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Lived Experience of Caregiver Burden among Black family caregivers caring for ill family members during COVID-19

Lisa King
Walden University

Walden University

College of Psychology and Community Services

This is to certify that the doctoral dissertation by

Lisa King-Hodge

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Review Committee
Dr. Ethel Perry, Committee Chairperson, Psychology Faculty
Dr. Valerie Worthington, Committee Member, Psychology Faculty
Dr. Kimberly McCann, University Reviewer, Psychology Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

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Abstract

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by

Lisa King-Hodge

MA, North Carolina Central University

BS, Shaw University

Proposal Submitted in Partial Fulfillment
of the Requirements for the Degree of
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Self-Designed Psychology

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Abstract

Black family caregivers have had to deal with many challenges while caring for ill family members during COVID-19. Black family caregivers have been burdened with caring for family members for generations, often without proper supervision, training, or support. In December 2019 Coronavirus, also known as COVID-19, changed the world. The impact of COVID-19 on the American population has created many difficulties for Black family caregivers and their family members, including limited support, isolation, and financial disparities. The purpose of this qualitative phenomenological study was exploring the caregiver burden among Black family caregivers during COVID-19. The research question for this study was "What is the lived experiences of caregiver burden in Black family caregivers caring for ill family members during COVID-19? Tamizi's concept of caregiver burden acted as a guide for offering an understanding of the lived experiences of coping with caregiving. This study consisted of interviewing 8 Black family caregivers who have taken care of ill family members for at least 3 months during COVID-19. The data was collected using semi-structured interviews to analyze the use of common themes related to the lived experience of Black family caregiver burden caring for ill family members. It is the hope of this researcher that the results of this study contribute to creating positive social change and become a tool to assist Black family caregivers who are dealing with caregiver burden during COVID-19. A semi structured interview instrument was used for this research. The data I received was analyzed for common themes. It is the hope of this researcher that the result of this study contributes to creating positive social change of caregivers' burden among Black family caregivers.

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Dedication

I would like to dedicate this dissertation to my mother, my daughter, and my son. To my mother Brendora King, for believing in me and being a friend, a confidant, and a shoulder to lean on during this process. To my daughter Marcellina Hodge, who inspired me to write on this topic. Marcellina taught me through her resilience, to never give up. And to my son Marcellin Hodge Jr, as his quiet strength always urged me to reach my goal. But most of all, to God be the glory, for answering prayer and wiping away every tear during this process.

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Chapter 1: Introduction of the Study

In the Nationwide Retirement Institute Survey (2020) Black family caregivers revealed that 71% would willingly choose to be caregivers. Of these Black family caregivers, 73% said they would prefer to be caregivers again. Caregiving plays an essential role in many Black families across the United States. Due to this recent pandemic, Many Black caregivers feared that they will not be able to protect their family members from getting sick (Nationwide Retirement Institute 2020). The duties of caregiving under normal circumstances could be harmful to one's health as well as their mental well-being (Meon & DePasquale 2017). COVID-19 has increased the levels of harm and risk with regards to caregiving as it could be transmitted from person to person, where carriers could be asymptomatic and show little to no indications of infection (Qian et. al 2020). The U.S. currently does not have a federal system in place, but relies on state policies to support caregivers, unlike other nations according to (Organization for Economic Cooperation and Development, 2011). Because COVID-19 is a new global pandemic there is not much research on the Black family caregivers taking care of ill family members during COVID-19. This study filled a gap in research related to COVID-19 and caregiving among Black family caregivers caring for ill family members. According to Stokes (2020), the U.S. has very few social and family welfare policies that are created to specifically support caregivers. The focus of this study is on the experience of caregiver's burden while caring for ill family members during COVID-19.

The first chapter summarizes the research literature related to the study topic. This chapter incorporates a problem statement that includes evidence that the problem is significant in the discipline. Furthermore, this chapter explores the purpose of the study. It includes the research questions, conceptual framework, and an explanation of the nature of this study, which is a descriptive phenomenological approach. The significance of this study, the assumptions, the scope, limitations, and definitions of practical terms is presented in Chapter 1.

Background

The Zarit scale was used as a reference tool to create an interview guide for this study. This guide assisted with gaining a better understanding of caregiver burden. Thorson-Olesen (2018) recognizes that outcomes may affect caregivers physically, emotionally, and psychologically, especially since caregivers reported the need for community resources such as social interaction, entertainment, time for personal self-care, and hospice services. An interview tool focusing on five domains of the caregiver burden assisted in offering insight to the experiences of the Black family caregiver.

The strain of obtaining continued professional care created by the COVID-19 pandemic has left caregivers unprepared. Little assistance has been available in and outside of the home due to the uncertainty of this pandemic. Stokes (2020) stated that the Family and Medical Leave Act (FMLA) only allows for uncompensated time off for the caregiver with only 12 weeks of health insurance benefits. However, in 2018 (RAISE) Recognize, Assist, Include, Support, and Engage, Family Caregivers Act was established. This Act offered some assistance to family caregivers. Stokes (2020) also reports that even with the use of this policy, caregivers of Hispanics and Black still reported having difficulties accessing the support services. Due to COVID-19 many wrap-around services have been reduced or put on hold until there is more clarity on how to protect professionals, caregivers, and the patients.

Problem Statement

It has been noted that the stress of caregiving may be harmful to the family caregivers mental and physical health (Moen & DePasquale, 2017). Russell (2020) noted that COVID-19 had introduced stressors related to fear of infection, disruption in work schedules, schooling, and availability of reliable information and resources. Studies have shown that caregivers face new challenges regarding health care decisions due to restrictions placed on limited support from community-based services such as respite care, adult daycares, and medical facilities due to COVID-19 (Greenberg et. al. 2020). These decisions range from keeping ill family members in medical facilities to bringing them home to take care of them personally. Family caregivers are experiencing an extreme decline in their health compared to five years ago, the job has been reported to be harder than once thought according to the National Caregiver Association and AARP 2015 report.

Purpose

This study aimed to gain an understanding of the caregiver burden among Black family caregivers caring for ill family members during COVID-19. This descriptive phenomenological qualitative study provided rich, in-depth insight into the Black caregiver's experience during the COVID-19 pandemic while caring for ill family members. This study explored the lived experiences of caregiver burden among Black family caregivers caring for ill family members during COVID-19. Due to the newness of this pandemic, the studies on this research topic were minimal.

Research Question

The research questions for this study is as follows:

Research Question: What is the lived experience of caregiver burden among Black family caregivers caring for ill family members during COVID-19?

Conceptual Framework: Caregiver Burden

This study used the conceptual framework of caregiver burden. The concept of caregiver burden is oriented around coping strategies and dominant feelings of mental and physical loss that distract caregivers from their sense of self-being. The ZBI 22-item questionnaire was used to develop the interview tool for this study. The interview tool used had five domains listed in the ZBI to assist in gathering the information as it related to the Black family caregiver's burden experiences. The five domains explored were the burden in relationship, the emotional well-being of the Black family caregiver. The social and family life of the Black family caregiver, finances among Black family caregivers, and final domain was losing control over one's life as a Black family caregiver. The Black family caregiver burden consisted of challenges experienced by the caregiver, including being physically exhausted, experiencing a lack of emotional and physical well-being, balancing caring for relatives and maintaining other responsibilities regarding work and family, and possible isolation. Tamizi et al. (2019) systematically reviewed the concept of caregiver burden related to strain and self-perception over time. Because of the scarcity of literature regarding the lived experiences of caregiver burden among Black family caregivers caring for ill family members during COVID-19, an interview tool focusing on 5 domains as it relates to the caregiver burden was appropriate to explore what Black family caregivers may have experienced while caring for ill family members during the COVID-19 pandemic. The caregiver's burden is further discussed in Chapter 2.

Nature of the Study

This research was a descriptive phenomenological study. The descriptive phenomenological approach was appropriate for gathering rich data used to focus on the subjective experience itself (Giorgi 2012). The phenomenon of interest was the caregiver burden. The descriptive phenomenological approach was intended to bring forth and bear witness to the subjective experience of individuals through conversational interviews with participants who can self-witness, reflect, and express emotions, beliefs, and examples of the phenomenon of interest. This approach also required considerable effort on the part of me, as the researcher to bracket my biases and preconceptions so that the essence of the participants' experience is accurately reflected (Willis et al., 2016).

This study used recruitment flyers throughout the community and social media outlets, such as Facebook, Instagram, and virtual community bulletin boards to recruit study participants. Participant selection occurred through snowball sampling. Snowball sampling identified prospective participants by recruiting them from their circle of acquaintances without regard to probability. These Black adult participants must have cared for an ill family member for at least three months during the COVID-19 pandemic.

Semi-structured interviews were used with a sample size of 8 Black caregiver participants ages 18-74 years old. The interviews were transcribed, and I used the five-step data analysis process of Giorgi (2012).

1. Examining the transcripts. Upon reviewing information that I obtained in the transcripts; I used bracketing. Bracketing allowed me as the researcher to determine my experiences with this phenomenon to assure the prevention of bias (Giorgi 2012).

2. Scientific Reduction. The next step in this process was constituting parts. This part of the process consisted of rereading each transcript looking for meanings experienced by the participant (Giorgi, 2012).

3. Meaningful Units. This part of the process required division of the parts by transforming words given by the participants into expressions (Giorgi, 2012).

4. Changing expressions to Scientific Meaning. This part of the process was inclusive of free imaginative variation, which was the process of projecting events and metaphors more distinctly to establish a structure of the experience (Giorgi, 2012).

5. Transferring meaning unit expression to experience. The final part of the process assisted with synthesizing the essence of the experience to create the interpretation of the raw data given by each participant (Giorgi, 2012).

Definitions

Blacks: relating to any African American persons having an origin in any of the Black racial groups, regardless of class, gender, or sexuality (US Census 2021).

Burden: is defined as a weight, a load or a strain.

Caregiver: is a family member or a paid helper who regularly looks after someone that is sick, elderly, disabled or child. (cdc.gov)

Caregiving: is defined as the act of regularly looking after the elderly, a sick child, or a disabled person. (cdc.gov)

Caregiver burden: can be defined as the anxiety or a load borne by an individual who looks after chronically ill, disabled, or elderly family members (Tamizi, 2019)

COVID-19: coronavirus called SARS COV- 2. (WHO. 2019)

Informal Caregiver: is defined as a friend or family member who provides regular care to friends or family members who are disabled or have health problems.

Formal Caregiver: is defined as caregivers who are paid for their services rendered and have had education and training and caregiving. (cdc.gov)

Pandemic: is defined as an outbreak of a disease that is prevalent over a global population (cdc.gov)

Overwhelmed- is to defeat completely and to give too much of a thing to someone.

Assumptions

Phenomenological assumptions revealed beliefs about the quality of a particular phenomenon that was investigated and its connection to the environment in which it occurs. It was assumed that Black family caregivers caring for ill family members may have shared similar experiences during COVID-19. Another assumption was that the participants would accurately describe their lived experiences of caregiving during COVID-19. Additionally, it was also assumed that the participants (a) had cared for an ill family member for at least three months during COVID-19, (b) was between the ages of 18-74 years old, (c) was of Black or African American descent (d) had at least a fifth-grade education and be able to articulate their experiences clearly, and (e) had no ulterior motive for participation.

Another assumption related to this study was that the unpaid participants would willingly engage in the interviewing process without anticipation of any financial gain, incentive, or reward. The awareness that participants may not complete the interviewing process is recognized. Additionally, the awareness that, if Black family caregivers were not truthful and forthcoming with their experiences of caregiver burden during the COVID-19 pandemic, I would not have been able to learn how Black family caregivers experienced caregiver burden while caregiving for ill family members during the COVID-19 pandemic. Lastly, the caregiver's confidentiality was maintained; therefore, I assumed that none of the other Black family caregivers would have knowledge of each other, which would have caused contamination of the study's data results. These assumptions would be necessary for the context of this study to explore the lived experiences of caregiver burden among Black family caregivers caring for ill family members during COVID-19 while maintaining the participants' privacy and confidentiality.

Possible Scope and Delimitations

The specific aspects of the research problem addressed in this study were the caregiver burden among Black family caregivers and their experiences during COVID-19. The participants in this study included Black family caregivers who are at least 18 to

74 years old and have taken care of an ill family member for at least three months since the start of the pandemic which according to the World Health Organization, began in the United States on December 31, 2019. This study did not include any individuals other than Black family caregivers. This research is not transferable to other races, genders, or minorities. The geographical location was the United States of America. Participants were not limited to specific regions of the United States as not to distort results.

Limitations

Limitations may be the use of this study's method, which was the descriptive phenomenological approach. This approach focused on a small sample size of participants of the lived experience of a specific population, which may cause an issue with transferability. The study's original contribution was to gain knowledge and insight into the experiences of caregiver burden among Black family caregivers caring for ill family members during the COVID-19 pandemic. Due to the newness of the pandemic, there is not much research in this area.

The implications of this in-depth research study may spark further investigation of the effects of the COVID-19 pandemic on the lived experiences of caregiver burden among Black family caregivers providing care for their ill family members. A potential barrier could have included difficulty recruiting participants for virtual video-conferencing interviews. Additional challenges could have included some participants experiencing flashbacks or emotional unrest while discussing their caring experiences for an ill family member during COVID-19. These challenges did not impede the completion of the interview process.

Significance

The study's contribution may provide insight into caregiver burden among Black family caregivers' lived experiences caring for ill family members during the COVID-19 pandemic. Given that the COVID-19 pandemic is new to the world, the result of the study may provide a more in-depth insight into the lived experiences of Black family caregivers caring for ill family members during COVID-19, to gain a better understanding of how to assist Black family caregivers with gaining and awareness and connecting successfully with support services. The study may support professional practices in health care and mental health counseling by offering evidence related to the lived experiences of caregiver's burden among Black family caregivers caring for ill family members. These results may be instrumental in creating positive social change by bringing awareness of the lived experiences of Black family caregivers caring for ill family members during the COVID-19 pandemic.

Summary and Transition

COVID-19 has made such an impact on the United States in 2020 that it changed the daily routine of family caregivers nationwide (Russell, 2020). Due to the increase in family caregiving, caregivers have been experiencing stress in multiple areas of their life. This research explored the effect of the caregiver burden on relationships, emotional and social well-being, finances, and perceptions of control over one's life in giving care to an ill family member during COVID-19.

Conducting this descriptive phenomenological research, it identified the critical experiences of caregiver burden among Black family caregivers caring for ill family members during the COVID-19 pandemic. This research has been outlined in Chapter 1. Chapter 2 contains a literature review related to the conceptual framework, historical research, and caregiving background.

Chapter 2: Literature Review

Introduction

U.S. families have been profoundly affected by the COVID-19 pandemic. Officials in Wuhan City, China, confirmed the first human cases of the novel coronavirus in December 2019 (World Health Organization, 2020), and since then, the virus has spread globally. Americans have experienced unexplained illnesses and unemployment, and stay-at-home orders were on the rise (National Academy of State Health Orders, 2020). Vulnerable populations have been hit hard, including communities of color, families with young children, and hourly workers. Blacks experienced a six-fold increase in death due to COVID-19 according to John Hopkins University and the American Community Survey (2020). Stokes (2020) discussed intergenerational relationships and the impact of the risk of spreading the infection of COVID-19. Because of COVID-19, multigenerational households are facing more challenges. The American Association of Retired Persons (AARP, 2021) indicated that multigenerational living, two or more adult generations living together, negatively affected Blacks during the pandemic.

Black family caregiving can present as burdensome to an unprepared caregiver. The Centers for Disease Control and Prevention (CDC, 2021) reported, among those who provided care or assistance to a friend or family member with health problems or disabilities, 22.3% reported providing care or assistance to a friend or family member. Among adults aged 45 to 64, 24.4% reported being caregivers, and 18.8% of adults 65 years and older reported being caregivers. One in four (25.4%) women are caregivers compared to one in five (18.9%) men. In terms of caregiving across racial and ethnicity, 23.1% of Whites are caregivers, 24.3% of African Americans, 17.9% of Hispanics, and 10.2% of Asians/Pacific Islanders. One in three caregivers (31.3%) provides 20 or more hours of care per week, and of these caregivers, over half (53.8%) have given care or assistance for 24 months or more (CDC, 2021). Of caregivers, 10.4% reported providing care or assistance to friends or family members with dementia or other cognitive impairment disorders (Keller, 2021).

The National Alliance for Caregiving (2020) created a fact sheet on the typical African American caregiver based on research conducted for caregiving in the U.S. in 2020; this fact sheet indicates that Black family caregivers often have more demanding caregiving situations than their non-Hispanic, White, or Asian counterparts. Caregivers also tend to be a younger single population, have declining health, and deal with the challenges of balancing caregiving and full-time jobs (Keller, 2021). Some of the demanding situations caregivers were required to perform without proper training due to the disruption of COVID-19 includes tube feedings, home dialysis, catheter care, and injections (Polenick et al., 2020). There has been limited research on the lived experiences of Black family caregivers taking care of ill family members during the COVID-19 pandemic.

The purpose of this research was to explore the caregiver burden among Black family caregivers’ lived experiences while caring for ill family members during the COVID-19 pandemic. The findings of this study have increased understanding of the needs of Black family caregivers and may lead to the identification of available resources for Black family caregivers. These outcomes may strengthen, support, and inform Black family caregivers and community professionals regarding how to support Black family caregivers effectively. In this chapter, I discuss the conceptual framework for this study, which is caregiver burden. The literature review includes a discussion of the literature search strategy I used existing research related to various concepts and variables related to the phenomenon of this study.

Literature Search Strategy

I obtained resources for this literature review from the Walden University Library, the American Medical Association, and the American Psychological Association for this literature search. I also included recent African American family surveys and other media resources. Information was gathered from the World Health Organization and American Psychology Association related to Black family caregivers taking care of ill family members during COVID-19. I searched for literature in the following databases: the Education Source, ERIC, Psych INFO, PsycArticles, Google Scholar, and SAGE. Keywords used for searches included: ca*regiver burden, family caregivers, burnout, COVID-19 patients, caregiving hours, Blacks, Black family caregivers, caregiver demographics, adult child caregivers, African American, social support, husband and wife, adult child, social relationships, long-term care, nursing facilities, Alzheimer's disease, caregiver stress, women and caregiving, men and caregiving, spousal caregivers, quality of life stress, COVID-19, the role of a caregiver, aging population, pandemic, informal caregivers, racial differences in caregiving, caregiving experience, psychological experiences of caregivers,* and *caregiver statistics.* I used information and available resources to seek other sources. Sometimes sources cited other relevant literature that had not been found using the keyword search.

Conceptual Framework

Caregiver Burden

The caregiver burden was the conceptual framework for this study. This framework explores a caregiver's burden related to the challenges of providing care (Pearlin et al., 1995). The caregiver burden exposes similar negative characteristics experienced by caregivers, such as economic and occupational issues and psychological challenges including anxiety and depression (Tamizi et al., 2019). Studies show that family caregivers with high levels of education have more access to healthcare and health-related information for self-care (Oliveira et al., 2019). Yildiz et al. (2017) reported that caregivers' quality of life decreases as the burden of caring for other family members increases. Holt (2015) noted that social isolation and loneliness have been connected to adverse health conditions.

The caregiver burden places high demands on both the caregiver and the care recipient. Caregivers experience a significant imbalance in structure due to a lack of access to resources, training, and education. Imbalances can result in a deficiency of care, which is detrimental to the recipient (Crouch, 2017). For instance, if a care recipient is unable to be left alone for periods of time, the caregiver becomes unable to take a break, which can be associated with increased levels of distress and fatigue for both caregiver and care recipient. Experiences of loneliness and social isolation are a significant factor in predictors of caregiver burden (Lee et al., 2016).

Zarit (1980) created the Zarit Burden Interview (ZBI), including the caregiver burden scale, to define caregivers' factors. This scale is designed to measure a caregiver’s perception of strain or burnout related to their care for a sick or chronically ill person. The ZBI was a 29-item questionnaire revised to 22 questions that required caregivers to rate their experiences on a 5-point scale of feeling burdened, where zero means never feeling burdened, and 4 means nearly always (Gratão et al., 2019). The ZBI scale rates five domains that were used to guide this research. The first domain is the burden in a relationship. This domain consists of six items with questions such as "How burdened do you feel caring for your relative? The second domain is the emotional well-being of the caregiver. This domain consists of 7 items, with questions such as "Do you feel strained around your relative? The third domain is the social and family life of the caregiver. This domain has four items that focus on questions such as "Do you feel that your social life has suffered because you are caring for your relative? The fourth domain is finances. This domain consists of 1 item and asks the question, "Do you feel you do not have enough money to care for your relative, in addition to the rest of your expenses? The fifth and final domain is losing control over one's life. This domain also consists of four items. The questions in this domain ask questions such as "Do you feel you have lost control since your relatives' illness?” This questionnaire takes about five to ten minutes to complete in its entirety.

Lithin (2020) conducted a recent study to explore the relationship between palliative care needs and caregiver burden among persons diagnosed with neurodegenerative diseases. This study also used a cross-sectional design to explore this relationship. Using 120 participants (60 patient-caregiver dyads) of motor neuron disease (MND) and Parkinson's disease (P.D.) from a quaternary referral care center for neurology in South India. This study used the ZBI scale and the palliative care outcome scale to explore a possible relationship. The Zarit burden inventory used in this study focused on the distress experienced by caregivers of persons diagnosed with neurodegenerative disease. Results found that the palliative care outcomes score positively correlated with caregiver burden (r = 0.597). Misra (2020) conducted a cross-sectional study with adults in rural populations focusing on adults with cognitive impairment (CI) and caregiver's burden. The objective was to assess Cognitive Impairment (CI) in adults over 59 years old in rural and tribal areas. In West India, two hundred forty household participants were given the mini status exam and the ZBI scale, but only 212 adults were studied. Interviews of primary caregivers showed 32 (35.16%) caregivers had little or no burden, 53 (58.24%) had mild-to-moderate burden, 6 (6.59%) had moderate-to-severe burden, and none had a severe burden. The research presented by Lithin (2020) did not use the five domains of the caregiver's burden scale as a conceptual framework; thus, this study examined the extent to which the five domains provided insight among Black family caregivers' experiences. The concept of caregiver's burden is best applied to this study because it explores the experiences of strain, emotional wellbeing, burden, and uncertainties among Black family caregivers caring for ill family members during COVID-19.

The United Nations (2020) reports that the burden of care has increased tremendously during COVID-19 due to the lack of medical accessibility during the pandemic. Some of the facts that support this research are the burden of care and challenges caregivers face, such as mental, physical, and social challenges (Brooke et al, 2020). Caregiving-related burden may lead to higher health risks among Black family caregivers than White caregivers due to the onset of age-related diseases earlier in Blacks than Whites (Thorpe, 2016). For this study, the five domains of the caregiver's burden scale were adopted as the conceptual framework to understand the lived experiences of caregiver burden among Black family caregivers caring for ill family members during the COVID-19 pandemic.

Literature Review Related to Key Variables and/or Concepts.

General Outcome of Caregiving

According to the United Nations Policy Briefing (2020), there has been a decrease in availability of professional health services in the United States. Since the pandemic "The Virtual Roundtable on COVID-19 and the future" (2020) focused on the caregiving rendered by women and girls nationwide, which is at the center of response efforts. The burden of caregiving has increased and has been compounded by the fact that children are no longer in school, and the elderly need additional care. For example, before the COVID-19 pandemic, data released showed that family caregivers were already taking on unpaid caregiving responsibilities within their homes. Among caregiving of family members, Pozzan (2020) provides empirical data that demonstrated that before COVID-19, caregivers performed at least four hours and 25 minutes of domestic care daily. During COVID-19, caregiving responsibilities increased by an hour and 23 minutes, for a total of nearly six hours daily. Blacks, who represent 57% of caregivers, spend about 30 hours per week providing caregiving for recipients versus Whites, who represent 45% of caregivers (Family Caregiver Alliance [FCA], 2016). These results indicated the pandemic challenges among the family structure for informal and formal caregivers among the Black and White populations. Caregiving can be informal or formal. Informal caregiving is an act by an individual, such as a parent, spouse, adult child, or grandparent, through which primary care is provided for a family member, spouse, or significant other. Thorson-Olesen (2018) reports that compassion fatigue is at a higher incident rate for informal caregivers. In terms of informal caregiving, providers often fail to receive financial compensation for their services. Formal caregivers receive compensation for services rendered in facilities or residential homes. Time plays a significant role in the amount and quality of service provided to individuals in need of care. Time is also a core factor when determining caregiving burnout. The researchers view caregiver burnout as the primary intermediate between the demands on caregivers and their different vast overall impacts (Onwumere et al., 2017). The negative impressions of caregiving supersede the positive impact, with the minimum instance of positive impression overshadowing the negative impacts (Maslach & Leiter 2016). In some situations, positive and negative effects can coexist. Furthermore, caregiving burnout can indirectly impact care recipients via undesirable treatment such as abuse and neglect (Friedman et al., 2015).

Caregiving can affect both the caregivers and the care recipients. From the caregivers' perspective, an informal caregiver strain can result in negative psychological and physical outcomes. Generally, caregiver strain can diminish well-being or create additional psychological strain, more adverse and negative emotions, and decreased life quality (Al-Rawashdeh, 2016). Caregiver strain is a primary concern for verbal and physical incidents linked to violence for both informal and formal caregivers (Fang, 2016). Even with a strong bond, there is a possibility of caregivers neglecting a recipient. The recipient's dependence upon the caregiver is often associated with the caregiver's level of drain and burnout. This interactive social dynamic is familiar within dementia populations (Tramonti et al., 2018). Due to caregivers' drain and burnout, respite care has been introduced to assist caregivers with the overall effects of caregiving. Parker and Fabius (2020) state that respite care enabled the caregivers to attend to their health needs. Respite care is short-term relief for the primary caregiver. Respite care is also planned, or temporary emergency care provided to the caregiver in short-term limited breaks for families in need. Respite care aims to provide positive feedback and a much-needed break, as well as positive experiences for the persons receiving care. Research shows that challenges in associations with healthcare experts are linked with caregiver burnout. There is inadequate evidence of the effect of using respite and support services; some in-home services lead to a lowered burden, though informal caregivers who waited for such services for a longer time were more burned out (Vandepitte et al., 2016).

Family Caregivers

During 2019, the COVID-19 pandemic emerged and presented many challenges to institutions, healthcare facilities, and family caregivers (Greenberg 2019). These challenges caused family caregivers to become overwhelmed by trying to take care of sick individuals while providing safe and healthy care for themselves. The caregivers, due to the pandemic, may not have been given an opportunity to choose whether they will become a caregiver, which promotes high levels of personal burden (Goksel et al., 2020). According to Zavagli et al. (2019) any individual within the family who provides emotional or physical care of a patient, such as an adult child, spouse, or parent, is considered a family caregiver and an extension of the current healthcare system. According to Revenson et al. (2016), caregiving duties are practiced more by females than males. Further research has determined that there is no correlation between sex and caregiver stress (Kokurcan et al., 2015). This research has also shown no reliable impact on the caregiver's age. Although there is a distinction in the type of relationship between caregivers and recipients, it could be argued that the experience of caring may be different at various stages in life. (Parker & Fabius. 2020).

The National Alliance on Mental Illness (NAMI) found that negative caregiving experiences place a greater burden on Black family caregivers in a family-to-family study (Smith, 2014). The essential incentive to caregiving seems to be a guarding characteristic for informal caregiver burden. In caregiving, regularly worrying and a sense of duty to control are risk factors because they require continuous awareness on the part of caregivers (Crouch, 2017). Abramson et al. (2019) interviewed 13 Black female caregivers to determine the barriers associated with their inability to provide needs in a study of people with dementia. Many of the caregivers for this study were female (n = 10, 77%). This study demonstrated that the primary obstacle of providing care was the inability to gain resources due to the challenges of the caregivers leaving their family member unattended.

Pickard (2019) conducted a study that examined the relationship between religiosity and the use of alcohol to cope with stress among African American women caregivers. Using a cross-sectional study, data included 521 midwestern urban and rural Black women who cared for nature of study aged 65 years and older. This study examined characteristics related to caregivers, such as those with lower levels of religious attendance and those who were more likely to use alcohol to cope with the stresses of caregiving. Samson (2016) analyzed qualitative focus group data consisting of 32 African American family caregivers to explore issues related to culture and race regarding culturally sensitive interventions. This study focused on how caregivers were impacted while caring for dementia patients. This study noted that among Whites, Latinos, and Blacks, the Blacks showed no overall improvements regarding self-care, social support, and their quality of life. This study also gave insight into the fact that educational programs were needed to develop knowledge and skill for caregivers and promote self-care. Additional knowledge and skills are needed with the complexities of taking care of one's spouse. Becoming a spousal caregiver can be complex and tremendously impact the caregiver's mental, physical, and social functioning. A recent study by Hawkley et al. (2020) revealed that caring for a spouse becomes more prevalent with age; from 50-64, it is 9%, from 64-74, it is 24%, and from 75 and older, it is 46%.

Spouses are also considered a risk element in that caring for a woman is less demanding than caring for a man (Onwumere et al., 2017). Galvin et al. (2020) studied the individual quality of life in spousal ALS patient-caregiver dyads. This study explored factors related to the informal caregiver's experience of caring for their spouse. Within the Black community, husbands and wives have lost loved ones during the pandemic. Spouses lack the proper medical skills for taking care of their loved ones. The stress of family caregiving upon a caregiver can be identified within five specific domains. These domains include 1) the impact of burdens within the relationship between the caregiver and the care recipient, 2) emotional wellbeing of the caregiver, 3) social life of the caregiver, 4) finances of the caregiver, and 5) the loss of control over one's life as it relates to the caregiver, which is now considered an urgent public health issue, according to the (National Academies of Sciences, Engineering, and Medicine, 2016).

Burden in Relationship

Maslow (1962) expressed that people are mentally motivated by physiological needs, safety needs, love and belonging, esteem, and self-actualization, all of which play a role in caring for loved ones and themselves. Limited research has addressed the health-related dynamics, factors, and challenges of caregiving within the Black community. This limited research does include studies associated with mental illness, gender, religiosity, and providing care. Literature on caregiving indicates that giving care to older individuals can be stressful (Kim et al., 2018). It is not uncommon for adult caregivers to report deficiencies in physical and mental health, social relationships, and economic conditions (FCA, 2016). These deficiencies might be exacerbated because many Black family caregivers are also employed outside the home (FCA, 2016). Overall, caregivers will experience stress, depression, anxiety, and a lower quality of life due to taking care of their loved ones (Tatangelo et al., 2018). Due to the robust nature of caregiving, the caregiver's health plays a significant role in caregiving. Healthy caregivers can handle caregiving roles more effectively than those with failing health. Caregivers who experience chronic pain, somatic disorders, or other illnesses can experience added stress (Jutkowitz et al., 2020). Stress can affect family caregivers in providing care because it can be harmful to the caregiver’s health as well as negatively impact other daily challenges (Moen & DePasquale 2017). Often caregivers can experience numerous factors that cannot be altered, which adds to caregiving stress, particularly among Black family caregivers.

A study associated with role theory revealed the stimulating effect of multiple roles on caregivers (Fernández, 2018). Distinct functions, such as parenting within the role of an informal caregiver, were identified as a source of strain faced by caregivers. Other research has shown that informal caregivers who are parents have a higher probability of encountering parental fatigue (DePasquale, 2018). Research shows sheltering at home for an unknown amount of time may have an unprecedented impact on the parent-child relationship due to the pandemic, (Russell 2020). Caregivers who simultaneously work as formal and informal caregivers (Mello, 2016), are more likely to experience professional weariness than formal caregivers. This study has revealed similar instances in occupational strain. The informal caregiving duties can impact the caregiver's other responsibilities. This correlation can be multidirectional, and the effect of additional duties on caregiving burnout must be researched to comprehend what leads to caregiver stress. A study by Cheng (2020) notes that African American people with Alzheimer's disease or related dementias (ADRD) are more likely to live in poor social-economic communities than any other race with less ADRD-specific support resources (Desin et al., 2016). Due to the lack of desired resources, "intensive informal care" is given to Black family members (Friedman et al., 2015). Intensive informal care consists of caregivers performing more than 200 hours of care for a family member per month, increasing the family caregiver's burden.

Emotional Well-Being of Caregivers

According to North (2018), community-wide disasters have a substantial impact on the mental health burden of individuals and families. Horesh (2020) reports that due to the high levels of traumatic stress caused by COVID-19, preexisting mental health-related disorders will worsen and become a new disorder over time. Yu, et al. (2019) identified experiences related to caregiving that may cause mental health issues such as depression, stress, and anxiety. Thoughts, primarily dysfunctional or functional cognitions, and supposed capability, also affect caregiving practices. Remarked capacity to deal with the recipient's sickness or characteristics determines the caregivers' challenges and stress (Oechsle et al., 2019). The psychological experience of caregiving during the COVID-19 pandemic will likely result in elevated levels of emotional stress. Caregiving is physically and mentally challenging, costly, and time-consuming (Singhai et al., 2020; Stall, 2019). A study that explored the existence of burnout within the parent-child relationship indicated that alexithymia, which is a lack of emotional awareness, leads to elevated levels of stress and emotional burnout (Le Vigouroux et al., 2021). A parent-child psychological wellbeing study was employed by Gassman-Pines (2020), which noted that within this study, all parents acknowledged a decline in their psychological wellbeing since the beginning of the pandemic. The increased responsibility of providing care is more emotionally, physically, and financially challenging. This study also noted that these challenges were due to interrupted access to care for the care recipients and the caregivers. Thus, limited access has resulted in lifestyle adjustments resulting in increased worries and fears of becoming infected or being one on that passes the infection along (Qian 2020). In this study, parents stated they experienced more pressure due to the COVID-19 outbreak; approximately 57% of mothers' mental health deteriorated, while 32% of father’s' mental health deteriorated. Due to homeschooling, a sizable portion of the burdens may be carried by mothers (Hamel and Salganicoff, 2020). The COVID-19 pandemic has caused parents to be unsure and unaware of how to care for and predict the outcome of their child's health.

Research reveals that emotional control abilities aid in preventing parental and occupational burnout and can be used to resolve informal caregivers' psychological suffering (Gérain et al., 2019). Another study identifies that those emotional abilities are an essential resource for the caregiver. Caregivers who engage in denial are more likely to suffer from burnout than caregivers implementing coping plans (Kokurcan et al., 2015). One of the methods to include in emotion management is using personal coping skills among caregivers. When caregivers use different coping approaches with strategies, they experience fewer personal struggles (Onwumere et al., 2017). Nonetheless, these coping techniques are typical for dealing with emotion management. Investigating the use of emotional coping approaches implemented among Blacks may enhance understanding of whether these techniques effectively resolve stress experienced by Black family caregivers.

Social and Family Life Among Caregivers

Conway (2018) stated that social relationships can be disabled or disassembled due to dealing with the life demands of caregiving. Because of these life demands, it is likely for family Caregivers to experience depression and become unable to adapt to demanding conditions. These demanding conditions can cause elevated levels of caregiver burden, which may lead to emotional depletion and burnout (Gerain, 2019). Depletion and burnout can often predict abusive caregiver behaviors (Alves et al., 2019). In addition to emotional burnout, social factors also impact caregivers. Specific social determinants, such as lack of resources, healthy food, job opportunities, living wages, and social support, significantly impact Black family caregivers (Jayasinghe, 2015). The cultural basis of the caregiving role can also influence the caregiver's appraisal (Konerding et al., 2016). Caregivers can perceive their roles as either a normal circumstance or a burden.

The social environment is subdivided into professional support such as virtual support during COVID-19 and informal support. Informal social support aids in reducing emotional drain and fatigue (Kokurcan et al., 2015). The availability of other informal caregivers is perceived as a resource. Informal caregiver support can turn into strain due to different opinions, conflicts, worries, or inequities (Williams et al., 2016). An example of informal support includes the care provided by the elderly. Black grandparents' caregiving in a community in the southern rural communities was studied by (Clottey, 2015). This study focused on caregiving due to parental incarceration, addiction, unemployment, or illness.

This study revealed that these Black grandparents encountered several challenges regarding their health, finances, and emotional strain. These problems for these caregivers ranged from chronic pain, mobility issues, and lack of sleep to financial strain. This study indicated that the financial strain affected the caregiver's health because the grandparents neglected to purchase their medication to afford the medical necessities for their grandchildren. In general, studies revealed that social inequality, racism, and injustice among Black grandparents prior to the pandemic period contributed to chronic stress, which increases vulnerability to certain diseases, including COVID-19 (Plater, 2019).

Finances and Caregivers

The government has been attempting to reduce the social-economic gap in the medical gap. In 1935 the Old Age Assistance Act became the Social Security Act signed by then-President Roosevelt. This act allowed more families to receive private nursing care for their chronic illnesses that family members could not provide. Also, in the 1930s and 40s, health care professionals sought many cost-effective ways to care for the chronically ill but were unsuccessful until the later years around 1960.

Additionally, the CDC (2020) health equity stated that everyone should realize their health potential; when this does not happen, it creates barriers and challenges in today's societies for Black family caregivers to receive the necessary support. Many States are expanding legal support services and unemployment benefits, COVID– 19 Tax Credit, to support people struggling financially because of COVID-19 pandemic restrictions. Under the new Families First Coronavirus Response Act (FFCRA, 2020), many full-time employees can claim a tax credit that offers a refund credit worth up to 10 days of sick leave if they must leave work. This leave requires one to be subject to a quarantine or isolation order or obtain a medical diagnosis or care for coronavirus symptoms. Other reasons would be caring for an individual quarantined due to COVID-19 concerns or if one is home caring for a child whose school or daycare has closed (Setianingrum et al., 2021). Systemic injustices and historical discrimination have deterred many Black family caregivers from legal support services. As caregivers are providing informal care, they can experience a protective aspect that helps them let go of burnout by providing an emotional interruption. The working protecting effect may not apply when caregivers retire early or take an occupational break to give care to the recipient. The other occupied caregivers have fewer duties in caregiving and have less caregiving stress (Williams et al., 2016).

Considering all the discussed elements, the effect of professional standing is more complicated than how it has been perceived. Schmaderer et al. (2020) stated that the caregiver's burden increased due to economic issues and caring for others. While patient care was necessary, many lacked the funds to send their loved ones to healthcare facilities and often bartered with the family or neighbors to care for their loved ones. Before daycare centers and Nursing homes, the caregivers were friends and family. During COVID-19, the closing of these institutions led back to friends and family members taking on caregiving responsibilities. A study done by Kemp (2020) noted that many Blacks in Louisiana are essential workers; thus, it is impossible for them to work virtually, increasing their chances of contracting COVID-19. Of these crucial workers, 61% have a lower possibility of being tested for COVID-19. This study showed that race-based testing disparities likely increase the burden during COVID-19. Carmen et al. (2020) noted a survey was done to determine the gender consequences of the outbreak. The results revealed that the outbreak had been more challenging for women of color due to high layoffs, with 54% losing their job revenue compared to 27% of White women losing their job income. In part, this tendency traces to imperfections in governmental programs.

In most cases, this survey demonstrated that caregivers turn to family or friends first, Nonprofits, and then the government in the communities. Another Survey by Nationwide Retirement Institute (2021) revealed that 38% of African American Gen Xer and 35% of Millennial caregivers were concerned about the effectiveness of caregiving on their jobs. Among Black family caregivers, Millennials (32%), and Black Gen Xers (42%), are worried about losing their job due to their caregiving duties for their aging parents (news.nationwide.com, 2021). Gassman-Pines (2020) did a study that revealed how the pandemic has increased family hardship. The one-time survey reported that two-thirds of the family members surveyed experienced a loss in income and showed 45% of these families faced increased caregiving burdens, and 12% had a family member sick since the pandemic began.

Caregivers Loss of Control Over Life

Chandola et al. (2019) noted that working mothers disclosed feeling the pressure of balancing work and the family roles 40% more than the average person. Many unpaid care providers such as spouses, parents, children, other relatives, partners, or friends help patients who cannot take care of themselves because of a chronic illness or disability. Caregivers' duties may include assisting with personal needs, household chores, or medical/nursing tasks. Duties may also include managing a person's finances or arranging outside services. Health issues change the functions and the association in the dyad between the future caregiver and the forthcoming recipient (Bjørge et al., 2017). Rosner (2020) studied the duties of the caregivers' burden on issues related to isolation, loneliness, and fear. Epps (2016) completed a study that revealed African American dementia caregivers suffered from a lack of proper resources such as volunteerism. Many caregivers revealed that leaving the care recipient alone was a common concern. However, all the duties of caregivers may not be burdensome. The caregiver also has roles and responsibilities, such as offering emotional support, companionship, and daily activities. Among all these responsibilities, the association between a caregiver and recipient is the primary reason caregivers resume their roles (Revenson et al., 2016).

Informal caregivers are affected by illness, less personal and free time, and unpredictable health issues (Lond & Williamson, 2017). Informal caregiver burden is also associated with losing friends, having little time for a social life, and choosing to disregard personal needs due to Caregiving (Gérain & Zech, 2019). The physical burdens are significant, just as is the emotional strain. Emotional burden can affect the association between a caregiver and care recipient, leading to mixed emotions related to the caregiver's roles, such as bitterness, which can be the result of the care-receivers (Williams et al., 2016). A low-quality relationship between the caregivers and recipients leads to stress and exhaustion. Caregiving can be exhausting emotionally, socially, relationally, financially, and physically and it can also be a rewarding experience that can change a person's lifestyle.

Summary

In summary, Black family caregivers have faced challenges such as improper medical training, financial decline, an increase in the number of ill family members receiving in-home care, and lack of preparation for the unknown related to the COVID-19 pandemic. Blacks who provide caregiving rely significantly on sources of psychological wellbeing. The rate of diseases such as Alzheimer's and other related disorders (ADRD) projects an increase to about fourteen million by 2050 (Alzheimer's Association, 2019). The rate may be shocking but not as stunning as ADRD, which is twice as high among the Black population than the White population (Green-Harris et al., 2019). Because of the increase of ADRD, many Americans depend profoundly on their family members for care and support (Alzheimer's Association, 2019.) Mouton et al. (2019), researched individuals with illnesses such as dementia and found there may be comorbid behavioral issues that can increase the caregiver's burden.

Care recipients can become aggressive and physically abusive to their caregivers. Caregivers incorporating activities such as exercising, cooking, and art can assist with proper caregiving. This pandemic has caused African American caregivers to experience a decrease in the healthcare system's service, such as respite care, due to healthcare professionals' teleworking. CDC (2020) affirmed that the COVID-19 pandemic had created an issue for African American caregivers needing downtime due to isolation and social distancing. Although studies on caregiving lack information explicitly focusing on the Black family caregivers' strengths, support, and needs, these caregivers are successful in their tasks during COVID– 19. This study was designed to focus on the gap in research regarding the challenges of the caregiver burden among Black family caregivers caring for ill family members during the COVID-19 pandemic. Scholars need to research the COVID-19 pandemic effects on caregiver burden among Black family caregivers. Thus, in chapter three, I revealed the methodology to study the effects of the COVID-19 pandemic on caregiver burden among Black family caregivers caring for ill family members.

Chapter 3: Research Methods

Introduction

Caregivers are dealing with increased levels of distress due to new challenges related to COVID- 19. These challenges for caregivers include whether ill family members should be removed from caregiving facilities, finding proper care for family members, and whether to become the sole caregiver during COVID-19. These stressors may also include issues with lack of proper resources, lack of information on how to care for loved ones properly, and possible interference with the work schedules of the caregivers, according to Park et al. (2020). As stated previously, the purpose of this descriptive phenomenological study was to explore the lived experience of caregiver burden among Black family caregivers caring for ill family members.

In this Chapter, I described the research design and the rationale for using a descriptive phenomenological approach used to explore the research questions, my role as the researcher, the recruitment of participants for the target population, and the rationale for the study. In Chapter 3, I described the participants used in this study, sample size, the process used for recruitment and data collection, and data analysis. This Chapter concludes with data collection, analysis as well as issues of trustworthiness and ethical procedures for protecting participants' data and with a summary.

Research Design and Rationale

The rationale for using this research design is that it clarifies the meaning of the caregiver's experiences. The research questions asked Black family caregivers the meanings of caregiver burden, and the conceptual model is reflected in the research questions.

Research Question: What is the lived experience of caregiver burden of Black family caregivers caring for ill family members during COVID-19?

This study employed a descriptive phenomenological research design. The purpose of phenomenology is to study one's conscious experience of their everyday life and social interaction. This philosophy is heavily associated with Giorgi’s (2012) descriptive phenomenological psychological analysis method, which consist of steps such as examining the transcripts, scientific reduction, the use of meaningful units, changing expressions to scientific meaning and finally transferring the meaning unit expression to experiences. This method was chosen because it allowed the researcher the use of themes and meaning units to explore the individual experiences of the caregiver. According to Patton (2015), this method depicts the fact that there is an essence of experience. This research methodology was selected to explore and understand the personal experiences of Black family caregivers caring for ill family members during COVID-19.

This approach is vital, especially in the often ignored or excluded population of Blacks. The phenomenological approach is well suited for this study because it focuses on intense emotional and human experiences. Using this approach allowed us to understand the caregiver's thoughts, feelings, and emotions as they relate to providing care.

Role of the Researcher

In this study, my role as the researcher in this qualitative phenomenological research was to explore and understand the personal experiences of Black family caregivers caring for ill family members during COVID-19. Researcher -participant rapport was established for this study to ensure the participants are comfortable with the process and as well as the researcher. Rapport was developed at the beginning of the process by presenting myself as friendly and cordial and assuring the participants that their responses will be confidential (Hagan, 2018). Obtaining a good rapport allowed the participants to be comfortable with divulging information related to caring for family members during COVID-19 and their struggles and triumphs during this time. As the role of the researcher, it was necessary to make sure that this study was theoretically grounded by critically analyzing the perspective of power relations within the qualitative study (Steinberg & Cannella, 2012). This analyzation was necessary to examine the power relation due to certain assumption that change is going to happen when participants are asked questions as it relates to data collection and their experiences that may affect change in their consciousness (Kemmis et al., 2014).

In the role of the researcher, I'm aware of the relationship with the participant reflective of the insider/outsider issues, positionality issues and the importance of research reflexivity. Due to the participant being an adult Black family caregiver it is reflective of the researcher’s previous experience. It was also noted by the researcher that developing trust may be more natural if the aspects of the researcher’s position were similar to that of the participants (Merriam & Tisdell, 2016). Due to the similarities of experiences of the researcher and the participant, the researcher carefully journaled to reduce and eliminate any biases that may come about from the researcher.

Willis et al. (2016), stated the essence of the participant experience would be accurately reflected using bracketing on the behalf of the researcher. The use of bracketing allowed me, as a researcher, the freedom to explore the phenomenon without the interference of my experiences (Englander 2020). The use of reflective thinking assisted me in developing psychological meaning units. This process allowed me, as the researcher, to reflect on my personal experiences, to shape my interpretation of the participant's experience. Additionally, I however, remained aware of my role as the researcher and did not take on a therapeutic role, but maintain clear professional boundaries.

As the researcher, I also considered potential ethical issues before conducting this research. I am also aware of the guidelines of Walden University's Internal Review Board and the American Psychological Association code of conduct 2017. The guidelines, as mentioned above, allowed me to work with the participants in a professional manner. Informed consents were obtained before any research began, and the clarification and understanding that all participant information remained confidential.

Methodology

Participant Selection Logic

The target population was 8 Black family caregivers between 18 to 74 years of age who had taken care of ill family members during COVID-19. These participants were adult Black family caregivers who resided in the United States providing care for family members during COVID-19. Due to COVID-19 being a new pandemic, there was very little information regarding Black family caregivers taking care of family members.

These Black family caregivers will need to have provided care for ill family members during COVID-19 for three months. Recruitment for 8-10 participants will be through social media. I used convenience sampling in which, as the researcher, allowed a targeted participants based on their experiences to participate in this study. I also looked for participants to assist in identifying other potential participants. These self-reported Black family caregivers were obtained by posting to Facebook, Instagram, community bulletin boards, other social media groups, and snowball sampling referrals.

Inclusion Criteria

The criteria for an individual to be included in this study was that each participant must be an adult (18 to 74 years old), a Black family caregiver of an ill adult family member. The participant must have been able to articulate and understand English. The participant must have had at least a fifth-grade education. The participant must have taken care of an ill family member specifically during COVID-19 for at least three months. The participant had access to a telephone, the internet, or other means of communication, as necessary. I verified via email or telephone if the participants met the criteria.

Exclusion Criteria

Exclusion criteria for participation in the study are those who were of races other than Black; did not take care of an ill family member for at least three months during COVID-19; are not ages 18 to 74 years old, does not have at least a fifth-grade education and cannot articulate and understand English. All criteria for inclusion had to be met before any individual was considered appropriate for participation in the study. Any participant who fell into the exclusion category during the study was not participants selected for this study.

Instrumentation

I created a semi-structured interview guide using open-ended questions to encourage participants to share stories and examples while remaining focused on the research purpose (see Appendix A). (Hagan, 2018). I developed the interview instrument from domains identified in the ZBI scale to develop needed questions; this guide consisted of 11 interview questions and four follow up questions.

The interview questions were developed according to the conceptual framework of caregiver's burden. The first question of the interview is regarding the caregiver's burden. Additionally interview questions 2 and 3 focused on the burden in relationships in Black family caregivers providing care for ill family members during COVID-19, (b) interview questions 4 and 5 focused on Black family caregivers' loss of control over their lives due to providing care for ill family members during COVID-19, (c) interview questions 6 and 7 focused on the financial strain on Black family caregivers providing care for the ill family members during COVID-19, (d) interview questions 8 and 9 focused on the social and family life in Black family caregivers providing care for the ill family members during COVID-19, and (e) interview questions 10 and 11 focused on the emotional wellbeing of Black family caregivers providing care for the ill family members during COVID-19. Four follow-up questions were proposed to explore the discoveries participants made as a part of the care giving experience. An example is: What do you feel would have improved your experience of caring for an ill family member during COVID-19? This question was asked to assure a full understanding of the caregiver’s perspective was captured.

Procedures for Recruitment, Participation, and Data Collection

Upon approval from the IRB 10-13-22-0281816, a recruitment invitational flyer was sent out via social media and virtual community bulletin boards (see Appendix B). These flyers consisted of information related to the study. The flyers had information such as a contact email and phone number for those interested in participating in the study. Interested people contacted me and I reviewed the criteria for inclusion via telephone. Upon meeting criteria, I emailed participants informed consents. Once participants consented to the study. I scheduled individual interviews by phone. Depending on the participant's choice, the interviews were conducted through telephonic communication or Zoom conferencing.

Data Collection

The interview process was the first step in data collection. For data collection, notes and audio recordings were taken while video conferencing or by telephone, saving time and promoting accuracy. There were audio recordings for each interviewee to maintain accuracy of the interview. The interview was semi-structured using open-ended questions, beginning with small talk to assist the participant with becoming comfortable with the interviewing process (Hagan, 2018). Then questions were asked about the caregiver's experience of caregiver burden during COVID-19. I did not coerce or guide the participant in their responses. As a researcher, I did, however, assist the participant in staying on task concerning the questions asked. I listened carefully as the participants discussed their feelings, emotions, and perceptions of their individual experiences of caring for family members during COVID-19. The interviews took 20 to 60 minutes to complete.

This collection process took place in two ways. The first was direct verbal responses; the participants responded during the interview process. Participants were informed that they can leave the study without any repercussions or issues if they no longer wish to continue or remain in the study. Participants were debriefed; this debriefing gave the participant time to make any changes to the transcript. Upon completion of the transcript reviewed participants was given my information as the researcher. If participants had any further questions or concerns about this study, they could have contacted me. Upon completing this study, participants were given information to access a free counseling hotline if needed. As a part of the research member checking was introduced to the participants. Participants were emailed their transcripts with the opportunity to review and or make any changes to the transcript. This process ensures the information has been captured accurately.

Data Analysis

I looked at the pre-reflective experiences; these are experiences that reflect what we live in, and through in our everyday life (Van Manen 2014). The primary method of gathering information through phenomenological research was through interviews. Per Giorgi (2012), I employed these five steps during this research process:

1. Phenomenological Attitude: before interviewing, I as the researcher understood my own experiences to reduce bias of my own personal prejudices and assumptions (Giorgi, 2012). Monitoring happened by documenting information to review regularly as it relates to my own thought process This process called "epoche" which means refraining from judgment in Greek.
2. Constituting Parts; once the epoche was understood, I temporarily set aside or brackets all my assumptions to examine the experiences (Giorgi, 2012). By doing this I develop meaning units.
3. Phenomenological reduction: I continually returned to the essence of the reason for this study as I gained and understanding of the experience to focus on the meaning itself (Giorgi, 2012). I then focused on how the experience became what it is through imaginative variations.
4. Horizontalization will then occur; I then organize the data into units or clusters, by placing the information on a Word Data Analysis table to give scientific meaning to each experience.
5. I then synthesized the units by using the Data Analysis Table to interpret the research data (Giorgi, 2012).

Issues of Trustworthiness

To ensure the trustworthiness of this study, I continually referenced the research questions to accomplish the goal of gaining an understanding of in-depth experiences about how an individual gives meaning to a phenomenon such as a caregiver's burden Babchuk (2017), during COVID-19. To maximize the trustworthiness of this research study, each participant responded to the same questions consistently. Time spent with the participant allowed the researcher to understand and recognize possible inconsistencies that may hinder the development of trust between the research and participant Cohen & Cohen (2006). I recognize that research data must be credible, transferable, confirmable, and dependable to be replicated (Lemon & Hayes, 2020).

Credibility

According to Patton (2015), credibility heavily depends on me, the researcher's integrity. All interviews were audio recorded with detailed notes to solidify the study's credibility. As the researcher, I maintained frequent and consistent communication with my chair and second committee member to ensure the credibility and validity of the study.

Transferability

To achieve the transferability of the findings of this study, I provided clear and concise details concerning the methodology, data collection, and the data analysis process (Merriam, 2016). Doing this allowed future researchers to continue with this study in whole or part without duplication. The data from this research may also be transferable to other caregivers and their experience of taking care of family members during COVID-19.

Dependability

To achieve dependability, detailed instructions were given about data collection, the population, and data analysis. Additionally, the researcher clarified the interpretation of the research findings for the researcher to understand (Merriam 2016).

Confirmability

Confirmability consists of dependability, transferability, and credibility (Patton 2015). These steps show that my findings derived from the data and not my imagination. Data obtained, such as audio-recorded interviews and detailed notes, was used to clarify and interpret the participant's feelings without the researcher's bias or interference.

Ethical Procedures

Before beginning this research study, I recognized that I must abide by strict ethical standards. The APA Code of Ethics (2013) requires APA members to adhere to strict ethical standards. I requested formal approval from the Institutional Review Board (IRB) for application. Upon approval from IRB, I sent out flyers via social media to obtain participants for this study. Interviews were scheduled via telephone or Zoom conferencing upon receiving signed consent. Participants established a clear understanding of confidentiality and their ability to withdraw from the study. Participants have the researcher's phone number and email regarding any additional information they may need about the study. Participants also were made aware of the dissertation process and its completion. I will also retain interview information for five years. After five years, transcripts will be sent to the participants if requested or disposed of by shredding. For this study, I took extra precautions to maintain confidentiality.

Summary

This study aimed to gain knowledge and understanding of the lived experiences of caregiver burden among Black family caregivers caring for ill family members during COVID-19. I employed a phenomenological descriptive qualitative method to obtain an in-depth awareness of Black family caregivers to gain this information. This research offers insight into financial, psychological, relational, social wellbeing and the loss of control of one's life, of the Black caregiver's experience. My methodological approach enriched the knowledge of how caregivers of Black descent experience caregiver burden during COVID-19. This information hopefully will initiate the possible creation and or exploration of programs that may assist Black family caregivers in providing care for ill family members during COVID-19.

Chapter 4: Results

Introduction

During COVID-19 caregiving for ill family members has become a very demanding responsibility. In a very demanding time having to make critical decisions for ill family members can be challenging. COVID-19 swept the world by storm creating multiple uncertainties consisting of how to care for oneself as well as their loved ones. The use of personal protection gear has become necessary and life changing. Black family caregivers faced challenges of providing care for ill family members with little to no training or medical background (Moen & DePasquale, 2017). Provision of care for ill family members had produced a negative impact on caregivers over the last 5 years according to the National caregivers Association in the AARP 2015 report. The burden of caregiving for Black family caregivers is the focus of this study. Black family caregivers have experienced issues of burden with personal relationships, emotional wellbeing, social and family issues and financial challenges as well as losing control over one's life as a Black family caregiver during COVID-19. This burden experienced by Black caregivers during COVID-19 can affect the caregivers' experiences including physical exhaustion, family and work frustration and isolation.

In this Chapter, I have presented this qualitative phenomenological study. This chapter begins with the presentation of my research setting. I describe how I applied the data analysis process outlined in Chapter 3 to the data that I collected. I have presented how I established data trustworthiness needed to make the participants feel comfortable enough to share their experiences with me. Also, in this chapter I have presented the findings of this study.

Settings

It was very important to me as a researcher to present a safe and confidential environment for the participants to participate in the interview and speak freely. Participants were allowed to choose where their interviews would be conducted. Participants chose confidential and private settings for their interviews. Participants chose from options such as face to face, via Zoom, or over the telephone. The goal was to interview at least 8-10 participants for the study, saturation was achieved by the 8th participant. Seven of the eight participants completed their interviews over the phone. One participant chose face to face. Interviews consisted of dialogues that consisted of open-ended semi-structured questions with regards to the topic research question. Because participants were allowed to choose their time and their setting each interview was productive and uninterrupted.

Demographic

For this study participants provided demographic information needed to participate in the study. The demographic of the participants included their gender, race and the length of time they provided care for an ill family member. The demographic also included their ability to understand and speak English. Participants in this study were referenced as study Participants 1, Participant 2 and so forth to maintain confidentiality. Each participant in the study identified themselves as a Black family caregiver. The participants in this study's ages varied from 18 to 74 years old.

Participant Description

For this study eight Black family caregiver participants that met the qualifications for this research were invited to participate in an interview with respect to their lived experiences of being a Black family caregiver during COVID-19. This pool of participants yielded two males and six females. The interview process was face to face for one participant and via telephone for the other seven. Among these participants five out of eight had medical background, knowledge, and experience, and were currently working in their fields. These participants were once again made aware that their information would remain confidential for this research.

Several of the participants within this research declared that there was no burden experienced during the time of COVID-19 while caring for their ill family members, but most stated that they were overwhelmed with the process. Within this study it is important to note that four out of eight of the participants provided care for their parents, three out of eight participants provided care for their child and one participant provided care for his older sibling. Participants were free to give their account on how they handled caregiving during COVID-19.

Table :1

Descriptive Information of the Participants Ill Family Members

INDENTIFER	GENDER	AGE	RELATIONSHIP	MEDICAL BACKGROUND
P1	FEMALE	70	MOTHER	NURSE
P2	FEMALE	56	MOTHER- IN -LAW	MD
P3	FEMALE	57	FATHER	CNA
P4	MALE	40	BROTHER	NON-MEDICAL
P5	MALE	51	DAUGHTER	SPOUSE OF CNA
P6	FEMALE	57	MOTHER	NON-MEDICAL
P7	FEMALE	52	DAUGHTER	NON-MEDICAL
P8	FEMALE	38	SON	MEDICAL ADMIN.

Data Collection

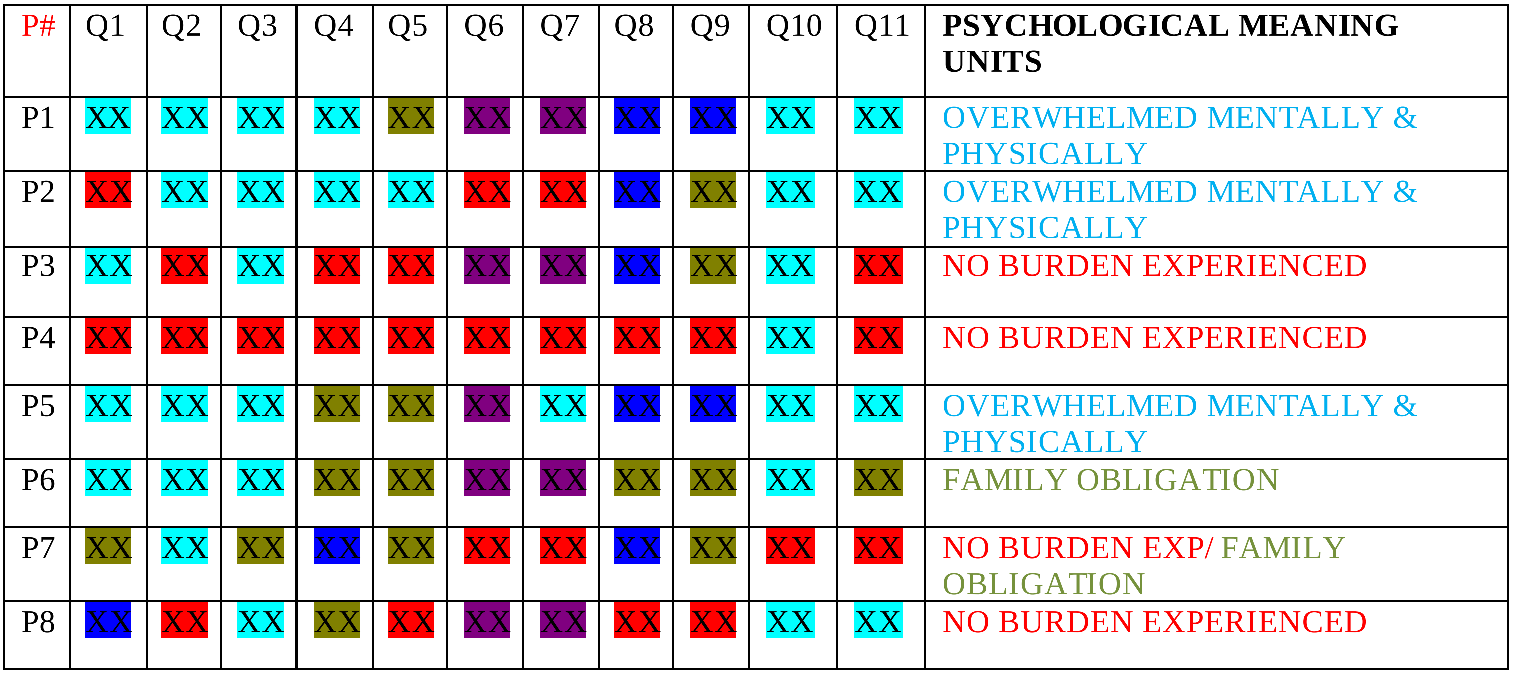
Upon approval from Walden's IRB #10-13-22-0281816 my study started November 11, 2022. I posted the flyer on LinkedIn and other social media sites. Participants were scheduled for an interview, and they were provided with an electronic consent form with instructions to respond to the consent form with the words I consent. All participants were asked to give permission to have their interview audio recorded. Participants were also informed of their right to stop the interviewing process at any time they felt uncomfortable with answering questions or continuing the interview. Within the first week my first appointments were scheduled. The interview process took anywhere from 30 to 60 minutes depending on how much information the participant provided.

Data Analysis

For my data analysis I used pre-reflective experiences. According to Van Manen (2014), these experiences reflect what the participant lives in and through in their everyday lives. The data gathered for this qualitative descriptive phenomenological research was done by performing eight interviews. Five steps were employed during this research process. The first step in this process is the phenomenological attitude, I as the researcher, documented my thoughts regularly throughout the interviewing process of my participants. The purpose of this documentation was to decrease and refrain from using my own personal judgment. The second step in this process was the constituting parts. This involved bracketing all my assumptions during the interview process to help me develop the meaning units. Once the meaning units were developed using the hand coding approach, the information was then sorted and reviewed for possible relationships. The third step was a phenomenological reduction. Psychological reduction, which was used to help me gain an understanding of the experiences expressed by the participants in this study. As reported by Giorgi (2012), through imaginative variations the experience is the focus and its meaning. The fourth step in this process was horizontalization, developing the meaning units. These units were completed by me by organizing data units into clusters and using a data analysis table to give specific meaning to each experience. The fifth and final step was to synthesize this information. This was done by using the data analysis table which I interpreted. It is also important to note that not all meaning units could be reduced into all five steps. There were some responses that could not be reduced any further

Table:2

RESEARCH QUESTIONS 1-11 OUTCOME



P#	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	**PSYCHOLOGICAL MEANING UNITS**
P1	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	OVERWHELMED MENTALLY & PHYSICALLY
P2	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	OVERWHELMED MENTALLY & PHYSICALLY
P3	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	NO BURDEN EXPERIENCED
P4	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	NO BURDEN EXPERIENCED
P5	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	OVERWHELMED MENTALLY & PHYSICALLY
P6	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	FAMILY OBLIGATION
P7	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	NO BURDEN EXP/ FAMILY OBLIGATION
P8	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	XX	NO BURDEN EXPERIENCED

COLOR LEGEND

P = PARTICIPANTS
Q= QUESTIONS

XX = NO BURDEN EXPERIENCED
XX = SOCIAL ISOLATION
XX = FAMILY OBLIGATION
XX = FINANCIAL STRESSOR
XX = OVERWHELMED MENTALLY & PHYSICALLY

Table:3

FOLLOW UP QUESTIONS 1-4 OUTCOME

F/L	Q1	Q2	Q3	Q4	**PSYCHOLOGICAL MEANING UNITS**
P1	OO	OO	OO	OO	CHANGES NEEDED IN CARGEGIVING
P2	OO	OO	OO	OO	CHANGES NEEDED IN CAREGIVING
P3	OO	OO	OO	OO	MORE INFORMATION NEEDED
P4	XXX	XXX	XXX	XXX	NO CHANGES NEEDED IN CAREGIVING
P5	OO	OO	OO	OO	MORE INFORMATION NEEDED
P6	XXX	XXX	XXX	XXX	NO CHANGES NEEDED IN CAREGIVING
P7	OO	OO	OO	OO	MORE INFORMATION NEEDED
P8	OO	OO	OO	OO	MORE INFORMATION NEEDED

COLOR LEGEND

OO = MORE INFORMATION NEEDED
OO = ADDITIONAL ASSISTANCE NEEDED
OO = CHANGES NEEDED IN CAREGIVING
OO = CAREGIVER UNCERTIANITY

XXX = NO MORE INFORMATION NEEDED
XXX =NO ADDITIONAL ASSISTANCE NEEDED
XXX= NO CHANGES NEEDED IN CAREGIVING
XXX = NO CAREGIVER UNCERTIANITY

Evidence of trustworthiness

Credibility

I established credibility by reviewing all data given among participants. This credibility was established by conducting transcript verification with all participants.

Each participant was provided with a copy of their transcript for accuracy. If participants felt the need to make changes or revisions, they notified myself as the researcher and the revisions were made. Participants then contacted me via telephone with regard to the changes that were made in their agreement to them. Each participant reported that the transcripts were accurate. In addition, my chair provided feedback to me as I progressed through my collection and data analysis processes. And finally, throughout the interviewing process, data collection and participant transcription review, participants were given clear and concise information with regards to the phenomenological study throughout the process.

Transferability

Transferability in this qualitative research study was obtained by giving clear and concise details concerning this study, its methodology, the data collection and the data analysis process (Merriam, 2016). In this research I established transferability by collecting all data possible with regards to the research as it relates to the demographics to replicate the study for additional findings and similar research. Hand coding was used to gain the most descriptive insight on this population. The findings associated with this data may help assist other Black family caregivers providing care for ill family members during and after COVID-19.

Dependability

Dependability was accomplished in this study by clearly describing each step and process. I used it for population selection, data collection, data analysis, interpretation of the data and the research findings. I established dependability by gathering detailed information from each participant who shared their experiences in this study. Member checking also aided me by giving the opportunity to participants to review and respond to transcripts.

Conformability

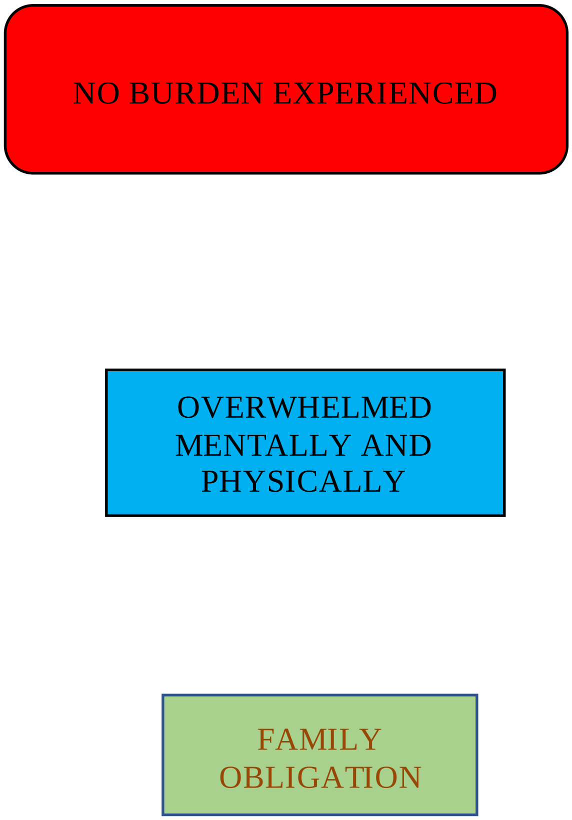
According to Patton 2016, conformability consists of dependability, transferability, and credibility. In this qualitative study the steps I used to complete my findings were derived from the data given by the participants and not my personal biases. This data I obtained was for conformability which was gathered through audio recorded interviews, and detailed notes. The information that was obtained allows for clear interpretation of the participants' feelings without interference of my bias.

Results

The data analysis yielded six reoccurring psychological meaning units as it related to this study. The psychological meaning units identified in this phenomenological qualitative study for these participants were as followed; no burden experienced, being overwhelmed mentally and physically, family obligation, more information is needed, changes are needed in caregiving and no changes are needed in caregiving. The structure of these six psychological meaning units displayed in figures 1 and 2 are presented in this section.

Figure:1

Psychological Mean Units of Structural Outcome for questions 1-11



Participant Legend

P3, P4, P7 and P8 all expressed the feeling “No Burden Experienced”.

P1, P2, and P5 expressed the feeling “Overwhelmed Mentally and Physically”.

P6, and P7 expressed feeling "Family Obligation.”

Psychological Meaning Unit One: No Burden Experienced

Upon completing this research, the data shows overwhelmingly that these Black family caregivers did not feel burdened with the experience of caring for an ill family member during COVID-19. This I also recognized that these participants stated that being overwhelmed was more of the problem than being burdened.

> Participant #2 reports that it was fairly easy. Mainly because the person I was taking care of was my mother-in-law. She has dementia, but the stage that she was in was not a bad stage. She was still very coherent; she still was able to get around on her own, she was, you know, pretty much able to do everything that she normally did. So, it was not as difficult as it probably was for some other people.
>
> Participant #2, when asked in question 6 about the financial challenges, she stated that one of the things that I did not have, was financial challenges.
>
> Participant #3, when asked if she was burdened in question 2, she stated it is my passion; I loved taking care of people, whether it was COVID or just anybody, elderly or sick in general. I love doing it. For question #4, Participant #3 stated she had no loss of control over her life; no, it was separate; it was my passion, taking care of someone. Then coming home, I know I have to take care of my family just as well. She also stated she has never felt uncertain at all.
>
> Participant #4 who appeared to be the least affected by COVID-19, answered "No" to questions, 3,4,5,6,7,9, and 11.
>
> Participant #7 also stated that she has had no issues or burdens with financial stressors due to COVID-19 and caregiving. Participant #7 also answered "no" to

questions 10 and 11. She has not experienced any issues with being emotionally unbalanced or experienced any feelings of uncertainty.

Participant #8 stated that this experience has not burdened her. Participant #8 also stated there was no loss of control over her life in question 5; no, not really, because, you know, I have learned to adapt to his way of life because he had this sickness before COVID. I am cautious about who I am around, still cautious. Yes, I am because you know I am a single parent, so yeah, sometimes. So, I've learned to adjust my life to his life, so no. Participant #8 reports that there were no issues with her social life or relationships with others.

Psychological Meaning Unit Two: Overwhelmed Mentally and Physically

Multiple participants throughout the interview process admitted to being very overwhelmed while caring for ill family members during COVID-19. Participants throughout this study often denied the feeling of being burdened. Multiple participants were eager to discuss their definition of being overwhelmed and the different ways they experienced caregiving during COVID-19. Several participants felt overwhelmed with acquiring and assuming multiple roles, responsibilities, time management, and lack of support from other family members.

Participants described the lack of assistance they received from family members while caring for their ill family members during COVID-19. Participants also described their struggles with their feelings and emotions regarding providing the needed care for their ill family members during COVID-19. The psychological meaning unit two captured the experience of what it was like for participants to provide care for their ill family members without assistance from other family members. These participants had hoped or expected to receive help from other members of their families during COVID-19. It is notable that in the Black community, caregiving is focused solely on an ill family member, usually receiving care from within the family unit.

> Participant #1 stated; yes, I have felt very burdened taking care of my mom because it causes me to neglect my responsibilities, this being a wife and a caretaker at home during COVID-19. Also, there was hardship between siblings because of the disagreements and the agreements of providing care for our mother. For question 2 for Participant #1, she also stated that other siblings closer to her mom could have been more responsible in her care. Participant #1, question 4 stated, " I have lost control because I haven't given attention to myself; I have not taken the time to sit down and define my purpose in life. Participant #1 also discussed her mental conditions in question 10. She also stated I'd taken time to get away, sit down, and cry because I had become so overwhelmed.
>
> Participant #2 stated. in question 3, Yes, overwhelmed all the time with work and school and things of that nature because although we were at home working from home. I teach, I still had to keep up with my classes and the students and make sure that they were on track and then making sure my children had what they needed for school, making sure they were doing their lessons and doing everything they needed to do plus, my schoolwork and do my school work and having to take care of her on top of that it was just a lot. In question 4, when asked about the loss of control, Participant # 2 reports, yeah, that happened a lot.

It is a challenge to keep everything together when taking care of her, so there are quite a few times that I did feel that I didn't have control or grasp of the whole situation. In question 10, regarding feeling emotionally unbalanced, Participant #2 reports there were bouts of tearful moments for sure, you know, cursing moments, all the above, so yeah, OK, absolutely cursing moment.

Participant #3, when asked question1 about their experience, the participant reported, for one, it was difficult. It was harder than I thought it would have been to care for them, but it got worse. When question 3 asked about being overwhelmed; this participant reported yes, several times because it began to get too much physically to see someone deteriorate; you take on that, it's like there's nothing else that I can do, so your heart hurts. When Participant # 3 was asked about feeling emotionally unbalanced, she reported, yes, I did; just seeing someone deteriorate the way that they do, and there's nothing you can do, so I had a lot of emotional moments. Participant #4, when asked question 10 if he felt emotionally unbalanced, reported yes, just exhausted sometimes.

Participant #5, when asked question 1 about his experience, he reported it was a little stressful. You cannot access the medical team because nobody can come out, so it was like the difficulties learning the little things you have to worry about. In question 2 participant #5 was asked if he felt burdened, and he reported, I would say yes sometimes. Participant # 5, when asked question 3 about being overwhelmed, he reports, I mean really, yes, you know, if you stayed away from everybody, that was the better thing going on at the time. When asked question 7 if he felt stressed meeting monetary obligations, he reported, not so much physically but mentally; you know, you think about this, you got to keep the heat on because we've got all these other kids here, you got to keep the ledger full of course, and then there are the cold months, so yeah. It was just the mental aspect of it all, to keep everything going smooth. Participant #5 responded to question 10 about feeling emotionally unbalanced, yes, from the medical stuff that was needed to the emotional stuff to the physical. Question 11 was asked about feeling uncertain, and he responded yes, from finances to mental and physical frustration and not knowing if I'm providing the care needed correctly.

Participant #6 for question 1 discussed her experience: my experience with my parents wasn't too easy at all, but I had to make sure that they had things they needed. I mean like because, I'm not medical. But going down to see my mom taking them food, making sure they had medicine for both of them, and taking them to the stores. OK, stuff like that I kept doing during COVID, it did make it harder; it always made it harder for me, yes.

Participant #6, when asked question 2 about feeling burdened, reports, I felt like that sometimes, I felt like that. When it was just um, when we had to go down to her house a lot every weekend and take care of her during the week. When we had to run down there making sure they had everything just fine sometimes. When asked question 3 about feeling overwhelmed, Participant #6 responded, it can get overwhelming, but no, it was all right. I mean, it was kind of like that’s something you have to do, so in the end, it got a little overwhelming with my mom sick.

> Participant #6 also stated when asked about being emotionally unbalanced, like you know, from crying spells to frustrations and anxiety. I knew my mom was dying, so I emotionally cried a lot about that.

> Participant #7 reports she had felt burdened a little bit. Participant #8 reports he felt overwhelmed, from time to time, trying to get gas, food, and tissue, you know, because of COVID, so yeah, OK sometimes because of the economy being that way, and you know, of course, we don't want all those things running low so yeah, OK from time to time.

> Participant # 8 also stated in question 10 she felt emotionally unbalanced, yes, I am; having a sick child or having a child with special needs is never easy for any parent, so yeah, from time to time, it's emotional, you know, wanting to make sure that you're able to provide everything that the family member needs while trying to provide for the household.

Psychological Meaning Unit Three: Family Obligation

Participant #1 presented very stressful for the need for other family members to offer some assistance in taking care of their mother. The feeling of having to take care of a family member is a shared behavior among Blacks. When question #5 was asked about time spent providing care if it took away from her, the participant responded, yeah, it takes away a lot from a person when they have to take care of another family member, probably especially mom’s in their older age because, it's like they go back into a childhood stage, where you know you have to just be careful with them.

> Participant #2 when questioned about whether there was an effect on her relationship with other people, she, said, absolutely, yeah, it affected my relationship with my spouse because it was his mother. I felt like it was not my mother, so I felt like I was bearing the brunt of the responsibility for taking care of his mother, so it would make me lash out at him; it's like, you know, this is your mom. It's not my mom, so I felt it was all being pushed onto me when it was not my job to do so. I was supposed to be there in my mind to help him, versus when it was flipped, it was, he was helping me, yeah, that didn't flow well with me.
>
> Participant #5, a father of six in question 1, was asked whether he felt like providing care took away from himself, and he stated it's not about you; no, it's about them.

When Participant #6 was asked question 4, she requested an additional explanation of the question. Upon rewording the question for this participant, she was better able to answer the question.

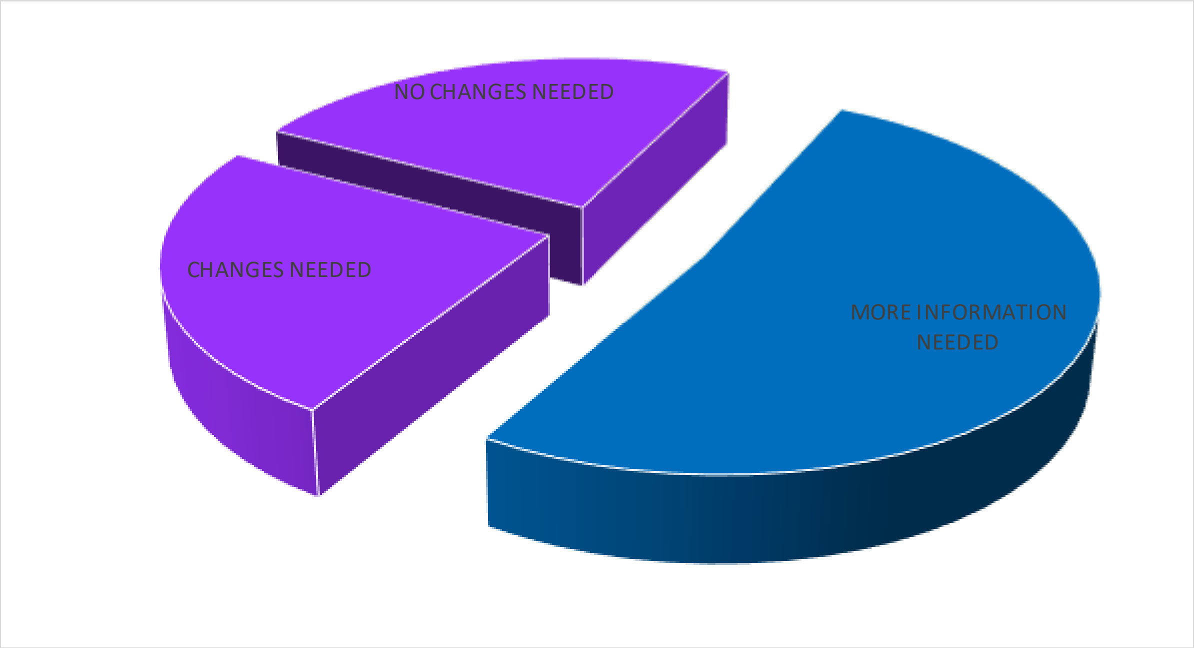
> Participant #6 responded, oh, I'm going to be honest. It was all focused on taking care of my mom; your focus is making sure that they are well taken care of, so you know, when you focus on that, it's hard; I mean, you don't know; I'm sure for me it was more of, that's what I'm supposed to do, so I had to do it. Participant # 6 was also asked if time spent providing care for parents took away from what you needed for herself during COVID-19, she stated, probably so, but I didn't. I mean,

for me, and everybody's different, for me, I didn't feel like I didn’t take care of myself; as I said, it was more like that was my job.

Participant #7 discussed that her obligation to her family grew because, during COVID-19, she was responsible for another family member who moved in with her. Participants #7 when asked question 9, responded other family members are having to be here simultaneously.

Figure: 2

Psychological Mean Unit Structural Outcome for follow up questions 1-4



Notable Results

P3, P5, P7, P8, felt more information was needed while caregiving.

> P1 and P2 are a nurse and medical doctor, and both feel that changes are needed in caregiving.
>
> P4 and P6 have no medical experience, and both feel that no changes are needed in caregiving.

Psychological Meaning Unit Four: More Information Needed

Responses in this section were interesting per the Black Family caregivers' occupation, connection, or knowledge to the medical field. It is important to note that five of the eight participants have firsthand medical experience as it relates to offering caregiving to a family member.

> Participant #3 was asked what they would like to have experienced differently. The participant responded knowledge, you know, I never knew anything about COVID-19, so it came from out of nowhere. Participants also commented on what would have improved the experience, Participant responded just me being there, trying to figure things out and how to do things, so more help would have been much appreciated.
>
> Participant #5 commented on the fact that he was able to provide care for his daughter, him and his wife because she had firsthand information with regard to COVID-19 and how it affected the population as a whole.

The fact that COVID-19 was a new pandemic, and no one really knew what to expect, many governmental agencies shut down for a while. Upon reopening, it was a bit of an adjustment trying to get everyone's life back on track.

Many parents dealt with not having enough information to successfully teach from home.

Participant #7 expressed her frustration with the lack of information given about COVID-19, even within the school system. She responded to what she would like to experience differently. She reported she needed better schooling online instead of teachers just sitting there and not doing their job. When asked, what would have assisted you to better care for the ill family member during COVID-19? Participant #7 stated more people having a well-rounded knowledge and understanding of how and what COVID was and when it came out; yeah, and even though they were scared, they didn't care and disregarded what could happen.

Participant #8 was aware and abreast of the latest information because she worked in pediatric neurology. This Participant was taking care of her 10-year-old son at the time of COVID-19. This Participant reported, being cautious when it comes to it (COVID-19), but it's made me more cautious now that not only are we dealing with COVID but these different strains of flu out here, so I've always been cautious just maybe of the people, and what’s surround us.

The information made available to her is not the norm given to the population because she was working on the frontlines in the provision of care during COVID-19. When asked question 2, if the experience has impacted her understanding, she stated: the germs we can't afford that, and you know, so I'm cautious when I go out there, and when people over they’re washing their hands and different things like this.

Participant #8 also discussed how working in the hospital during COVID-19 has benefited her while taking care of her ill family member. She stated,

> because being that I work at a hospital, information was literally available to me, and it was provided for me and my family.

Psychological Meaning Unit Five: Changes Needed in Caregiving

When reviewing the data analysis table, it is interesting that the two participants that show the need for more changes needed in caregiving were the medical doctor and the nurse. These two participants initially decided to further their education in the medical profession wanting to offer a positive contribution to the community. Therefore, it is not unlikely to see the data show these participants want to see changes in the caregiving field, being that they are front-line healthcare professionals.

> Participant #1 responded to follow-up question one, asking What they would like to have experienced differently. While caring for an ill family member during COVID-19? The participant stated I don't think it's much you can experience differently. I think the only thing is I would have appreciated a little more assistance from my siblings in the care of my mom. Participant #1 also stated I think if they never had COVID-19, then you can deal more with the illness. But when you have a family member sick and unable to continue to care for themselves, where they can't get out and do things, I think the isolation part of being here and away from people is what was the hardest part of that. The little bit you have to do, to go out, to take her to venture out and to shopping, and to the park and you know, things that she enjoyed doing on the outside of the house

even in her sickness. Participant #1 did, however, express her understanding of the COVID-19 caregiving experience. Participant #1 reported I think it has impacted me greatly; I'm able to assist elders if they're going through the same situations that I have gone through; I'm able to tell them. Basically, there are ways that they can get through caring for their loved ones, even in a time such as COVID and the isolation process.

Participant #2 responded by saying; I would have liked more assistance from my husband as it relates to taking care of her, and while I was, I would have liked for him to have eventually had someone come in or get a caretaker to come in and help, it was just my husband being slow and to move on it. Participant #2 stated having a caretaker come in sooner would have improved her experience of caring for an ill family member yourself during COVID-19. Participant #2 also discussed the need for relief for the caregiver and the ill family member. She commented that just possibly places where people go, but they have places where they stay out for respite stays, so maybe just to have her go somewhere away from the house and, you know, just me having my core family there that would have been different.

Psychological Meaning Unit Six: No Changes Needed in Caregiving

The data analysis table also showed that two participants in the study had no medical experience. These participants replied that they did not need any changes in the caregiving of an ill family member during COVID-19. Here are their comments.

Participant #4 was asked, were you ever worried about not being able to take care of your brother during COVID-19, he responded No to this question. He was also asked if he would have liked to have changed anything that would have help him take care of his brother, like more information, more access to the doctor's office, and better transportation. Is there anything that would make it easier to do what you needed to do during COVID-19? Again, he replied, no. This Participant were further questioned for clarification of the study, were you good with the way the doctors had changed their rules and the appointments and everything? He replied Yes and sounded unbothered with the changes.

Participant #6 was asked, while you were taking care of your mom during COVID-19, were there any times that you felt uncertain about the care you provided her? Participant # 6 replied, no, it took everything, but not really; OK, so she was suffering, but no. Participant #6 was also asked a question for clarity, what would you like to have experienced differently during COVID-19 while caring for your ill family member? What would have made it smoother for you? Participant #6 stated, what would have made a difference for me? I asked her again, what would you like to have seen differently? What would have made it smoother for you, or was the way it worked out ok? It all worked out like it should have as far as caregiving. First, caregiving, and I'm going to be honest with you, I can't really say anything about that because I think it went the way it should, I mean the way my mom was, then, it was kind of alright for me, only

> because even if it wasn't cool, she was still wanting her way. My mom would still be at home, but not going out of the house, stuff like that.

Summary

In this chapter, I presented the findings of this study of the lived experiences of Black family caregivers during COVID-19. The key findings of this phenomenological qualitative study indicated that Blacks experienced “no burden” while providing care for ill family members during COVID-19. The results also displayed that participant’s experienced the feeling of being overwhelmed while caring for ill family members. Another result showed that family obligation was high with these Black family caregivers. The overall results from this study revealed that many Black family caregiver participants experienced no feelings of burden while taking care of ill family members during COVID-19 but did experience feelings of being overwhelmed due to family obligation.

In the follow-up questions of this study, the findings were, more information was needed during the caregiving of ill family members during COVID-19. The results also revealed that participants who had previous medical healthcare experience felt that changes were needed in caregiving during COVID-19. Ironically participants that had no medical background reported no changes were needed in caregiving during COVID-19. In this Chapter I discussed how evidence of trustworthiness was established and maintained throughout the study. In Chapter 5, I have discussed the findings presented in this Chapter in greater detail concerning the literature on the topic.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This qualitative phenomenological study explored the lived experience of caregiver burden among Black family caregivers caring for ill family members during COVID-19. Most of the research on this phenomenon is nonexistent due to the newness of this pandemic. For this design, a descriptive phenomenological approach by Giorgi (2012) was used to gather rich data and focus on the participant's experience itself. The ZBI, Zarit burden inventory tool was used to assist in establishing an interview tool that would aid in exploring the psychological meaning units that resulted from the data analysis. This phenomenological study used the caregivers' burden concept by Tamizi et al. (2019), to assist with systematically reviewing the Black family caregiver's burden related to strain and self-perception over time. This study used caregivers' burden to explore areas of similar negative characteristics or otherwise experienced by Black family caregivers. The concept of caregiver's burden was used to further look at the coping strategies and dominant feelings of mental and physical loss that may distract the Black family caregivers from their sense of self-being.

This research design supported the lived experiences of eight Black family caregivers. In this study data was collected, examined, and analyzed to gather results from these eight Black family caregiver participants. A key finding in this study identified that Black family caregivers reported that they did not experience being burdened while taking care of ill family members during COVID-19. It is also important to note these Black family caregivers did report experiencing being overwhelmed mentally and physically. It is vital to provide information regarding this research's findings and how they fit the purpose of this study. It is also inspiring to reflect on the inspiration for this project, the study, and the developed follow-up questions. This qualitative phenomenological research design was appropriate to resolve the proposed research question.

Interpretation of Findings

This study explored the caregiver burden among Black family caregivers during COVID-19, focusing on the research question of the lived experience of caregiver burden among Black family caregivers caring for ill family members during COVID-19. A previous study confirmed that high demands placed on caregivers had created a significant imbalance in structure due to the need for more training, resources, and education, which can result in a deficiency of care (Crouch, 2017). The result revealed that among Black family caregivers during COVID-19, most of these participants reported they did not experience caregiver burden. The results also demonstrated that Black caregivers did experience being overwhelmed. Furthermore, the study confirms that COVID-19 created hardship for the Black family caregiver regardless of gender, financial obligation, and previous medical experience.

The analysis of the findings of this study was explored with the proposal of a research question. From the research question, an interview guide was used to collect the data from the eight Black family caregivers who cared for an ill family member during COVID-19. The data collected included descriptive information about each participant and for whom they have provided care. The findings revealed six major phenomenological psychological meaning units that emerged from this study's data analysis. These psychological units were 1) no burden experienced, 2) overwhelmed mentally and physically, 3) family obligations, 4) more information was needed, 5) changes needed, and 6) no changes needed.

Psychological Meaning Unit 1: No Burden Experienced

The first finding that was analyzed as a psychological meaning unit was Black family caregivers verbalizing no burdens experienced. P4, P7, and P8 stated that as primary caregivers, they did not experience any burdens while caring for an ill family member during COVID-19. In comparing this study finding to the study by Smith (2014), who demonstrated that the negative experiences of caregiving of Black family caregivers placed a significant burden on Black family caregivers, this study's finding disconfirmed that Black family caregivers experienced burdens. The key finding of this phenomenological qualitative study indicated that these Black family caregivers during COVID-19 experienced no burden while providing care for their ill family members. Upon completion of this study, it is apparent there may be a different understanding of the word burden among Black family caregivers. The definition of *burden* in dictionary.com is a load, typically a heavy one, an obligation. The definition of *burden* in the Urban dictionary is defined as something that weighs you down, usually a worry or a sore point you don't share with close friends. Although in a google search of “what burden means among blacks”, the definition is, it is a metaphorical reference to the burden of shame, guilt, and oppression that the African Americans bear on their backs. Greenberg et al. (2020) reported that many challenges and changes presented themselves during COVID-19. These challenges resulted in the necessary healthcare decisions that were needed to be made by many family caregivers as it relates to the limited support from community-based services and other restrictions. Goksel et al. (2020) reports, many caregivers may not have been given an opportunity to choose whether they will become a caregiver due to the pandemic. Among the participants, P3, P4, and P8 all declined being burdened while caring for ill family members during COVID-19. However, they expressed their frustrations and exhaustion while caring for their ill family members. This position of the caregiver was reported by Kokurcan et al. (2015); burnout could become present when caregivers deny suffering and have a nonexistent coping plan.

Psychological Meaning Unit 2: Overwhelmed Mentally and Physically

The psychological meaning unit 2 findings confirmed that feelings of being overwhelmed mentally and physically while caring for their ill family members during COVID-19 were experienced in some form by all eight participants. The definition of overwhelmed is to defeat completely and to give too much of a thing to someone. A further explanation can be described as an individual experiencing issues and not knowing how to deal with their experiences that may affect them strongly, thus creating a deficiency. Similar results were conveyed by P1, who stated she "had been so stressed she had to seek help for depression. "In agreement with this current study, FCA (2016) reports deficiencies in physical and mental health, social relationships, and economic conditions are often presented in adult caregivers.

Yu, et al. (2019) revealing that mental health deficiencies could be the outcome of caregiving which confirms the outcome of this current study. Notably, these deficiencies, such as stress, depression, anxiety, and a lower quality of life, are experienced by caregivers due to taking care of their loved ones Tatangelo et al. (2018). In this study P1, P2, and P6 reported crying spells and frustration while caring for their ill family members. Moen & DePasquale (2017) reported that stress could be harmful to the health of the caregiver and their responsibilities. Samsons' (2016) qualitative focus group demonstrated that Blacks experience no overall improvement compared to their counterparts concerning their quality of life, social support, or self-care. Additionally, participants indicated that feeling overwhelmed was related to a family obligation.

Psychological Meaning Unit 3: Family Obligation

Reportedly**,** the COVID-19 pandemic has caused a tremendous increase in the burden of care due to the changes and the lack of medical accessibility for families (United Nations 2020). In this study, all participants expressed the belief that caregiving is a family obligation. P1 reported, "I was under too much obligation" as far as family caregiving was concerned. P3 reported, “I know I must take care of family". The weight of the obligation to give care can depend on the caregiver's various stages in life. Parker & Fabius (2020) reports that the weight of caregiving can vary from being too much for the caregiver to bear to being comfortable and expected of them. The participants in this study were taking care of their parents, sibling, and their children. It appeared that regardless of the connection of the caregivers to the ill family members, there was an unspoken rule which stated, "a family member must be the one to take care of the ill family member."

The feeling of family obligation was reported several times during the interviewing process of this study. This study showed results like the Gassman-Pines (2020) parent-child psychological well-being study, which reported a decline in the parent's psychological well-being since the start of the COVID-19 pandemic. The family obligation experienced by these Black family caregivers created many challenges mentally, physically, and emotionally. These challenges were due to the new responsibilities such as medical homecare, and isolation precautions that were put in place since the outbreak of the global pandemic COVID-19 in December 2019, according to the World Health Organization. The result from this study revealed that many participants experienced no burden of taking care of ill family members but did feel overwhelmed due to their family obligation.

Psychological Meaning Unit 4: More Information Needed

The follow-up questions for this phenomenological qualitative study revealed that more information is needed to assist in caring for ill family members during COVID-19. Information presented during COVID-19 constantly changed because this pandemic had never been experienced worldwide. Of the participants, P3, P5, P7, and P8 believed that more information given during the pandemic could have created an easier adjustment period during the outbreak of COVID-19. Therefore, its newness made it unclear how to respond to or treat the virus or protect anyone from its effects. Wang (2020) reports more information, emotional support, and financial support may be necessary for low education and low-income families.

Psychological Meaning Units 5 & 6: Changes Needed in Caregiving

This study revealed four participants shared-needing changes in caregiving and four participants shared no changes needed at all. Polenick et al. (2020) focused on the lack of proper medical training as a demanding caregiving situation. According to this study, P1 and P2 reported changes were needed in the health care system. Also, it is necessary to point out P1 and P2 were medical professionals, a medical doctor, and a licensed practical nurse. These two professionals fundamentally believed in improving the healthcare system. Many Black family caregivers have issues with trusting the healthcare system. The lack of trust in the medical community is an unfortunate truth within the Black community, as reflected in P4 and P6 shared lived experiences. The impressions left by P4 and P6 were that asking for help may create a problem. Thus, creating the tie between needing changes in caregiving and no changes needed in caregiving. The National Alliance for Caregiving (2020) noted that Black family caregivers, compared to their counterparts, often have more demanding caregiving situations.

In summation, caregivers' burdens served as the theoretical framework for this research. This study directly supports the descriptive phenomenology to examine caregivers' burden, defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member. This study detailed the experiences of physical and mental strain or lack thereof experienced by Black family caregivers while caring for ill family members during COVID-19. This study revealed Black Family caregivers experienced no burden, although results showed that Black family caregivers were overwhelmed mentally and physically. The study also demonstrated caregiving in the Black community is a family obligation and is an expectation of the Black family caregiver. Once trust is built between medical professionals and the Black community, more information will be helpful for Black family caregivers.

Limitations of the Study

In this study, I identified several limitations. The first limitation identified in the study was that the scope of this study was limited to only participants that were Black family caregivers who cared for ill family members for a minimum of three months during COVID-19. The volunteered participants identified in this study may have experienced a different outcome than those who did not participate in this study. Many factors in this study were not looked at, such as social and economic status and the education level of the Black family caregiver, which could have resulted in a different outcome. This study did not look at each participant's spiritual connection or aspect, as it may have yielded a different result.

In this study, all participants were Black family caregivers, but this study did not look at the different cultures and diversities among Black family caregivers. For example, African American families compared to West Indies families or other ethnicities such as African families. It is possible that a more specific diverse population may have yielded a different set of circumstances and experiences, such as the different connections each culture has with its elderly population. In addition, this study's findings may be more representative of Black family caregivers caring for ill family members during COVID-19. These findings are not generalizable to the population as a whole. However, this in-depth qualitative research was aimed at gathering information on the shared experience of Black family caregivers. The data collection collected by me as the researcher could result in some possible researcher bias. However, I minimized the possibility of being biased by using strategies such as audio recordings to increase the trustworthiness of the research.

Recommendations

One of the imperative recommendations to this study would be to ensure that Black family caregivers understand the difference between being burdened and being overwhelmed as it relates to the research topic. Furthermore, recommendations for future studies would be that of using a focus group that focuses on the different dynamics of Black ethnicities of caretakers during COVID-19. This phenomenological approach is recommended to be explored further through qualitative and quantitative studies. For example, researchers may wish to explore the lived experiences of caregiver's burden among black family caregivers caring for ill family members by including their social and economic status or requiring a higher educational background. New studies could also explore the diversities of Black family caregivers as it relates to the culture of the family from which the Black family caregiver may derive, which may offer a different perspective or insight into the Black family caregiver's experiences. Additional recommendations would be to look at the social and economic status and gender differences in a quantitative study.

This qualitative phenomenological study explored the caregiver burden among Black family caregivers during COVID-19. In this current study, participants were identified as Black family caregivers with at least a 5th-grade education. It is possible that the outcome may have been very different if the Black family caregivers were participants that held a high school diploma, a college degree, or higher-level education. It may have also been more insightful to focus on a diverse group of participants who were medical professionals, as Black family caregivers providing their experiences of caregiving for an ill family member during COVID-19. The spiritual aspect of the caregiver's burden may also reflect a different outcome for Black family caregivers. The connection to a higher power may change the perspective of the Black family caregivers. For example, these participants may feel that it is a blessing to have the opportunity to care for an ill family member or believe that all things are in the hands of a higher power which may reduce stress in the provision of care.

Implications

My goal in the study was to use the caregiver's burden to better understand and gain a more in-depth insight into the lived experiences of caregiver's burden among Black family caregivers caring for ill family members during COVID-19. The preliminary findings of this study may contribute to an existing body of knowledge on caregivers' burden and its available treatments. This study may also promote further research once published in a peer-reviewed journal on caregivers' burdens among black family caregivers. Furthermore, this study may result and helping to educate and enlighten medical professionals, clinicians, and educators about the conditions that may better help with providing additional support to Black family caregivers. The results of this phenomenological qualitative study may lead to a positive social change by informing the medical and professional world of ways to assist Black family caregivers.

Conclusion

Caregivers burden is a problem that currently exists within our society. The COVID-19 pandemic created a greater caregiver burden among all families as well as Black family caregivers. The CDC in 2020 affirmed that Black caregivers needed more downtime due to the isolation and social distancing of COVID-19. The Alzheimer's Association (2019) also reported that Americans depend heavily on their family members to support their ill family members. Notably, there is very little or limited information on the caregiver burden among Black family caregivers during COVID-19. Therefore, this phenomenological qualitative study aimed to explore the lived experiences of Black family caregivers taking care of ill family members during the COVID-19 pandemic. This study was designed to offer some insight into this phenomenon.

For the study, I used Tamizi et al. (2019) caregivers burden approach. This concept reviewed the multiple areas of similarities of negative characteristics and other experiences experienced by the caregiver. The ZBI scale was used to create an interviewing tool for the purposes of this study. This interviewing tool assisted in obtaining the desired information needed to complete this study. The overall study results revealed that Black family caregivers experienced little to no burden while caring for an ill family member during COVID-19. Participants specifically reported feeling overwhelmed and having a strong family obligation to provide care for their ill family members during COVID-19. Some participants also stated that caregiving for an ill family member was not a burden but did, however, admit to feeling that assuming the responsibility of caregiving was expected of them. Participants also reported that more information was needed to provide care for an ill family member during COVID-19. Participants also had an equal difference of opinion regarding the need to have changes in caregiving and no changes required at all.

In summation, by conducting my study and possibly publishing it in a peer-reviewed journal, a greater understanding of the caregiver burden among Black family caregivers during COVID-19 might be achieved. The results of my study might support professional practices in the mental health and behavioral health field as well as clinical psychology by providing an understanding of the caregiver Burden among Black family caregivers during COVID-19. Additionally, educators and medical and mental health professionals might be provided with an awareness of the caregiver's burden that may offer a more effective teaching strategy for improving the overall outcome of the caregiver's burden. Furthermore, my study results may be instrumental in positive social change through the expanded use of this information to assist Black family caregivers.

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Appendix A: Interview Guide

Hello, I will be asking you some questions as it relates to your experience of caring for an ill family member during COVID-19.

Let's start with a question about your experiences,

1. Can you please tell me about your experiences of caring for an ill family member during COVID-19.
    a. Probe for contextual issues (e.g., illness of the person, how long, relationship to you, did they get ill during COVID)
2. Can you tell me if you felt burdened while taking care of an ill family member during COVID-19?
    a. Probe for examples. And other burdens
3. Can you tell me if you felt overwhelmed trying to meet the needs of an ill family member during COVID-19?

4. Can you please tell me if you have ever loss control over your life while providing care for your ill family member during COVID-19?

5. Can you please tell me if you felt the time spent providing care for ill family member during COVID-19 takes away from what you need for yourself?

6. Can you please tell me about the financial challenges while taking care of your ill family during COVID-19?

7. Can you tell me how you felt stressed trying to meet the needs of your monetary obligations while caring for an ill family member during COVID-19?

8. Can you please tell me how your social life has changed while taking care of your ill family member during COVID-19?

9. Can you tell me if you felt caring for an ill family member during COVID-19 affected your relationship with others? Can you give me an example?

10. Can you please tell me if you have ever felt emotionally unbalanced while taking care of an ill family member during COVID-19?

11. Can you please tell me if you have ever felt uncertain while taking care of an ill family member during COVID-19?

Follow up Questions:

1. What would you like to have experienced differently while caring for an ill family member during COVID-19?

2. What do you feel would have improved your experience of caring for an ill family member during COVID-19?

3. How has this experience changed your understanding of caring for an ill family member during COVID-19?

4. What do you feel would have assisted you to better to care for an ill family member during COVID-19?

Appendix B: Recruitment Flyer

CONTACT: Lisa King-Hodge: (lisa.king-hodge@waldenu.edu) FOR MORE INFORMATION.

If you are 18 to 65 years old and have taken care of an ill family member for at least 3 months during COVID-19, you may be eligible to participate in a research study.

Lived Experience of Caregiver Burden among Black family caregivers caring for ill family members during COVID-19.

- Volunteers 18 to 65 years old are needed to take part in a study regarding experiences common to Black caregivers taking care of ill family members for at least three months during COVID-19.
- Your participation in the study may help practitioners to better understand what Black caregivers are experiencing during COVID-19.
- As a participant in this study, you would be asked a series of interview questions so that you can share information with the researcher regarding your experiences of caregiving during COVID-19.
- If at any point you feel uncomfortable, you may choose to not answer any question(s) or may simply leave the study.
- Any responses will be collected under a fictitious name or alias, so that no one will know who you are other than the researcher.
- Participants will not receive any payment or reimbursement for time spent taking part in the study.

Location

- Telephone or teleconference Interview appointments may take up to 60-90 minutes of your time broken down over 1-to-2 days.

Are you eligible?

- Black caregivers 18 to 65 years old, who have taken care of an ill family member.
- Black caregivers must have provided care for at least three or months during COVID-19.

If you're unsure you meet the requirements, call or email:

- Researcher: Lisa King-Hodge
- lisa.king-hodge@waldenu.edu

- Study Supervisor: Dr. Ethel Perry, PHD; ethel.perry@mail.waldenu.edu

Study conducted for the completion of dissertation under Walden University

Appendix C: Consent Form

You are invited to take part in a research study about "Lived Experiences of caregiver burden among Black family caregivers caring for ill family members during COVID-19". This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study seeks 8-10 volunteers who are:

- At least 18 to 65 years of age
- Must have a fifth-grade education and is able to articulate and understand English.
- Must have access to a telephone, or other means of communication.
- Must have taken care of an ill family member during COVID-19 for three or 4 months prior to the research.

This study is being conducted by a researcher named Lisa King-Hodge, who is a PhD student at Walden University.

Study Purpose:

The purpose of this study is to gain an understanding of caregiver burden among Black family caregivers' caring for ill family members during COVID-19.

Procedures:

This study will involve you completing the following steps:

- taking part in a confidential, audio recorded semi structured interview (phone or teleconferencing) (60-90 mins)
- review typed transcripts of the interviews to make corrections if needed (10-15 minutes)
- speaking with the researcher to follow up after the interview to hear the researcher's interpretations and share your feedback (which may take 20-30 minutes, via phone or teleconferencing)

Here are some sample questions:

1. Can you please tell me if you have ever felt burdened while taking care of an ill family member during COVID-19?
2. Can you please tell me if you have ever loss control over your life while providing care for your ill family member during COVID-19?
3. Can you please tell me if you have ever had financial challenges while taking care of your ill family during COVID-19?
4. Can you please tell me if your social life has changed while taking care of your ill family member during COVID-19?

Voluntary Nature of the Study:

Research should only be done with those who freely volunteer. Everyone involved will respect your decision to join or not.

If you decide to join the study now, you can still change your mind later. You may stop at any time. "Please note that not all volunteers will be contacted to take part".

Risks and Benefits of Being in the Study:
Being in this study could involve some risk of minor discomforts that can be encountered in daily life such as sharing sensitive information. With the protections in place, this study would pose minimal risk to your wellbeing. If there are any concerns with your wellbeing contact SAMHSA's National Helpline (800) 662-4357 for free counseling.

This study offers no direct benefits to individual volunteers. The aim of this study is to benefit society by supporting professional practices in health care and mental health counseling by offering evidence as it relates to the lived experiences of caregiver burden among Black family caregivers caring for ill family members during COVID-19**.** Once the analysis is complete, the researcher will share the overall results by automatically posting online in Scholarworks (a publication of Walden University research). Sharing the Scholarworks link is an appropriate method of results dissemination for participants who are professionals in the field. However, when the abstract contains jargon that might not be clearly understood by participants, the researcher is required to develop tailored results report in layperson language.

Payment:
None

Privacy:
The researcher is required to protect your privacy. Your identity will be kept confidential, within the limits of the law. The researcher is only allowed to share your identity or contact information as needed with Walden University supervisors (who are also required to protect your privacy) or with authorities if court ordered. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. If the researcher were to share this dataset with another researcher in the future, the dataset would contain no identifiers so this would not involve another round of obtaining informed consent. Data will be kept secure using codes and password protection. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:
You can ask questions of the researcher email lisa.king-hodge@waldenu.edu. If you want to talk privately about your rights as a participant or any negative parts of the study, you can call Walden University's Research Participant Advocate at (612) 312-1210. Walden University's approval number for this study is **IRB will enter approval number here**. It expires on **IRB will enter expiration date.**

You might wish to retain this consent form for your records. You may ask the researcher or Walden University for a copy at any time using the contact info above.

Obtaining Your Consent

If you feel you understand the study and wish to volunteer, please indicate your consent by replying to this email with the words, "I consent"