions. The researcher determined six categories of effects within the physical type of adverse impacts represented the caregivers' responses. The caregivers identified 16 distinct symptoms of adverse physical effects. The following statements provide illustrations of how some of these caregivers described the impact on their emotional and physical health:

Psychological (Adverse) Effects

As previously stated, many of the caregiver's adverse effects had a detrimental impact on the caregiver in both categories of physical and emotional effects (i.e., vigilance demands). For example, Derrick recalled the inability to leave his spouse alone for fear of self-harm:

> I have to be aware of what she does and how she does it in everything. And I can't; I can't leave her here by herself because she's liable to leave out the house. You know, 'cause I've had some experience where some of the things that she picked up to try to digest or would try to put in our mouth was some things that … uh … wasn't good for her.

Blake shared these comments regarding his vigilance in keeping his mother safe:

> I have to constantly watch her tell her, "Don't do this. Don't do that." And sometimes she wants to go to the park, or sometimes she wants to go to a store to

> … like Macy’s or something, and she has a mask on … and just constantly watching keeps me a nervous wreck. Because even though I tell it ten times, she’ll forget in five minutes if that makes any sense. So, constantly watching over her. It’s just constantly watching over her, like a little baby, really it is.

Loneliness is another emotional response that caregivers may incur. Derrick depicted this emotion in this response: “I’m in the house by myself, this is the way it’s going to be when she got when she’s gone. And this is what I’m gonna have to deal with.” The following statements further illustrated the responses regarding the psychological impact on the mental or emotional health of these men:

> Greg: So, my worry level, my stress level on the worry side, is a lot higher. And then, uh … I’m a lot more tense. it’s like, I feel like she can’t function, think, or operate without me—coming, being here. … But if I don’t show up. If I don’t show up … there’s tears, frustration, calling me three times, waking up at six o’clock in the morning … wonder when I’m coming. So, it’s that part of it … between me and her that’s stressful.
>
> Quinn: Sometimes I just, uh … (umph) … don’t know, no, kind of rages … so, I’m not gonna say that I feel bad. But a lot of times, I just, you know, feel some … sometimes defeated, as to not being able to uh … you, know … stop this from happening (*progression of mother’s dementia*).
>
> Clarence: I might get stressed out. I might get stressed out. Might get a little frustrated. So, me as a caregiver, we sometimes take a lot of that verbal abuse because of their inability to do what they used to do. Sometimes when you take care of your loved ones, they seem to … sometimes can remember … sometimes the bad and not the good. What you have to be a caregiver, you have to just kind of keep pushing on … strive past it and kind of in one ear out the other. The reason I say it monotonous because sometimes it goes on and on. And you still have to stand there and take it … and do what you have to do.

He later posed these questions for future caregivers: “*Does your parents or those you care for… do they talk to you hard? Do they find fault in you? Do they bring up your past mistakes*?”

> Derrick: So when you say, Well, I’m gonna fix so and so for dinner. And I go and start fixing, and when she comes down to down there, oh, I don’t want that. But that’s what you said you wanted, you know, one of those things. And there comes the frustration, you see?
>
> I’m trying to converse with her; she’s silent, doesn’t say anything. And that’s frustrating to me. My daughter doesn’t (doesn’t) get as frustrated as I do.
>
> Keyon: … the mental stress is really the worst um, it (it’s) it crippled my body. There’s no hugs; there’s no kisses, there’s no thank-you (s), there’s you know, there’s none of that; there’s no companionship, basically.
>
> Blake: I take care of her, even though I have a lot of challenges on my own. (mental health illness)
>
> John: So, I’d say that was one of the big, hardest adjustments, and it was a disadvantage. When (*wife*) could no longer work. I was close to selling the house, selling one of the cars. I’d never been in a space like this. And even though I was a saver, I was running out of money. I tapped into my 401k. And it was … it was difficult.
>
> Griffin: And sometimes, I guess when I’m a little irritated or frustrated and not so much for her. It could be just life in general.
>
> Jordan: there has to be a balance. I don’t know how you get there. But I’m just saying, if you not, it will wear you down. And then, if you’re not careful, if you’re not careful, you can easily slip into a spirit of resentment.
>
> We had this emotional thing all the time … y’all trying to do me dirty (Granny’s response).
>
> Maybe there’s a better way of saying of finding a release for stress and the ebbs and flows and the roller coaster ride one minute we have it one minute; I don’t know, we’re gonna make it. You don’t say, Okay,

what are you doing? Okay, the next moment we got to get out of here ‘fo [before] something happened.

Wendell: It’s a balancing act, you have to, you have to balance everything on how much attention you got to give your mate how much attention you gotta give your, your caregiver, how much attention you gotta get your kids, the job, how much sleep you’re gonna get it all is balanced, you have to balance and put things in perspective.

If you have a mate, that’s emotionally draining when you and your mate ain’t on the same page on how to “CAREGIVE’ (*emphasized*). And how much the other person is willing to do or not do. That emotion comes in when you’re not getting the support that you need from whoever your mate is because you’re feuding over different issues.

I think that part of the whole dynamic of what gets you down is you’re not having to be on page with your spouse, and you (you) being … you have a vision, your spouse may not always have that vision.

Physiological (Adverse) Effects

The caregivers described impaired health behaviors or lack of self-efficacy, such as neglecting one’s own health care needs. Emotional or mental health effects (i.e., depression) are extensively cited in the literature. Conversely, none of the caregivers used the word ‘depression’ or ‘feeling depressed’ outright in their responses. Six of the thirteen participants did not mention any physical adverse effects of caregiving (Jordan, Jamel, Quinn, Clarence, Derrick, and Griffin). The researcher noted that physical health conditions were identified in two caregivers in the ‘no reported physical effects’ group. They related their health state as “related to pre-existing conditions,” as heard in Griffin, Blake, and Derrick’s narratives. Blake, who has an underlining mental health condition, indicated this illness nine times during the interview. It would appear to this researcher that the challenges of the caregiving role may have led to exacerbations of his mental health condition, leading to physical health effects:

> I don’t sleep for a day or two. … I don’t like the word draining; I want to say it can be challenging. And that’s just because of trying to juggle everything and still needing … having enough energy to get it all done.

Griffin shared that he has a chronic diagnosis of sleep apnea: “Never realized that I had anything to do with sleep apnea. I thought snoring was good sleep. I didn’t know it’s a respiratory problem.”

Bowling is a light exercise that can be used as a coping strategy to relieve the mind and body of stressors, such or worry. The researcher determined this way of coping as a way that Derrick found respite in his caregiving role. Derrick, as an avid bowler, was recovering from orthopedic surgery. Due to his numerous caregiving responsibilities, he has limited time to practice, compete in tournaments, or engage in his sporting league. He offered this response: “Wherein normally, I would have gone out like maybe on Friday or Saturday and just practiced … I can’t do that now.” Keyon detailed the physical effects on his body caused caregiving:

> And now … trying to get back into things, I got it, ‘cause stressors caused some cosmetic changes in me. So, I have to get some things done to me visually. And just the level of stress being a diabetic also, losing teeth because of the clenching and my mouth and the grinding. I am recovering from partial sight … eyesight from stress. (*points to the eye*)
>
> You don’t sleep because you’re listening to find out if my mom would get up at night, you know. Is she up as she walking around? And my father, at one point I don’t know … it must have been a drug he was on … he thought there were

> raccoons under his bed. So, ah … you know your (your) attempt … to ease them … Um, so stress … uh … (is) the killer when it comes to caregiving.

Other caregiver statements that illustrate the physical effects of caregiving for some of these caregivers were described as:

> John: I notice you just hover over your wife like ... you just hover. He said it sounds like your adrenaline is stuck. (wife's therapist)
>
> I told her recently that, you know, I gotta get some help because I'm getting older. And I don't want to just completely wear myself out with all the lifting and transferring.
>
> Fred: So, physically, that's how it impacted me because I could, and I knew what was happening. And there was physical evidence that was occurring with my sarcoidosis and the stress of caregiving.
>
> Griffin: So, this this last I say this last year or so I've really slacked off on working out … And plus putting these pounds on … So, I really got to stop being lazy before I do hurt myself (*changes voice intonation and laughs at his statement*)

Benefits (Gains)/Health Outcomes

Caregiving can be beneficial, as mentioned elsewhere. In this study, the researcher regarded health outcome benefits or gains, during the caregiving timeframe, as self-reported physical or emotional improvements. The researcher saw these as optimization of coping strategies or stress-reduction techniques. Few of the participates reported improvements in their health status (n = 5), directly or indirectly. For those that did, the following statements reflect the following benefits: Clarence described his personal health as "healthy as a horse." The researcher saw the primary health benefit he gained was seen by managing his stress and frustration levels. His management was made possible through an effective coping strategy—primarily his spirituality. When describing the effects of caregiving on him emotionally, he stated,

> it frustrated me to death. Then I found out that … when I surrendered all them emotions and frustrations … put ‘em to the side and allow God to do it. Why should I let frustration control me when I’m greater than the frustration? Sometimes, sometimes you just gotta let some things go. (*stated with strong emphasis*)

Fred, on the other hand, saw stabilization of his sarcoidosis by minimizing the stressors that caused his condition to become exacerbated:

> I was commuting back and forth to (*a city named*). But because of the stress of that nursing home, commuting to (*a city named*) every day, except when I’d visit night shift, and then having to come straight from (*a city named*) and go help take care of my mother, especially … when she had come back home from the rehab facility.

Moreover, this medical advice supported his decision of self-efficacy. In a conversation with his medical advisor,

> Unless you reduce your stress level, and he said, You need to, you need to get back here in (a city named), and you need to stop. I mean, you can’t drive back and forth to (a city named) every day [to those] facilities.

The researcher determined an indirect psychological health benefit in the emotional well-being of Blake as indicated by the following statement: “We take care of each other really … It’s not that I just care for her because she helps me too emotionally. She’s a mother.” John also described health-related benefits by the decisions he made to invest in his self-care. As aforementioned, following the medical recommendation from his therapist allowed him time for self-care (i.e., personal time, social activities). These activities supported his physical and mental health. Of mention, given that John's caregiver role occurred early in his marriage and as a middle-aged man, he did not convey any reference to intimacy (sexual). His only reference to a feminine aspect was regarding the resumption of her menstruation cycle. Lastly, Derrick**,** as mentioned, is a bowler. Using his financial resources and a local caregiver grant, he can participate in more bowling-related activities. The opportunity to return to bowling was determined to positively benefit his mental (coping) and physical (exercise) health.

Researcher Field Notes

Qualitative field notes were an essential means of documenting the contextual information observed or heard by the researcher and what the researcher was experiencing during the interview. In this study, field notes included the observed environment and interactions. For example, one participant was feeding his mother while he conducted the interview. He persistently moved away from the computer screen to attend to her personal (i.e., feeding) needs. Another participant engaged his mother during the interview by asking her specific questions to validate a particular point he was trying to make. Other examples included in the field notes were the use of body language seen through hand gestures and colloquialisms. At the end of the recorded interview, one caregiver asked if he could pray for the study's success and dissemination of the content. For the researcher, the field notes described his reliance on spirituality/religiosity as validated through prayer. Another participant told the unsteadiness of his mother's gait and the lack of regard for her personal safety (i.e., inappropriate footwear, not using a walker) in his telephone interview. The agitation and frustration that emanated from his change in voice tone and his description of the situation were vividly captured in the researcher's mind. A final example of how the researcher collected and used field notes is described when one participant struck up another conversation regarding his caregiving experiences after the recorded interview ended. In the notes, the researcher described how the participant described his views on being a caregiver and expounded more on societal perspectives of African American men and caregiving. In these notes, stigmatization took on a more detailed association for male caregivers. As a result, the researcher became more informed to responses around this issue. This caregiver also emphasized male masculinity and offered his insights into his experiences of gendered caregiving and woman's work.

One specific inquiry regarding the emotional well-being of participants was asked of two other participants, using a participant-requested query, "*Are you happy?"* In the researcher's field notes, she boldly emphasized not engaging in further inquiry for that particular question—with exclamation marks. Based on the responses of the two male carers, the researcher perceived frustration and agitation. Therefore, the researcher saw this emotive line of inquiry as better suited for future research. A final observation regarding field notes surrounds conflict with self-reported health status and the researcher's professional assessment of health. As mentioned previously, the caregivers described their health as either good or fair. Reflections in the notes indicated that some of these caregivers said they were in "good" health, the researcher's visual assessment was described as "fair." This nursing assessment was based on the self-reported history of medical diagnoses such as sleep apnea, hypertension, renal failure with dialysis treatment, dental decay, and morbid obesity as examples. Given this perceived state of health by the respondents and the researcher, this conflict in health status may be an additional phenomenon of interest for future studies. Based on the participants' shared experiences, in addition to the researcher's field notes, the depth of context collectively added to the data analysis and the robust findings of the current study.

Rationalization of Research Findings

In addition to providing qualitative descriptions in response to interview questions, a total of four major themes emerged from data analysis. The study's specific purposes, the SSCM domains chosen to explore those purposes, the themes, and the following categories that resulted from the data analysis are presented. First, the researcher aimed to describe the experiences of African American male caregivers who are (or were) the primary family caregiver to a dependent, chronically ill family member and explore how caregiving affected their health-related quality of life using the Revised SSCM to guide the study. The researcher developed two themes from the analysis that examined the conceptual framework's background and contextual domain. The first theme—*My Time to Take the Reins* and subsequent categories, answered the research question (RQ): (RQ1) *How do African American male caregivers describe their decision to become caregivers?* The second theme that resulted from the analysis—It's a Male Thang, emerged from two of the research questions: (RQ2) "*How do African American male caregivers perceive their caregiver role? (RQ3)* "*What coping strategies and support systems do African American male caregivers use?"*

For the second research question posed in this study, the researcher aimed to understand the psychological, physiological, psychosocial, and financial outcomes of African American male caregivers' health and well-being related to their caregiving experience during a COVID-19 pandemic. Two additional themes were derived from the analysis that examined the background/contextual, stressors, health outcomes domains of the SSCM. The third theme—*Caring Amid a Pandemic*, answered research four: (RQ4) *What has been the impact of the COVID-19 pandemic on the lives of African*

American male caregivers? The final theme—Effects of the Caregivers' Journey, answered the research question (RQ5) *What are significant stressors described by African American male caregivers before, during, or after the pandemic?*

Research Question 1

The first theme, **"My Time to Take the Reins,"** resulted from several categories: "Do What I Gotta Do," "The Heart of Caring," and "Spirituality/Religiosity." These categories answered the research question, *"How do African American male caregivers describe their decision to become caregivers?"* This question explored the background and contextual factors of the study's SSCM conceptual framework. The researcher described these factors as the attributes of the caregivers and the care recipients. Data from participants' answers to this interview question are located under the caregiver topic area, *"Some people, even though they provide a lot of care to another person, do not consider themselves as a caregiver"* of the semi-structured interview guide (see Appendix E). The researcher posed two guiding questions to answer the research question:

(a) C*an you share something about how you came to take on the caregiver role for your loved one?" and (b)* "*When did you first start being a caregiver for your (insert care recipient title)?"* Both questions guided the researcher to the main topic regarding caregiver role assumption.

Research Question 2 and Question 3

The theme, "**It's a Male Thang**," resulted from four categories: "*Coping*," "*Cultural Aspects*," "*Societal Perspective*," and "*Support Systems*." These categories are represented from two of the interview questions: (RQ2) *How do African American male caregivers perceive their caregiver role?* (RQ3) *What coping strategies and support systems do African Americans male caregivers use?* Guided by the SSCM domains of the conceptual framework—background/context, stressors, and mediators, specific interview questions that answered the two research questions were:

> What would you say it means to you, as a male caregiver taking care of your loved one?
>
> Do you think of yourself as a caregiver?
>
> Do others (i.e., family members/significant others) think of you as a caregiver? Please explain.
>
> How do you cope with the stress or burden of caregiving or being a caregiver?
>
> Tell me about the kind of support you get from your family or significant other.
>
> Tell me about any support you get within the community (i.e., church, support groups, etc.).
> What type of programs (support services) have you been made aware of in your community? Have you accessed these services/programs? If no, can you share why not?

> What type of support services would you say you need to maintain your caregiver capabilities?

Research Question 4

The theme, "**Caring Amid a Pandemic**," represented the data surrounding COVID-19 and the social interactions categories. This theme and the following categories answered the research question: (RQ4) *What has been the impact of the COVID-19 pandemic on African American male caregivers' lives?* The background and context domain includes the caregiver and care recipient factors, sociodemographic factors, a COVID-19 factor, specific to the country's emerging pandemic state (and globally), by the researcher. Other domains of the conceptual model, such as the stressor and mediator domains, were disclosed in the responses of the caregivers, as queried by the following guiding question:

> Tell me how being a caregiver during COVID-19 has (a) affected you personally (i.e., socially, physically, emotionally, or financially, and (b) affected your ability to provide the same level of care to your loved one*?*

Research Question 5

The theme, **"Effects of the Caregivers' Journey,"** was developed from three categories: "*Stressors: Positive/Negative Effects*," "*Physical/Emotional Adverse Health Outcomes*," and "*Benefits/Gains: Positive Health Outcomes*." This theme and the following categories answered the research question: *(RQ5) What are significant stressors described by African American male caregivers before, during, or after the* *pandemic?* The semi-structured interview questions that correspond to answering this research questions were:

> What types of benefits do you receive from being a caregiver?
>
> Please share any difficulties you may have experienced since you began caring for your family member.
>
> Please describe what makes you feel stressed in your caregiver role. Excess burden?
>
> What is it like for you to care for someone with a chronic illness or disability on a day-to-day basis?

Guided by the SSCM, specific factors that encompass this area of inquiry are the stressors and the outcomes domains. As has been mentioned, other domains of the model are identifiable based on the participants' responses.

Summary

Data surrounding the experiences of caregiving of 13 African American male caregivers were presented in this chapter. All 13 of the men provided care to a family member or multiple family members diagnosed with chronic, complex medical conditions. Many of the caregivers had complex medical needs of their own. These men offered insight into caregiving's multifaceted nature by providing their distinct experiences as African American male caregivers. Data for this study was collected through telephone and videoconferencing using Zoom technology. The semi-structured interview guide was developed by the researcher, as well as the demographic questionnaire.

Analysis of the transcripts revealed four major themes: (a) “My time to Take the Reins,” (b) “It’s a Male Thang,” (c) “Caring Amid a Pandemic,” and (d) “Effects of the Caregivers’ Journey.” Chapter V expounds on the study’s findings. A detailed discussion of the limitations, implications, and conclusions for this research study is presented next.

CHAPTER V

DISCUSSION

The purposes of this qualitative descriptive research study were to describe the experiences of African American male caregivers who are (or were) the primary family caregiver to a dependent, chronically ill family member and to explore how caregiving affected their health-related quality of life using the Revised Sociocultural Stress and Coping Model (SSCM) to guide the study. A second aim was to understand the psychological, physiological, psychosocial, and financial outcomes of African American male caregivers' health and well-being related to their caregiving experience during the COVID-19 pandemic. This chapter provides an interpretation and discussion of the findings and implications for practice, education, research, and policy. Finally, the limitations and recommendations for future research and conclusions of the study are provided.

Discussion of Study Findings

In order to gain a better understanding of the experiences of the thirteen African American male caregivers in the current study, this study sought to answer five questions. These questions were designed using the Revised SSCM. This conceptual framework stipulates that caregiving is a process comprised of background and contextual variables, stressors, mediators, and outcomes. Answering the research questions, the researcher linked the study aims to the domains of the conceptual framework and themes to the research questions. Specifically, for study aim one, the framework domains background/ contextual factors, stressor, and mediators were linked to two themes: My Time to Take the Reins and It’s a Male Thang. These components were linked to three research questions: RQ1) How do African American male caregivers describe their decision to become caregivers? RQ2) How do African American male caregivers perceive their caregiver role? And RQ3) What coping strategies and support systems do African American male caregivers use? To answer Research Questions 4 and 5, the researcher linked the study's second aim to the framework's background/contextual, stressors, and health outcomes domains. Relating these components to the themes: Caring Amid a Pandemic and Effects of the Caregivers' Journey, proved successful in answering the research questions in the current study. The following sections detail these connections with previous and present study findings.

My Time to Take the Reins

In the first theme, participants discussed their reasons for taking on the caregiving role. The current study’s findings showed that taking on the caregiver role was not an unexpected decision for all study participants except one. The chronic, deteriorating health of parents or spouses occurred over time before dependency on others was necessary. Although the men had time to prepare for their role assumption, none of them seemed prepared mentally and/or physically for the challenges of caregiver duties and responsibilities.

As Robinson et al. (2014) found, when it came to duties and responsibilities, male caregivers tended to struggle with the feminine nature of tasks, such as cooking, cleaning, and personal care tasks such as bathing or changing an adult brief. However, in line with previous studies (Lopez-Anuarbe & Kohli, 2019; AARP/NAC, 2020), the current findings challenge the traditional assumption that men are not very much involved in household work or personal care. In the present study, many male caregivers described discomfort with this personal care provision aspect, but they completed the tasks. Only two of the caregivers responded that they would not engage in personal care for their mother but managed other roles. Prior research would propose that many of the study's participants displayed a gendered approach to caregiving, which is seen with hegemonic masculinity or stoicism type behaviors (N. Greenwood & Smith, 2015; Milligan & Morbey, 2016; Spendelow et al., 2017). Spendelow et al. (2017) further postulated that this form of masculinity commences when males are placed in roles, such as caregiving, where nontraditional masculine norms require incorporation. In Mott et al.'s (2019) study, participants were described as being reluctant to ask for or accept help in the effort of maintaining perceived control of caregiving, similar to findings in the current study. Researchers have linked the constraint of holding traditional masculine values of caregiving (i.e., underutilization of formal or informal support systems) to Hanlon's conservative masculinities (Lopez-Anuarbe & Kohli, 2019). Contrary to what has been described as stoicism, several of this study's participants expressed the need for men to counter the old-fashioned ideas of masculinity associated with caregiving and offered, "it's okay to show emotion and let loose without judgment." And "Men should move beyond holding their feeling." These caregivers provided the narratives in the context of describing adversities and challenges. Several of this study's caregivers voiced their views of the caregiving tasks, namely as “woman’s work,” similar to previous caregiving findings (Black et al., 2018; Robinson et al., 2014). Another important finding in this study pertained to the “caregiver title” or “label” as perceived by the study participants. Given the current caregiving crisis, male caregiving is expected to increase (Mott et al., 2019; Sharma et al., 2016; Swartz & Collins, 2019). While over half (60%) of the men were acceptable to the title, the rest of the study participants gave an averseness to the term’s use. For those caregivers who did not ascribe to or identify with the title, they offered societal perspectives of the term’s use: “a means to categorize,” “a bucket to put things in,” “commercialized,” and “a professional term.” In previous research, the caregiver label for some male caregivers, as identified in the current study, was seen as a stoic approach to caregiving, leading to their resistance to identify as carers (Fee et al., 2020; Milligan & Morbey, 2016). This researcher found this resistance similar to the current study’s findings, supporting these authors’ conclusions. Black et al.’s (2018) study asserted African American men tended to see themselves in their primary roles of ‘husbands’ or ‘sons.’ Moreover, the label of “caregiver” made the act of “caregiving” seem obligatory. This finding was substantiated in the current study, as study participants voiced these same descriptions. In Brooks’s (2020) caregiving publication, director Rita Choula provided remarks regarding society’s perception of males as not family caregivers. Moreover, Choula reported that society perceived a male caregiver as “a brother that slides in and pays the bills and slides back out” (“Perception vs. Reality,” para. 1). Brooks (2020) further detailed that African American men were described as “uncomfortable” being caregivers because of a perception that Black men do not serve as caregivers, and people see them as “unusual” as caregivers. Several current study participants described their views on the stigma and societal perspectives regarding them as caregivers and men. The researcher considered their ideas a casual dismissal of intense emotional statements, which seemed to represent deep-seated pain, anger, and frustration.

One respondent related the act of caregiving to the topic of compensated or paid caregivers. According to the AARP/NAC (2020) report, about 53 million Americans provide care without pay to an aging loved one. Based on their findings, family caregivers were more eligible to get paid if caring for a U.S. military veteran. In the U.S., including the District of Columbia, consumer-directed personal care assistance programs are available through multiple types of Medicaid programs (American Council on Aging, 2021). None of the caregivers in this study stated he received caregiver compensation.

According to previous research (Dilworth-Anderson et al., 2007), church members’ supportive activities have been reported as prayer, help during the time of illness, advice, food or gifts, financial assistance, minister, spiritual leader visitation, respite care, and transportation assistance. Since most of the study participants specified a religious affiliation, the researcher anticipated that the church would serve as a social support place, and their faith would be viewed as a coping strategy. The findings showed that only a few caregivers reported church support, as demonstrated by prayer, financial support, occasional visitation (before the pandemic), food, and advice. This finding seemed contrary to prior research results, which indicated how African American churches had been a primary source of support for caregivers (Epps, Rose, et al., 2019; Jacobs, 2021; Samson et al., 2016). According to Jacobs (2021), African American families and communities will look out for one another and their comparatively greater commitment to religious traditions and values. This researcher suggests that the pandemic's unprecedented impact may significantly affect church members' type and support levels. However, minimal mention of congregational support was provided, despite the COVID-19 pandemic. It is important to note that these caregivers' spiritual/religious affiliations may have supported their ability to perform their day-to-day caregiving duties. As aforementioned, many of the caregivers described "honor" through their diverse roles and duties, which was seen as a source of "reciprocity" to give back. Thereby, their sense of "gratification" seemed to sustain them through their caregiving journeys. Furthermore, this fulfillment of their caring roles, supported by their spiritual beliefs, possibly contributed to their physical and emotional endurance, granting them the strength to fulfill their caregiving obligations. For the caregivers who did not see the church as a significant source of support, as corroborated in prior studies (Dilworth-Anderson et al., 2007; Samson et al., 2016), this lack of support may leave the impression that churches might not continuously optimize the role they could play in supporting caregivers of their older congregants. In the current study, three caregivers had active leadership roles in the church; however, they described minimal support in their narratives.

It's a Male Thang

The results of the study indicated that most of the men verbalized effective coping styles. According to the AARP/NAC (2020), African Americans may cope with caregiving better because their culture enabled them to feel more positively about caregiving. This stemmed from the deep sense of commitment and spirituality based on their culture (Liu et al., 2020; Weinland, 2009). In the current study, several men discussed their ability to reach out to family and friends and have a supportive network (i.e., co-workers, church members). The findings also indicated that several men accepted their responsibilities as caregivers, especially those without siblings or family support, and adapted to the role. The findings reflected the cultural aspects of keeping the care recipient within the home (i.e., free of nursing home placement). This was reflected in the number of men who cohabitated or adapted their lives to manage the loved one’s care. Overall, managing stress was not a problematic finding in the study, based on the caregivers’ narrative responses or self-reported health outcomes. However, the researcher’s awareness of voice changes (increased pitch, muttered speech, stuttering), positional changes (shifting in the chair), or shifting of eyes were observed and recapped in the field notes when the topic of positive and negative stressors was discussed.

Prior studies (Evans et al., 2017; Jacobs, 2021; B. G. Knight & Sayegh, 2010; Pharr et al., 2014) described the significance of culture related to caregiver burden and the personal determination for their endurance of the caregiver role. In the current study, cultural aspects of caring were similar to what has been described in landmark and recent caregiving studies (Dilworth-Anderson et al., 2007; Dilworth-Anderson et al., 2004; Pharr et al., 2014). Interestingly, in the current study, the caregivers also expressed a strong sense of “protection.” This guarded effect seemed to exist beyond the familial sense of duty or obligation.

Many of the study participants had limited knowledge of the various supportive resources available to them, such as national organizations and societies of specific diseases that offer multiple programs to ease the emotional burden. One specific researcher inquiry was the awareness of respite care services. Caregiver respite can be one means for family caregivers to take time for themselves and possibly avoid the need to relinquish their caregiving role (Lopez-Anuarbe & Kohli, 2019; Roberts & Struckmeyer, 2018). With a lack of research on African American male caregivers and their limited awareness or use of support networks, many participants in the current study lacked supportive resources, which possibly exacerbated their social isolation and susceptibility to caregiving's adverse impacts. Participants engaged in numerous caregiving tasks, often for many years. Many of these men were single carers due to the lack of siblings, family (or kin), or significant others. Plans for unpredictable emergencies or caregiver relief are needed to support these caregivers' physical and emotional strains.

Other findings regarding support systems revealed study participants lacked significant relationships with other men. In the current study, only two of the caregivers described a direct male relationship. In contrast, unspecified gender-related "friends" (e.g., therapist, counselor, lawyer) were referenced as confidantes by a couple of other study participants. A meaningful way for men to handle adversity in caregiving is reported through friendship with other men (Black et al., 2018); moreover, these same authors discussed this friendship as functional and significant value and resourcefulness to African American men as caregivers.

Caring Amid a Pandemic

For most men in this study, their roles as caregivers were established for a substantial amount of time before the COVID-19 pandemic. Only one of the caregivers was not involved as a caregiver during the pandemic. According to recent research (Holt-Lunstad, 2020; Sheth et al., 2021), the pandemic's impact on people's social interactions (social life or social isolation) was regarded as a significant stressor that led to mental health concerns or problematic health behaviors. In contrast, in the current study, the participants conveyed minimal disruption to their lifestyles, citing decreased or absent social activities before the pandemic.

A concerning finding related to the COVID-19 pandemic was seen as the hesitancy to accept the FDA-approved vaccine for a few caregivers. This is especially alarming given the increasing death toll in communities of color due to complications of the virus (Coustasse et al., 2020; S. E. Moore, Jones-Eversley, et al., 2020; Peek et al., 2021). While most caregivers were inclined to receive the vaccine immediately or later ("waiting to see how others faired"), nearly 40% opposed accepting the immunization. Based on the most current statistics, only 5.4% of African Americans have received the vaccine at the time of this writing, compared to 60% of non-Hispanic White Americans (Simkins, 2021). Results from a national survey conducted by the Kaiser Family Foundation (2020) reported 50% of African Americans would not take the vaccine, albeit safety risks and costs were not reasons for the refusal (Simkins, 2021). Given the findings of the current research, this study's results were consistent with the poll.

Effects of the Caregiver’s Journey

In this male caregiver study, participants described physiological and psychological adverse effects, similar to the health outcomes in the 2004 study conducted by Dilworth-Anderson et al. The researcher concluded the findings as inconclusive to the outcomes variables—depression and positive/gains in health outcomes. The participants refrained from using “depression” or its derivatives, and only a few described improvements in their general health since beginning the caregiver role. However, many of the caregivers reported symptoms of depression (i.e., inability to sleep, exhaustion, tiredness, tension). These findings were similar to prior studies (Cothran et al., 2015; Joling et al., 2015; Smith et al., 2014; L. A. Williams et al., 2017) that described caregiver symptoms as outcomes of depression and anxiety. Sheth et al.’s (2021) study showed that COVID-19 did not appear to have affected caregivers in terms of depression and self-efficacy, nor did it affect participants’ perception of their general overall health. More, the lack of adverse consequences due to the COVID-19 pandemic on caregiver health outcomes could be because the disease or threat of disease does not appear to affect these parameters or that they were quite high, to begin with, and possibly had reached a near-ceiling effect (Sheth et al., 2021). This researcher supports this supposition as this rationale can be applied to the findings in the current study. Healthcare concerns exist regarding the possible deficiency of medical interventions based on caregivers’ lack of awareness of symptoms of depression. Also, deficits in treatment may present due to the caregiver’s beliefs on the personal or perceived stigma associated with this diagnosis. Lastly, some male caregivers see depression as a sign of personal weakness rather than an actual illness that needs professional mental help (Chai et al., 2018).

Prior studies have described self-care deficits in caregivers' physical and mental health (Ejem et al., 2018; L. A. Williams et al., 2017). A concerning finding in this study was the lack of health care providers' awareness of the caregiver's physical and/or emotional health status. Many of the present study caregivers reported physical and mental health deficits, such as sleep apnea, sarcoidosis, bipolar, or cardiovascular complications. Characteristically in the caregiver literature, as caregiving demands increase, caregivers' own needs are often sacrificed (Roberts & Struckmeyer, 2018; Sullivan & Miller, 2015). In the current study, the researcher specifically asked caregivers if they were asked "*How are you?*" by their healthcare provider or the care recipient's provider. Most of the participants stated they did not receive this line of inquiry about their health.

An additional finding in the current study was the lack of disclosure on sexuality and intimacy as a secondary (adverse) consequence of being a male caregiver. Only one participant alluded to sexuality content during the interviews with the 13 participants. Research in this area of study was found sparse to non-existent in empirical studies for female and male caregivers, focusing on spousal marital relationships. Prior studies have explored the impact of sexual identity, sexual satisfaction, and intimacy for caregivers (Brotman et al., 2016; Davies et al., 2012; Hayes et al., 2009; Solli et al., 2018). Findings suggested that specific illnesses (i.e., Alzheimer's disease) can have a negative impact on intimacy in the spousal caregiver relationship based on lack of recognition or confusion on the part of the ill spouse (Brotman et al., 2016). Male spousal caregivers were more interested in sexual intimacy than caregiving wives (Davies et al., 2012; Hayes et al., 2009). Davies et al.'s (2012) study on gender, sexual behaviors, and spousal caregiver well-being affirmed male caregivers' alignment with dominant masculinity ideals that value sexual intimacy and, therefore, grieve its loss. It is noteworthy to mention that in the Brotman et al. (2016) study, all participants reported that one of the reasons caregivers do not discuss issues with providers was that "no one asks." In Solli et al.'s (2018) study of women with cervical cancer, the men described sex as an intimate and private matter and difficult to discuss. Sexual intimacy can suffer in many caregiving situations. For adult son caregivers, it is possible that fatigue, among other stressors, can affect the relationship between spouses or significant others. Literature exists around intimacy in spousal caregivers; however, to this researcher's knowledge, research on this topic for caregiving sons is limited or unpublished in peer-reviewed journals.

There is a need to explore further how African American male caregivers address the financial burden associated with caregiving. The sample represented demographic findings similar to other studies regarding education, health status, and employment. However, financial challenges existed due to annual income and caregiver demands. Over 38% of participants reported an annual household income of less than $50,000, and 15% reported $25,000 or less. The researcher thereby concluded financial strain to be a significant stressor for these caregivers. Notably, none of the participants verbalized a change in employment status due to the pandemic. It is extensively documented that lower-income and financial strain is linked to adverse health outcomes (Lopez-Anuarbe

& Kohli, 2019; Schulz & Eden, 2016). Thus, adverse health outcomes may be particularly problematic for African American male caregivers, who tend to have lower income levels.

Revised Sociocultural Stress and Coping Model (SSCM) Applied to Male Caregiving

The conceptual framework established the context for the study's relevant knowledge base laid the underpinning for the study's significance, the identification of the gap, and the research questions. The conceptual framework that guided the current study was the SSCM. A review of the concepts that encompass the domains of the model and its application to male caregiving would reveal that the model worked well in exploring the experiences and health outcomes for the participants in this study. The revised model permitted the researcher to incorporate theoretical concepts into caregiving research. These concepts included background and contextual factors, primary and secondary stressors, coping styles, social support, and spirituality/religiosity. A key component of the model is the inclusion of a cultural perspective that focused on the caregivers' individual and societal norms, beliefs, and attitudes in their caregiving roles. Another novel inclusion was the direct and indirect impact of the COVID-19 pandemic in the stress process. Although spirituality and religiosity are generally seen as components of "cultural values" within the model, the researcher elected to examine these related concepts separately in the adapted model. In addition to the framework's general health outcomes, the researcher explored the benefits (gains) of the caregivers' self-reported health attributed to their caregiver role.

Background/Contextual Variables

In alignment with the conceptual model that guided the current study, the background/contextual variables were generally described as gender, age, care recipient, caregiver’s health conditions and status, and relationship to the patient, among others. The background variable “COVID-19” was included based on the pandemic’s significant impact on families during this study’s data collection timeframe.

Stressors

The classification of the framework’s stressors as primary or secondary was a way to focus on the multiple stressors to which caregivers are exposed. The stress process model asserts that caregiving’s physical difficulties and the caregiver’s perceptions and resources work collectively to influence outcomes (Grace et al., 2016). In the current study, the type and quantity of caregiver stressors were multifaceted, which led to a cascade of mediating factors. Primary stressors were described in many ways, such as the care recipients’ problematic behavior, the ADL/IADL dependencies, or caregiver descriptions of role overload.

Secondary stressors were abundant in the current study. For example, over half the men described symptoms of financial strain or burden as caregivers. Also, a decreased or absent social life was characterized by most caregivers. The researcher assessed that this absence or decreased socialization carried over to the pandemic’s impact as an added contributor.

Mediators

Mediators (or moderators), often used interchangeably in the literature, are strategies or resources that are used to “confront stress-provoking conditions with behaviors, perception, and cognitions that are often capable of altering the difficult conditions or of mediating their impact” (Pearlin et al., 1981, p. 340.) They are generally seen as coping and social supports (Geiger et al., 2015). Coping and social support mediators can potentially intervene at multiple points along the stress process.

Coping Styles

Prior research (B. G. Knight et al., 2000) suggested that African American ethnicity is mediated through appraisal of stress and coping styles, which are seen as culturally transferred values and behaviors. In this same study, the study participants’ ethnicity was positively related to emotion-focused coping and increased emotional distress (i.e., anxiety, depression). Relating to the framework’s description of coping styles, the results of this study confirmed that the study participants used emotion-focused and problem-focused coping skills in dealing with their stressful situation as caregivers.

Support Systems

The use of support systems is a vital part of caregiving. The support of family, friends, or communities can help the caregiver cope with their caregiving demands. Guided by the study’s framework, the researcher described the supportive networks used by the respondents. As identified in the current study, the underutilization of community support services corroborated the findings of researchers Lopez-Anuarbe and Kohli

(2019). The researcher identified opportunities where supportive networks could provide more support to the caregivers and the care recipient (i.e., respite care, support groups).

Spirituality/Religiosity

These paired constructs conceptually overlap and are often used interchangeably in context and provide a sense of guidance, security, and meaning (Epps, Brewster, et al., 2019). The mediating effect of spirituality and/or religion on caregiving burden is proposed to influence caregiving's positive perception (Fauziana et al., 2018; Fields et al., 2019). In the current study, most of the caregivers were associated with a religious affiliation, which led to the researcher's perception that spirituality/religiosity was a significant construct in the study's framework.

Cultural Aspects

The impact of culture on caregiver attitudes and behaviors has been introduced in prior caregiver studies on race, ethnicity, and caregiving (Dilworth-Anderson et al., 2005; B. G. Knight & Sayegh, 2010; Pharr et al., 2014). A key component of the Revised SSCM was to examine a population's cultural effect in the caregiving role and duties. Guided by the study's framework, the researcher linked the participants' narrative responses to the model's cultural aspects. Many of the respondents spoke markedly on the influence of cultural values and beliefs, whereas other responses were indicative of African American colloquialisms and norms. The revised model examined the male caregivers in the present study by appraising cultural values and providing a framework to interpret traditional stress process variables through a cultural lens.

Health Outcomes

The variables that are generally described as health outcomes with the SSCM are depression, anxiety, physiological health, and cognitive or psychological health effect outcomes. In this study, the researcher was interested in the caregiver health outcomes surrounding anxiety, depression, and positive health outcomes. Prior studies have shown that caring for a frail older family member with chronic health problems and functional limitations is associated with adverse mental and physical health outcomes (B. G. Knight & Sayegh, 2010). These outcomes were substantiated in the current study; however, the effects were also present in younger care recipients and family carers, as found with several of this study's participants. As the caregivers shared their caregiving experiences, it was perceptible that their emotional and physical health were affected by their distinct caregiving journey. However, for a few of the caregivers, positive gains in their health outcomes were described. The self-reported stressors identified by the study participants throughout their caregiving timeframes resulted in an extensive description of codes and phrases placed in the researcher-developed codebook.

Implications for Practice

With an aging society, there is a trend for families to be smaller, more males to become the primary family caregiver, adult children to be more geographically mobile, and more individuals to live with numerous, chronic, and/or debilitating health conditions. These combined factors, amongst others, have the propensity to make caregivers and health care support networks more limited to the current and future aging population or disabled and dependent population. It is incumbent upon clinicians (i.e., nurses, physicians, social workers, and community health care providers at large to suggest strategies for male caregivers to participate in the continuing care and improved quality of life outcomes for their dependent family members. Moreover, healthcare providers must plan for culturally congruent care that acknowledges the caregivers' healthcare needs in their caregiving roles. Specifically, for the men in this study, recognizing the caregivers' self-care needs and ensuring resource information availability (i.e., respite care). Moreover, clinicians must observe for symptoms of depression in caregiving men and encourage self-efficacy practices and wellness visits with their medical providers. Finding creative programs that target male caregivers to meet these caregivers' needs is crucial; however, strategies are needed to encourage men to ask for help.

This study's findings may be used to bring awareness to other male caregivers across different racial/ethnic groups to inform the development of services and programs to assist underserved or marginalized family caregivers. Caregiver education should include resource information on (e.g., The Alzheimer's Association, National Family Caregiver Support Program (NFCSP), National Family Caregivers Association), such as support groups, psychoeducational programming, or referrals to mental health providers. The opportunity to use community family caregivers in the research process, through organized training, can significantly influence health behavior modification (McDonnell et al., 2019; Pierval et al., 2019); and thereby inform future research in the development of culturally tailored health promotion programs. Strategies to promote caregivers' engagement in activities that provide respite or distraction for caregiving activities can lessen the exposure of stress, burden, or burnout (Easom et al., 2018; Kally et al., 2014; Mollica et al., 2019; Schulz et al., 2017). Educators must be conscious of how respite care is introduced to caregivers. Respite care presented as a “break” from caregiving experiences, instead of a way to recharge, could be negatively perceived by some caregivers (Pharr et al., 2014). Prior research has shown that African American caregivers have been less likely to use respite service utilization (Parker & Fabius, 2020). This lack of service use especially concerns male caregivers who believe that external respite interventions at home are not suitable for men (Leocadie et al., 2018). Researchers and clinicians should collaborate to incorporate culturally-sensitive community programs, assess and tailor training and endorse supportive interventions to provide the necessary support for caregivers (Easom et al., 2018; Mollica et al., 2019). For African-American caregivers, tailored interventions must consider the quality of life, emotional effects (i.e., depression), and role demands, rather than the presumed usefulness of services and caregiver accessibility to these services (Desin et al., 2016).

Finally, the findings of the current study, and the few available studies, suggest that African American male caregivers have not participated significantly in social support groups. One recommendation to heighten the awareness of male caregivers and support groups through the improvement of social media advertisements. One study participant suggested that advertisement companies and marketing professionals who represent caregiver support groups should produce racial/ethnic and cultural-appropriate handouts, pamphlets, and brochures that depict all caregivers’ faces—including African American men.

Implications for Education

The results of this study have implications for nurse educators. Due to the various levels and types of care recipient health conditions, caregivers are tasked with complex medical/nursing tasks in the home. Therefore, nurses must offer family caregivers training, demonstrate these skills, and request “teach-back” to verify their knowledge of the information. This approach will allow the caregivers to feel more confident in performing the task. The education of current and future nurses about how to identify and support family caregivers is essential. Nursing curricula should address both emotional and practical skills to help nurses better support family caregivers (Reinhard & Brassard, 2020). Healthcare professionals should be more aware of the complexity of intimacy and sexuality regarding caregivers and care recipients. Understanding sexual health and relationship issues and the need to have these discussions in clinical practice is essential. Nursing programs and health care organizations can support clinicians through specialized training that addresses sexuality and intimacy that may be difficult for both the caregiver and providers. Minimizing the discomfort associated with this emotive topic requires healthcare professionals to identify and address their personal and social values that inhibit open discussion with caregivers. Caregiver support programs and counseling are other services that organizations can build to ensure that there is an opportunity to address sexuality and intimacy.

Implications for Research

Due to the lack of empirical research studies that include male caregivers, specifically, African American male caregivers, future research implications exist

(Thorpe & Whitfield, 2018). One consideration is to promote more qualitative studies on this research topic and disseminate the findings within peer-reviewed publications. Given the historical mistreatment of African Americans in research, researchers and nurse scientists must ensure engagement with and give back to the community as they conduct and disseminate their research (Fryer et al., 2016). Furthermore, implications for future research on male carers' experiences should consider the over-representation of female research participants may have led to a bias in selecting interventions and outcomes in caregivers' support (N. Greenwood & Smith, 2015).

The author proposes that the study's findings could be strengthened via a collection of data from a larger sample of African American male caregivers from a broader geographic scope that would include regions across the U.S. This would allow for collaborations amongst qualitative researchers from across the country to contribute their expertise in collecting data and interpreting research findings from a broader range of African American male caregiver participants. Broadening this research area's scope would provide qualitative researchers with an opportunity to work collaboratively from different regions of the country to increase academic studies. Future researchers should also consider longitudinal studies that examine the long-term effects of caregiving on male caregivers to enhance the science surrounding caregiver research, in addition to community-based studies that can provide information on unique cultural groups in given communities (Liu et al., 2020). Future research should explore the intimacy effects on caregiving couples, partners, significant others for African American males. Whereas caregivers in this study alluded to the intimacy topic, none described detailed concerns on the subject. Regarding concerns for undiagnosed and possibly untreated depression, future researchers must ask African American male caregivers directly if they feel depressed; for example, adding a statement to the semi-structured interview guide, such as “we will be asking you about your thoughts and/or experiences of depression.” A goal for future researchers is to clarify how healthcare professionals and caregiving individuals understand depression concerning its management and the impact on their physical and emotional health.

Concerning caregiver research surrounding the COVID-19 pandemic, local, national, and international groups’ collaborative efforts to develop action plans to protect from future pandemics must occur. Suggestions for study should explore the continuing research surrounding vaccination targets (i.e., herd immunity) and focusing on underserved and marginalized communities to ensure equity in administering the vaccines. These are essential steps for nursing and medical researchers and governmental decision-makers. Additionally, ensuring the inclusion of education and skill training to family caregivers on appropriate precautions and outpatient medical interventions (i.e., anti-SARS-CoV-2 monoclonal antibodies) in the early onset of infection (CDC, 2020a) is critical.

Implications for Policy

Professional nurses have a distinct role and responsibility in shaping policy and future healthcare delivery systems. This influence expands across all care environments—including clinical settings such as comprise acute care, in addition to the community or residential care, which contain home health care, long-term and residential-based settings. Nurses can influence policy development and shape practice standards and processes. This ability to impact policy is based on the ability to influence decisions related to health through political knowledge, effective communication, and collaboration with other members of the health team, which results in the improvement of nurses’ job environment and increases patient outcomes (Arabi et al., 2014). As nurses comprehend the importance of policymaking in the healthcare sector and their influence through competency, power, and advocacy, patient and family-focused needs and outcomes will become more transparent, demonstrating significance to legislators. These efforts gain momentum when nurses educate patients and families in the public domain about the necessity for policy changes and their influence to advocate for themselves with their legislators. As family advocates, legislators, and policymakers should demonstrate their commitment to care recipients and caregivers by alleviating or minimizing financial hardships and ensuring that support services are available.

There have been significant actions in policy around the issue of caregiving in recent years. Influencing the decision-making of local, state, and national legislative authorities who have the power and influence to provide the resources to support caregivers and vulnerable care recipients has been instrumental in the policy gains made for caregivers. For example, the Credit for Caring Act of 2019 was enacted to provide working family caregivers with a non-refundable tax credit of up to $3,000 to assist with out-of-pocket expenses related to caregiving. Caregivers can use this tax credit toward costs such as transportation, home modifications to accommodate a family member, medication management services, and training or education ("Caring Act," 2021).

Introduction of the Caregiver Advise, Record, Enable (CARE) Act of 2014 added another level of support to caregivers. The Act is a ‘state-by-state approach for health policy to improve support for family caregivers. The policy requires hospitals to record the caregiver’s name and contact information and actively engaged the caregiver in the appropriate training on the medical and nursing tasks included in the discharge plan (Anthony, 2018; Reinhard & Ryan, 2017). The Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act supported the adoption of person-and-family-centered care, assessment and service planning, education and training supports, respite options, and an emphasis on financial security and workplace issues. Lastly, the Patient Protection and Affordable Care Act (ACA) provided health insurance coverage that was more accessible and affordable for informal caregivers (Carbonaro & Lamont, 2015). The Act assured caregivers that their health coverage equipped them with the necessary tools to manage their health and/or any adverse health effects. A final consideration to lessen caregiver financial strain is for policymakers to enact or enhance existing caregiver legislation and then authorize local agencies to manage caregiver programs effectively. Given the diversity of factors associated with caregiver strains, innovative approaches to mitigate these strains, such as promoting caregivers’ ability to be paid, will lessen some of the burden imposed on caregivers.

Limitations

There are several limitations to this study. First, the sample was limited to men who met the study criteria geographically, located along the eastern region of the U.S. It is possible that expanding this study to other areas of the country would yield different results. A final limitation of this study is the effects of the COVID-19 pandemic on caregivers. The pandemic continued to evolve during the interviews and is incessant at the time of this writing. Therefore, given the pandemic’s evolving nature, this study’s findings may not be generalized to future studies that occur during a different time or in a non-pandemic public crisis.

Conclusions

The purpose of this study was to describe the experiences of these caregivers who are (or were) the primary family caregiver to a dependent, chronically ill family member and explore how caregiving affected their health-related quality of life using the revised SSCM to guide the study. An additional purpose was to understand the psychological, physiological, psychosocial, and financial outcomes of African American male caregivers’ health and well-being related to their caregiving experience before, during, or after a COVID-19 pandemic. These male caregivers’ individual and collective stories can enrich other caregivers’ lives, male research studies, and nursing and interprofessional caregiver research.

Guided by the SSCM, this study’s overall finding indicated that the participants saw the caregiver role as positive, highlighting attributes such as honor, commitment, reciprocity, sacrifice (care recipient), and duty. Despite these positive responses, there were adverse effects, such as decreased social interactions, sacrifice (caregiver), financial burden, and physical or emotional impact. This research also identified mediators (coping styles, support groups, spirituality, and religious beliefs) used by the caregivers to endure the role’s demands.

As the country’s aging population continues to reach significant growth projections and the chronic health issues of the U.S. society increase, so does the need for informal caregivers. One way to support what has been called “invisible or hidden caregivers” is through the enactment or amendment of health policies and laws that provide clear objectives that enhance the caregiver’s ability to continue in the role. Given the ongoing perceptions of stigma and medical mistreatment, as described by African Americans and respondents in the current study, the ongoing research in academic and medical societies in reaching those at the highest risk and most vulnerable is essential.

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APPENDIX A.

RECRUITMENT FLYER

INVITATION TO PARTICIPATE FLYER

INVITATION TO PARTICIPATE IN RESEARCH

YOU CAN BE IN A STUDY OF AFRICAN AMERICAN MALE CAREGIVERS

- If you are presently or was a previous caregiver
- You provide caregiving to a chronically ill, dependent family member for at least 6 months, or have done so in the past 2 years
- You are (were) the main support for your dependent loved one
- You are (have been) caring for your loved one at home

Then, you are the person I am seeking!

My name is Barbara Deskins, a doctoral candidate at The University of North Carolina at Greensboro. I am presently working toward the completion of my Ph.D. program in Nursing. I am seeking African American men who provide care for a dependent family member who would like to participate in a research study.

If you are interested in sharing your story as a male caregiver and contributing to a better understanding of your caregiving experience, I am requesting your participation in this research study. You can reach me using the following contact information: bacooper@uncg.edu or cell phone: (336) 254-1734.

If you have any questions regarding the study, you can contact Dr. Susan Letvak, Dissertation Committee Chairman, at (336) 256-1024.

Your consideration to participate is appreciated.

Barbara Deskins, RN, Ph.D. candidate

PI: [Deskins] IRB # [19-0590] Title: Recruitment flyer (posted) Version Date: [11-08-20]

APPENDIX B.

RECRUITMENT LETTER

RECRUITMENT LETTER

UNC GREENSBORO

Dear Caregiver:

My name is Barbara Deskins, a nurse and doctoral candidate in the Ph.D. program at University of North Carolina at Greensboro, School of Nursing. I am recruiting participants for my dissertation research with the purpose of understanding the experiences of African American male caregivers of family members who are chronically ill and dependent upon your care. Very little research has been reported about male caregiver experiences. The results from this study will increase the awareness of the education, support, and services needed to support your caregiving and your physical health.

You are being contacted because you responded to a recruitment flyer that you are a caregiver and is interested in participating in this research study on African American male caregivers. I would appreciate hearing about your caregiving experiences. The study is voluntary and confidential. Your name will not be used in the study. Your information will be associated with a pseudonym (fake) name on your transcript to prevent identifying you as a participant in this research study. Researchers are committed to protecting your personal data and handling it with respect and integrity.

To be eligible for this study you must be a current male caregiver or previous caregiver that provides care for a dependent, chronically ill family member; or have done so in the past 2 years. You must also be the primary support person for your dependent loved one.

As a participant, you can expect to be interviewed one time with digitally audio-recording of the interview. The anticipated time to complete the entire interview is estimated to take between 45 to 60 minutes. The risks to you are rare; however emotional distress can occur. You can take a break, stop the interview, and discuss the emotions with the researcher, then resume the interview. All interviews will be conducted over the telephone or through the use of Zoom technology due to COVID-19 precautions. A $25 gift card will be offered to each participant as a "thank-you" for your time upon completion of the interview. Telephone or Zoom participants will be mailed their gift card or can select an electronic gift card.

Feel free to share any questions or concerns regarding your participation with me or you can direct questions to Dr. Susan Letvak, Dissertation Chair, at (336) 256-1024. If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.

If you are interested in participating in this study or know other male caregivers who may be eligible to participate, please contact me by email or telephone: bacooper@uncg.edu or mobile: (336) 254-1734.

Barbara Deskins, MSN, RN, PhD Candidate
University of North Carolina at Greensboro School of Nursing

PI: [Deskins] IRB # [19-0590] Title: [Recruitment letter] Version date [11-08-20]

APPENDIX C.

IRB INFORMATION SHEET

IRB Information Sheet Template

Project Title: *African American Male Caregivers for Adult Care Recipients During the COVID-19 Pandemic*

Principal Investigator: Barbara Deskins, PhD candidate, RN

Faculty Advisor: Dr. Susan Letvak, PhD, RN, FAAN

What is this all about?
I am asking you to participate in this research study because you presently provide care for a chronically ill, dependent family member or significant other, or have done so in the past 2 years, you have previously been the main support for your dependent loved one, and you are English-speaking. This interview is expected to approximately 45 to 60 minutes and will involve you being interviewed by telephone or videoconference, such as Zoom. The interview will be audio recorded.

How will this negatively affect me?
Participation in this study or this interview do not pose any anticipated risks. Other than the time you spend in this research interview, there are no known or foreseeable risks involved with this study.

What do I get out of this research project?

There are no direct benefits to participants in this study.

Will I get paid for participating?

There are no costs to you for participating in the study. In appreciation for your time and contribution to the study, a $25 dollar gift card is offered to you.

What about my confidentiality?
We will do everything possible to make sure that your information is kept confidential. All information obtained in this study is strictly confidential unless disclosure is required by law. Once the audio recording is transcribed and the study is complete, the audio-recording will be deleted. Only the principal investigator (Barbara Deskins) and committee Chair (Dr. Letvak)) will have access to view the data transcribed. All data will be secured in a locked file, and electronic copies placed in a secure location using the UNCG Box data storage location. No names of the participants will be used in this study. All of our participants' de-identified data will be kept indefinitely and will be posted to an on-line repository so other scientists can analyze the data and check our results. Your data may be used for future studies in a de-identified form unless you state you only wish it to be used for this study.

For Internet Research, include this wording: Internet Research does not apply to this study.

Use of audio-recording: Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the researcher will try to limit access to the recording as described in this section.

What if I do not want to be in this research study?

You do not have to be part of this project. This project is voluntary and it is up to you to decide to participate in this research project. If you agree to participate at any time in this project you may stop participating without penalty.

What if I have questions?

You can ask Barbara Deskins, principal investigator at (336) 254-1734. You may also contact me by email at bacooper@uncg.edu. You may also contact the dissertation chair advisor; Dr. Susan Letvak at The UNCG School of Nursing. Her contact number is (336) 256-1024, or by at saletvak@uncg.edu for anything about the study. If you have concerns about how you have been treated in this study call the Office of Research Integrity Director at 1-855-251-2351.

PI: [Deskins] IRB # [19-0590] Title: [IRB Information Sheet Template] Version: [11-08-20]

APPENDIX D.

DEMOGRAPHIC QUESTIONNAIRE SURVEY

DEMOGRAPHIC QUESTIONNAIRE

ID # ________________________ Pseudonym: _____________

Thank you for taking the time to share your caregiving experience with me. These questions are needed to collect personal information about you and the person you are caring for. Your information is anonymous, and your privacy is important to me. Your feedback will help health care professionals improve our knowledge of family caregiving and the services and support that matter to you and your loved one.

Caregiver

Age: ____________________

Marital status: ____________________

Including you, how many people currently live in your household? _____________________

Does this include the care recipient? _____________

Number of people, under the age of 18, live in your household? ________________

How many people are you caregiving for? ____________

Relationship to care recipient: __________________________________

Educational level: ____

Personal Health: ____

Religious Affiliation: ____

Are you currently employed and receiving a wage or salary? ________ If yes, Employment status: Full-time ____ Part-time _____ Occupation: _____________________

Annual Income range: less than $25,000 year ☐ Less than $50,000 a year ☐

More than $50,000 a year ☐ Decline Response ☐

If unemployed: Temporarily unemployed (due to COVID) ____ Retired ____

Length of time in your caregiver role: ____________________

Approximately how many hours do you provide care to your loved one weekly? _________________

Do you have siblings or significant others to assist with care provision to care recipient?: ___________________

Care Recipient

Age: _______________

Gender: _______________

Race: ________________

Chronic Illness/Disability: ____

PI: [Deskins] IRB # [19-0590] Title: Demographic Questionnaire Date: [11-08-20]

APPENDIX E.

SEMI-STRUCTURED INTERVIEW GUIDE

SEMI-STRUCTURED INTERVIEW GUIDE

As I have shared with you, I am conducting a research study on African American (AA) male caregivers during this COVID pandemic. Because limited information is available in the literature about the experiences of caregiving by AA men, this is an opportunity to share with the broader caregiving community, your experiences. In fact, many AA men caregivers have been referred to as "hidden caregivers." This research will allow you to share 'your' stories and experiences in the care you provide to your loved one.

Concept/Topic Area	Guiding Questions
Caregiving Experience	**1. What would you say it means to you, as a male caregiver (CG*) taking care of your (*insert CG title)?*** **2. What is it like for you to care for someone with a chronic illness or disability on a day-to-day basis?**
Caregiver Role	**Some people, even though they provide a lot care to another person, do not consider themselves as a "caregiver."** ● Why do you think that is? ● Do you think of yourself as a caregiver? ● Do others (i.e., family members/S. O.*) think of you as a caregiver? Please explain. ● Can you share something about how you came to take on the caregiver role for your loved one (*insert CR* title*)? ● When did you first start being the caregiver for your (*insert CR title*)? ● What sort of care do you help with?
Positive Affects	**What types of benefits do you receive from being a caregiver?**
Adverse (Negative) Affects	**Please share any difficulties you may have experienced since you began caring for your family member.** **Please describe what makes you feel stressed in your caregiver role.** **Will you describe your experience of excess burden since you began caring for your family member?**
Coping	**How do you cope with the stress or burden of caregiving or being a caregiver?**
COVID-19	**Tell me how being a CG during COVID-19 has:** a) affected you personally (i.e., socially, physically, emotionally, or financially). b) affected your ability to provide the same level of care to your loved one?
Support Systems	**Tell me about how caring for your (CR title) has changed your relationship with family or S.O.** **Tell me about the kind of support you get from your family or S.O.** **Tell me about any support you get within the community (i.e., church, support groups, etc.).** **There are many services available to support caregivers in the community.** ● What type of programs have you been made aware of? ● Have you accessed these services/programs? If no, can you share why not? **What type of support services would you say you need to maintain your caregiver capabilities?**
Summary	**Thank you for taking the time to tell me about your caregiving experiences. Is there anything else you think I should know?**

*Abbreviations: **CG** = caregiver; **CR**= care recipient; **S. O.** significant other

APPENDIX F.

CAREGIVER DESCRIPTIONS

Caregivers	Descriptions
Tony	Tony was a 62-year-old single male caregiver to an 89-year-old father with end-stage dementia, among other debilitating co-morbidities. The caregiver expressed a supportive sibling (sister), who, like him, resides in a different state from the care recipient. The primary caregiver, Tony, is a college graduate who is employed full-time, with an annual income of more than $50,000. Due to care demands, he temporarily relocated to co-reside with the parent for a little less than one year. The estimated amount of caregiving hours varied as the care recipient’s condition deteriorated and hospice intervention was needed. He reported his personal health as “good” and did not affiliate with a religious group.
Quinn	Quinn is a 38-year-old married male caregiver of a 70-year-old mother with Alzheimer’s disease. The son has been his mother’s healthcare proxy for over 7 years, with 4 years of co-residential dependency. The caregiver states that he has acquired an associate-level degree and is presently attending a local university to pursue a bachelor’s degree. He is employed part-time, and his household income is greater than $50,000 annually. He self-reports his physical health as “good” and acknowledges his religious affiliation as a Christian. His primary support source is his spouse, although he referenced “brothers” who appear to be of different parentage.
Wendell	Wendell is a 59-year-old male who recently lost his 80-year-old mother. He is married and has two adult daughters and two adult step-sons, all of whom are his significant support sources. The caregiver has attained some college-level education and reported his health as “fair.” He acknowledges a strong religious faith, “Baptist.” He is employed full-time and reported an annual household income greater than $50,000. Wendell was a caregiver to his mother for over 15 years. He intermittently shared the role with his sister; however, he was always the primary carer. The amount of time for care provision varied weekly. He also has a brother that did not actively participate in the care provision for the mother. The co-dependency required by the care recipient was due to a mid-life brain aneurysm with stroke, which led to enduring complications.
Keyon	Keyon is a 54-year-old male caregiver, presently the healthcare proxy to an older brother (age 58) and primary care oversight to an 87-year-old father. Until the past 2 years, he also was the caregiver to his mother. His

Caregivers	Descriptions
	caregiving experiences include the care provision of all three recipients. Keyon has a college degree, and he described his overall health as “good.” His religious preference was reported as Spiritual. He is self-employed with an annual salary of less than $50,000. The amount of time providing care has varied over the timeframe of 11 years, with the most time devoted to his mother’s care. No other siblings exist with the family unit. The father’s recent relocation allows for some family support for him.
John	John is a 61-year-old married caregiver with two adult sons. One son lives nearby of the parents; the other son lives with the parents in their home. The care recipient, age 59, underwent complications from a brain tumor over 24 years ago, leaving her in a dependent state of health since early in the marriage. The dependency requires ongoing daily care on a 24/7 basis. The caregiver reported his health as “good” and his religious affiliation as “Christian.” He has a BS-level degree and is officially retired; however, he has other forms of financial support to sustain the enduring costs to maintain his spouse within the home and as a form of coping. Their annual income is greater than $50,000. The couple has siblings and other distant kin who do not live in the immediate area.
Jamel	Jamel is a 50-year-old, single African American male who co-resides with both parents and a live-in sister, contributing to the caring role for their parents. Jamel is a full-time healthcare employee with a high school education. The annual income is less than $50,000, although details of other financial contributions were not detailed. While he has lived with the parents throughout his lifetime, it has been within the past 2-3 years that the caregiver and his siblings’ dependency has increased due to the progressive deterioration of their physical health. Both parents are in their upper 70s with multiple co-morbidities.
Jordan	Jordan is a 62-year-old married caregiver to a 100-year-old grandmother-in-law. He is currently unemployed and provided the bulk of the care provided to the care recipient before COVID-19. Presently, the wife can be of more assistance with some of the daily considerations as she works remotely from home due to the pandemic. The caregiver has a master’s-level degree and shared an annual family income of over $50,000. He is of religious faith and reported a strong network of informal supporters. He related his physical health to “good.” The care recipient has resided in the caregiver’s home for over 11 years. She has numerous age-related and disabling co-morbidities, leading to her dependent state of health.
Griffin	Griffin is a 67-year-old divorced caregiver for his 95-year-old mother. The caregiver co-resides with the care recipient and has been her primary source of support for over 12 years. The dependency needs age-related,

Caregivers	Descriptions
	in general, and requires minimal to moderate assistance daily. The caregiver has siblings and a supportive, informal network of kin. Griffin is a college graduate and is a retired manufacturer manager. He did not report his annual income; and reportedly has health as "fair to good." Regarding his religious affiliation, he stated that he is a "believer in God."
Greg	Greg is a 56-year-old divorced male caregiver, the primary caregiver for an 84-year-old mother, who has cognitive and physical co-morbidities. The caregiver has one sibling who is not active in the care provided to the mother; however, Greg has female family support (daughters and granddaughter), his primary sources of informal support. The caregiver is medically disabled and described his health as "fair." He has attained some college-level education and acknowledges a Christian religious affiliation. The annual income for the carer is less than $25,000. The duration of caregiving experiences has been 2 years.
Fred	Fred is a 66-year-old African American man who is married and has adult children. He was the previous primary caregiver to his mother (and father briefly), although he had a brother who participated in the care. Fred is a college graduate with extensive healthcare administrator experience. The caregiver's mother has been deceased for greater than 2 years (but less than three). He maintained his caregiver role for his mother for 5 years, diagnosed with several debilitating conditions, described as heart disease, stroke, and hypertension. However, within the interview, he reflects on his intermittent care responsibilities with his father, who was diagnosed with progressive dementia. Both parents were deceased at the time of the study. The length of time spent in the care of his father was not given.
Derrick	Derrick is a 77-year-old male who is the primary caregiver to his 77-year-old spouse diagnosed with progressive dementia. The couple has an adult daughter who lives nearby with dependent children. Derrick stated that he is in good physical health and acknowledges religious faith. His highest level of education was reported as "some college." He is a retired salesperson and has an annual income of less than $50,000. He shared that he is a part-time insurance agent. His caregiving journey began within the past year with an approximate amount of care provision in a weekly timeframe reported as varied.
Clarence	Clarence is a 62-year-old, divorced male caregiver of more than 6 years to a 98-year-old mother. The participant is a sole, unsupported caregiver, without siblings or a significant other. Clarence self-reported good health, "healthy as a horse." He is unemployed and has a high school degree. He stated that the annual income is less than $25,000, and his

Caregivers	Descriptions
	unemployment is not related to COVID-19. He also said that his religious affiliation is that of a “Believer.”
Blake	Blake is a 55-year-old single, gay African American man. He has no biological children, three female siblings (one deceased), and his mother’s primary caregiver. Blake is a college graduate and is employed part-time. He has been the primary caregiver for 2 years to his mother, who co-resides with him. The care recipient has been diagnosed with leukemia.