

Experiences of Black American Dementia Caregivers During the COVID-19 Pandemic

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Abstract

Dementia caregivers are responsible for the daily care and management of individuals who are among the most vulnerable to the serious consequences of COVID-19. This qualitative study explores the experience of Black dementia caregivers during the COVID-19 pandemic in the United States. Nineteen Black dementia caregivers were recruited to participate in semi-structured focus groups held in April 2021. Four overarching themes were constructed during analysis: *social isolation*, *decreased well-being*, *the good and bad of telehealth*, and *challenges fulfilling health care needs*. The results indicate the experience of Black dementia caregivers overlaps with existing literature on the experiences of dementia caregivers of other races during COVID-19. These results can assist in addressing the specific needs and improving the experiences of dementia caregivers in current and future public health crises.

Keywords

care partners, public health crisis, Alzheimer's disease, African American, telemedicine

Black American dementia caregivers (hereafter: Black dementia caregivers) experience a disproportionate burden compared with caregivers of other racial groups due to the increased prevalence of Alzheimer's disease and related dementias (ADRD) and systemic bias experienced in the Black community (Alzheimer's Association, 2021). The realities of caregiving while Black may be exacerbated by the fact that Black dementia caregivers report less access to support services and more unmet needs as compared with their racial counterparts (Fabius et al., 2020). Black dementia caregivers engage in more hours of intense caregiving and delegate more of their monthly income to caregiving than their racial counterparts (Cohen et al., 2019; Fabius et al., 2020; Moreno, 2012; Wells et al., 2017). In addition to spending significant hours providing care (Cohen et al., 2019; Fabius et al., 2020; Kasper et al., 2016), Black caregiving networks usually encompass multiple individuals with limited financial resources (Dilworth-Anderson et al., 2004; Young et al., 2020). Furthermore, systemic failures and disadvantages, particularly in the health care system, place a considerable burden on Black dementia caregivers (Alexander et al., 2022). Black dementia caregivers report

less access to primary care for persons living with ADRD and indicate that a sense of disregard by and distrust in primary care clinicians (Alexander et al., 2022; Moreno, 2012) contributes to caregiver burden (Alexander et al., 2022). Among Black dementia caregivers, there is a common perception of medical discrimination when seeking health care services for themselves and their family members living with ADRD (Alexander et al., 2022).

Overall, dementia caregivers are often isolated from their family, friends, and community while living with above-average rates of stress, burden, anxiety, and depression (Schulz & Sherwood, 2008). The COVID-19 pandemic has worsened stressors associated with dementia caregiving,

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producing devastating effects for caregivers and for those they care for (Hwang et al., 2021; Truskinovsky et al., 2022). Caregivers' mental health and well-being have been negatively affected by the necessary increase in care provided during the pandemic (Leggett et al., 2022). The public health efforts designed to slow the spread of COVID-19 through social isolation and decreased life space mobility have had adverse effects on caregivers and those living with ADRD (Smaling et al., 2022). Legitimate fears of spreading the infection to family members and friends with ADRD and the restrictions set in place due to the pandemic have affected normal rhythms of life for caregivers (Borges-Machado et al., 2020; Hwang et al., 2021; West et al., 2021). These realistic concerns have produced caution about leaving the home and allowing others—such as care attendants—into the home. The restrictions of caregivers from participating in in-person health care for persons living with ADRD, and the immediate switch to telehealth, further complicated caregiving (Truskinovsky et al., 2022). Restrictions also reduced or eliminated means caregivers may have employed to engage in self-care (Borges-Machado et al., 2020).

Rates of COVID-19 infections, hospitalizations, and deaths have been demonstrably higher among Black and Latinx populations (Centers for Disease Control and Prevention, 2022b). To date, only a few reports have examined the effects of the pandemic on Black dementia caregivers. This gap seems especially salient given the much higher prevalence of dementia in the Black community (Alzheimer's Association, 2021) and the differential impact of the pandemic based on race and socioeconomic status (Centers for Disease Control and Prevention, 2022b). In this article, we seek to fill this gap by qualitatively examining the effects of the pandemic on 19 Black dementia caregivers and exploring how their experiences are similar to or different from the majority of caregivers who have been included in the recent research.

Method

A descriptive qualitative study was conducted using focus groups to capture the experiences of Black dementia caregivers during the COVID-19 pandemic. This study was implemented with low levels of interpretation of data and events from researchers to accurately analyze Black dementia caregivers' experiences (Colorafi & Evans, 2016). This study was given Institutional Review Board approval (STUDY#00002078).

Recruitment

Researchers utilized purposeful sampling techniques, specifically snowballing and convenience sampling, to recruit a sample of Black dementia caregivers from across the United States with a broad variety of caregiving experiences (Treharne & Riggs, 2015). In partnership with an external

Table 1. Focus Group Interview Guide.

Questions

1. What was your stress level before the pandemic? Currently?
2. What has produced the change in your stress level?
3. How has COVID-19 affected your interaction with the health care system?
4. What are your thoughts regarding receiving the COVID-19 vaccine? For you or your person with dementia?

advisory board (i.e., Black dementia researchers and health care experts) and community partners (i.e., nonprofit organizations serving Black communities), advertisements were disseminated throughout their networks to catalyze recruitment. Caregivers identifying as Black American adults and owning responsibility for most health system interactions within the past year on behalf of their family or friend with ADRD were eligible to participate in this study.

Data Collection

Electronic consent with digital signature was obtained through REDCap, a secure web-based software platform, after discussing the study and procedures over the phone with caregivers. Twenty-two caregivers were approached and consented to this study; however, only 19 caregivers participated in the focus groups. A member of the research team (S.G.B.) moderated two semi-structured focus group sessions in April 2021; see Table 1 for the interview guide. Each focus group session ($n = 9$, $n = 10$) lasted 1.5 hr and was audio recorded through the university's HIPPA-compliant videoconferencing platform (i.e., Zoom). Caregivers were compensated with a \$40 electronic gift card. During transcription, caregiver names and locations, such as cities of origin, were de-identified using identification numbers. Caregivers were from four states (CA, GA, IL, and NC), represented a variety of age ranges, and provided care for persons over a broad range of stages and types of dementia. To ensure confirmability and credibility, researchers provided a brief list of the group's main observations; the group was asked to clarify or add information before the focus group session concluded. The team also shared a summary of the final findings with the participants for respondent validation. In addition, team meetings were held to discuss biases, preconceptions, and thought processes during this study to achieve research reflexivity.

Data Analysis

After transcription and de-identification, a secure cloud network, available to all involved in the study, was used to store the transcripts. Researchers (S.O., K.A, F.E., and K.H.) thematically analyzed the two focus group transcripts following the six phases described by Braun and Clarke (2006). In Phase 1, team members familiarized themselves with the

Table 2. Caregiver Demographic Profile.

Participant ID	Age	Gender identity	Education	Relationship to person with ADRD	Caregiving length (years)
P1	61	Female	Graduate degree	Spouse	5
P2	59	Female	College graduate	Child	20
P3	66	Female	College graduate	Friend	1
P4	54	Male	Some college	Spouse	4
P5	47	Female	Come college	Friend	2
P6	73	Female	College graduate	Spouse	3
P7	54	Female	Some college	Spouse	5
P8 ^a	75	Female	Graduate degree	Spouse, child	8
P9	60	Female	Graduate degree	Child	11
P10	53	Male	College graduate	Nephew	1
P11	75	Female	Graduate degree	Spouse	17
P12	62	Female	Graduate degree	Child	8
P13	46	Female	Graduate degree	Child	8
P14	51	Female	Graduate degree	Child	1
P15	72	Female	Some college	Spouse	8
P16	46	Female	Some college	Child	6
P17	54	Female	Graduate degree	Child	11
P18	66	Female	Graduate degree	Child	25
P19	68	Female	Graduate degree	Child	3

Note. ADRD = Alzheimer's disease and related dementias.

^aCaregiver was caring for more than one person with ADRD.

data by repeated reading of the transcripts. Phase 2 consisted of manually generating 13 initial codes, later condensed to 10 after team discussions. Next, team members organized quotes from the transcripts into categories created by the final codes. In Phases 3 and 4, four overarching themes were developed and refined from the initial code groupings. In Phase 5, the themes were named and defined. Phase 6, producing the report, was done to tell the story of Black dementia caregivers of persons with ADRD during the COVID-19 pandemic.

Results

Nineteen Black dementia caregivers participated in one of two focus groups. The mean age of the caregivers was 60 years ($SD = 9.5$), and the majority of the participants were female (89.5%, $n = 17$). The average number of years spent caregiving for a person living with ADRD was 7.7 years ($SD = 6.5$). All caregivers had some form of college education and approximately half of the sample had a graduate degree (53%, $n = 10$). See Table 2 for caregiver demographic information.

Themes

Four overarching themes were constructed during descriptive qualitative analysis of the transcripts: (a) *social isolation*, (b) *decreased well-being*, (c) *the good and bad of telehealth*, and (d) *challenges fulfilling health care needs*.

See Figure 1 for a graphic representation of the codes and derived themes.

Below, we fully describe each of these themes, illustrating them with selected quotes from focus group participants and their de-identified study ID designators.

Social isolation. Overall, caregivers agreed that the onset of social isolation due to the pandemic was challenging for themselves and their family members living with ADRD. Stressing the toll that social isolation imposed, one caregiver stated,

Yeah, it [the pandemic] does get overwhelming. It's depressing and just being in COVID, during that isolation, you need that other human interaction. (P14)

The constant lack of human interaction and time spent in quarantine increased caregivers' level of stress. One caregiver shared how social isolation had affected their household, describing the environment as "more agitated," experiencing "more arguing," and noting that the "atmosphere in the home is very tense" (P11).

Caregivers primarily focused on the effects of isolation on their family members living with ADRD. One caregiver expressed how difficult it was for her mother living with ADRD to not have much human interaction other than with her and providers from the care team; they believe other persons living with ADRD were affected in this way during the pandemic:

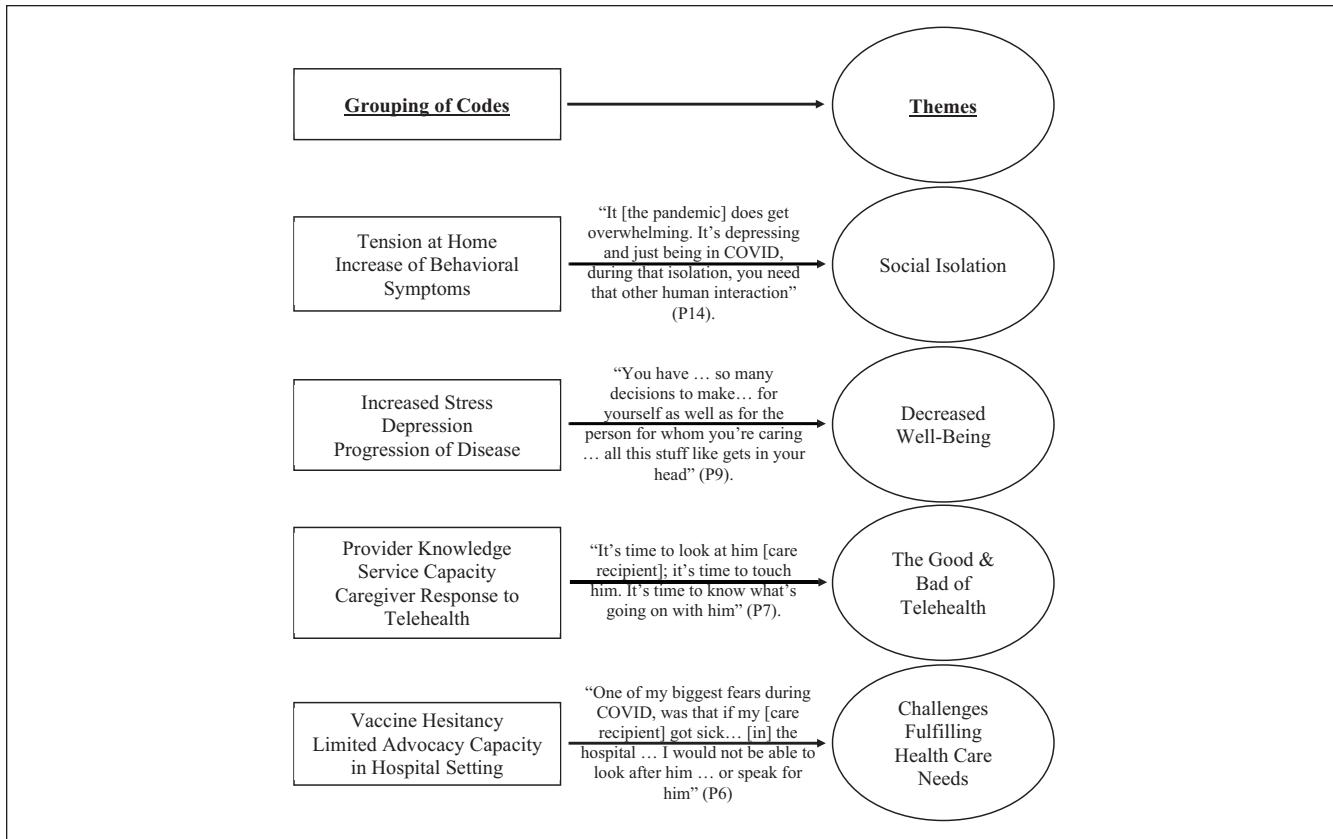


Figure 1. Identification of codes and themes.

I think . . . it was the downfall of her . . . I saw how she declined through this whole crisis. I think a lot of it was because she could not interact with anyone other than myself and her caregiver . . . I'm sure she was not alone in this. (P8)

Another caregiver described that the lack of human interaction was especially challenging for her mother living with ADRD who has an extroverted personality:

I think the difficulty with the pandemic became . . . She likes to be out and about and, you know, go different places, and see different people. And so I think that was a huge challenge, and I was very . . . protective of allowing visitors, or her to go out at the very beginning of the pandemic . . . it was just us in the house, and I'm sure she was sick of it. (P13)

Decreased well-being. Caregivers recall the negative effect of the pandemic on them and their family member's well-being. The pressure of living in another state while still providing care had caused a caregiver to feel drained:

My mental status itself has changed . . . I am an only child and I'm split between two states. . . and I am the caregiver. I . . . have children, but you can't always depend on anyone else . . . So, for me, it really started to drain me mentally and I had to find a way to find myself. (P7)

Other caregivers discussed becoming depressed because they felt "overwhelmed" by all that had been brought on by the pandemic and no longer having an "outlet" (P6). Another spoke about being overwhelmed due to increased decision-making:

You have . . . so many decisions to make. And you have to make decisions for yourself as well as for the person for whom you're caring. And so, all this stuff like gets in your head. (P9)

When discussing how the pandemic decreased well-being for persons living with ADRD, a few caregivers indicated that they felt the pandemic had heightened their family member's dementia-related behavioral symptoms. One caregiver shared her experience of caring for her husband living with ADRD:

I feel that during the COVID time that it did expedite more of the symptoms of the dementia or Alzheimer's. . . . He was—used to be—very sociable. (P6)

Another reported that before the pandemic, their mother living with ADRD was "a lot more independent" (P13). As the caregiver, they are now "fairly stressed" because her mother's "behaviors have increased and become more significant . . .

particularly just being oppositional and argumentative . . . that has increased a lot" (P13).

The good and bad of telehealth. Caregivers had mixed reactions to the sudden shift from in-person health care visits to the extensive use of telehealth methods. One caregiver reported, "with the pandemic, everything had to be on Zoom, and so it got a lot more stressful . . . you have a system in place and it just gets wrecked" (P5). Confusion associated with the change seemingly affected caregivers and clinicians alike. One caregiver described their experience as horrible, "the technology, all of the doctors, like they can't talk to each other through their technology" (P14). They went further to emphasize the increased impersonality they felt:

When they did finally get on it and we started having appointments via telehealth, they only wanted to do the phone portion. They didn't know how to access the video. I'm like . . . "I'll teach you how to do that! You know, I would like to see you." (P14)

One caregiver stated, "I think it's [telehealth] getting better, but once again, I'm still kinda struggling. What happens when you're not in the same state" (P9).

There were positive experiences associated with telehealth. One rural caregiver described their experience:

And she's [the doctor] kinda no nonsense. So, it was no surprise to me that her office would be extremely efficient, even through telehealth, and she was. We prefer in person visits, but that wasn't plausible. But I think they did an outstanding job in terms of [mustering] services for us during- and now . . . I've been very pleased. (P1)

Caregivers also identified limits to telehealth. Many perceived their experience as being adequate until they "thought it was really important that we needed to go in to see [the doctor]" (P6). A caregiver went into further detail describing their process:

Didn't have any problems [with telehealth] . . . Now the last appointment that we had . . . they asked did we want a telehealth-teledoc appointment, and I chose not. I said, 'it's time to look at him; it's time to touch him. It's time to know what's going on with him.' And at that point we were able to find some things that were going on with his blood pressure that she may not've even noticed if it was just virtually [done]. (P7)

A caregiver echoed this opinion by saying, "I think my husband just needed to be in the doctors' office, quite frankly" (P8).

Challenges fulfilling health care needs. Caregivers have found themselves uniquely challenged during the COVID-19 pandemic in carrying out key responsibilities related to navigating the health care system and health care decision-making

on behalf of their family member living with ADRD. Advocating for a family member living with ADRD in a health care setting is a primary role of caregivers, many of whom reported their ability to do so was severely constrained by COVID-19 restrictions. One caregiver was frustrated by not knowing "what he [husband living with ADRD] experienced [in the hospital] because I was not allowed to be there." (P15) Another shared that

One of my biggest fears during the, the COVID, was that if my husband got sick . . . I would not be able to go to the hospital, and I would not be able to look after him . . . or speak for him. (P6)

Caregivers serve as decision-makers, but the pandemic added painful complexity to the decisions having to be made, such as decisions regarding vaccination. One caregiver indicated that a key factor in deciding whether to get vaccinated or not was "whether anything could . . . take me off my feet" (P9) and therefore affect their ability to provide care. The decision to have their family member living with ADRD vaccinated was also complex, having perhaps less to do with hesitancy about the vaccine than the practical issues surrounding vaccination. Another caregiver stated,

I went to take the first one, and they had indicated there would be a line, and I was thinking about my husband. And I got there and I said, "There's no way he's gonna stand in this line and no way he's gonna keep the mask on. So, I held back from getting it. (P8)

Discussion

This study aimed to fill a gap in the literature by exploring the perceptions of Black dementia caregivers concerning the effects of the COVID-19 pandemic and the restrictions imposed by regulatory and voluntary measures designed to protect individuals and limit spread of COVID-19. The results of this study suggest that the onset and sustained presence of COVID-19 altered the Black caregiving experience in relation to social isolation, well-being, telehealth, and addressing the health care needs of family members living with ADRD. What is striking about the themes identified in this study is how readily they might be submerged in findings of the broader, that is, majority White, COVID-19 dementia caregiving experience (Borges-Machado et al., 2020; Hwang et al., 2021; Smaling et al., 2022; Truskinovsky et al., 2022). There seems to be a universality to the caregiving experience during COVID-19; thus, the findings of this study suggest that the Black caregiver community experience overlaps with existing literature on the experiences of caregivers of other races.

The experience of Black dementia caregivers during COVID-19 should be placed in the broader context of the social determinants of health and the disparities that Black

Americans, and those of other racial/ethnic groups, face in managing their health, providing care for persons living with ADRD, and interacting with health care (and other) systems. From a public health perspective, it has become increasingly evident that Black Americans bear a greater burden of poor health than other population groups. Black dementia caregivers began behind the health curve before the pandemic (Alexander et al., 2022). In this study, caregivers' reports of decreased well-being must be understood in terms of the existing racialized disparity.

Before the COVID-19 pandemic, social isolation had been linked to worsening mental health and well-being in older Black Americans (Chatters et al., 2020). Caregivers in this study expressed feelings of stress in themselves and their family member living with ADRD. This study confirms the existing literature, highlighting that the need for social distancing causes challenges for caregivers and can exacerbate or lead to a state of decreased well-being among racially and ethnically diverse caregivers (Chatters et al., 2020; Smaling et al., 2022; West et al., 2021). Previous research correlates dementia caregiving with a predisposition for increased rates of stress and other mental health issues (Borges-Machado et al., 2020; Truskinovsky et al., 2022). Caregivers in this study reported feeling stressed prior to the pandemic, but many expressed an uptick in stress after navigating care during the COVID-19 pandemic, stating they felt mentally drained, overwhelmed, and depressed.

Caregivers' perceptions of heightened symptoms and decreased well-being in their family members with ADRD are consistent with previous research, which delineates the snowball effect of home confinement (Borges-Machado et al., 2020). Confinement and isolation contribute to unfavorable behavioral and psychological symptoms in persons with cognitive disorders (Borges-Machado et al., 2020). Worsening symptoms of dementia have been continuously reported during the COVID-19 pandemic (Hwang et al., 2021). Caregivers in this study reported the need to be more attentive to their care recipients, who experienced increased behavioral symptoms, such as agitation, opposition, and argumentation in tandem with COVID-19.

More research is needed to validate the advantages and disadvantages of using telehealth in people living with ADRD (Hatcher-Martin et al., 2020). Our analysis did not suggest that the use of telehealth improved the relationship with clinicians in the health care system. Participants did not report that these interactions were any less biased or dismissive than in-person encounters. In this study, caregivers referred to telehealth as stressful and difficult, but efficient. Despite hearing a mix of good and bad experiences among participants, caregivers supported the value of using telehealth services to address the health care needs of their family members living with ADRD during the pandemic.

The difference in experience with telehealth seemed most stark based on provider knowledge and interaction on the

virtual platform. Many caregivers expressed how telehealth worked up to a certain point but requires balancing with in-person care. Caregivers mentioned a lack of knowledge on the provider's part regarding fully utilizing videoconferencing platforms and that organizational protocols were not suited to telehealth constraints (lack of consistent protocols). There was also the perception that health care providers paid less attention when on this platform than would be expected in an in-person setting. Caregivers described concerns and limitations with using telehealth when caregiving from a distance. Navigation of regular care across state lines presents new sets of challenges, but with telehealth, it can become even more complicated. When using telehealth, many clinicians cannot administer services if the recipient is not in the same state due to rules and licensing requirements in state and federal policies (Health Resources & Service Administration, 2021).

Our study does not account for the underlying disparity affecting the use of telehealth, as all caregiver participants had the ability to connect with providers online. Telehealth has not been as much of an option for Black dementia caregivers as it has been for other caregivers. Whether for reasons of location or economics, Black Americans are less wired in, with less access to home broadband services than their White counterparts, and report less internet usage than Whites and Hispanics (Pew Research Center, 2021). There have been limited studies on caregiver acceptance and satisfaction with telehealth, and now, with the expanded use of the service and reports of dissatisfaction derived from this study, there is an even greater need to assess caregiver, persons living with ADRD, and provider experience with telehealth services.

Due to the pressures of COVID-19 combined with the daily challenges of managing and providing care for a person living with ADRD, caregivers in this study experienced specific constraints to caregiving during COVID-19. COVID-19 created a dynamic for some where family caregivers were more heavily relied on for providing and managing daily care for family members with ADRD (International Family Nursing Association, 2020). Caregivers in our study found it difficult to be the sole caregiver throughout the pandemic for two main reasons: the inability to stay with their family during hospitalization and vaccine hesitancy. Data published during the pandemic heighten fears, validating Black dementia caregivers' concerns. As noted, Black and Latinx individuals have experienced much higher rates of COVID-19 infection and hospitalization than White individuals (Centers for Disease Control and Prevention, 2022b). Therefore, concerns about potential hospitalization are justified. While many hospitals have reported overcrowding and staff, equipment, and supply shortages at the peak of pandemic waves, hospitals serving low-income racial and ethnic minority communities appear to have been most severely affected (Sullivan & Jingnan, 2021). Information regarding the socioeconomic status of the caregivers participating in this study was not

gathered; therefore, it is unknown whether the sample was utilizing hospital systems facing such challenges. Caregivers mentioned delaying taking their family members living with ADRD to a hospital because they would not be able to advocate for or provide care for them once admitted to the hospital due to COVID-19-specific protocols. The difficulties of communication and advocacy in such situations likely affected all caregivers, but these pandemic conditions only worsened historical challenges faced by Black dementia caregivers.

The issue of vaccine hesitancy was raised mainly due to concerns of one experiencing symptoms such as fever, muscle pain, and headaches soon after receiving the vaccine (Centers for Disease Control and Prevention, 2022a). In our study, caregivers without additional support or access to respite care were worried they may get taken off their feet once vaccinated, potentially leaving their family member living with ADRD without their usual standard of care. This was an issue that multiple caregivers stated as to why they did not immediately get vaccinated; it highlights how the pandemic exacerbated the lack of access to supportive services for Black dementia caregivers. Differences in vaccine hesitancy during COVID-19 exist between racial and ethnic groups (Beleche et al., 2021). Thus, while caregivers in this study may have worried about the effects of vaccination, they may also have been affected by difficulties in obtaining the vaccine.

Strengths and Limitations

A strength of this article is the inclusion of an advisory board, which is vital when promoting community engagement in research while understanding the community's culture (Connors et al., 2019; Stewart et al., 2019). In addition, we confirmed the preliminary observations and final findings with the focus group participants. This involvement from the participants assisted with the conceptualization of findings and provided an outline for study implications. Another strength of this study was exploring this phenomenon within one racial/ethnic group, which allowed for a detailed exploration of the experience of Black American dementia caregivers. Despite the above-mentioned strengths, this study has various limitations. Caregivers were recruited from a convenience sample. Many caregivers had a prior connection with the principal investigator, possibly resulting in selection bias. Second, the educational range of the focus group participants was relatively homogeneous, with the majority having attended a higher education institution, limiting generalizability. In addition, focus group questions may have been leading, possibly resulting in biased responses. Finally, the focus groups were held virtually due to COVID-19 precautions. While this allowed for a more geographically diverse sample to participate, the virtual platform was not highly accessible by all due to a lack of internet access.

Future Research and Implications

Further research can illustrate the similarities and differences Black dementia caregivers face during public health crises compared with their racial counterparts. More specific probing would determine the extent of and ways in which their experiences relate to their being Black in a context of disparities and discrimination. Examining the effects of the pandemic on traditional support resources (family, community organizations, churches, etc.) should be pursued as well. Ideally, future researchers will target a more educationally diverse sample. In summary, these study findings can ultimately lead to the development—and testing—of culturally tailored educational programs and interventions directed at Black caregivers of persons living with ADRD to manage care during a public health crisis.

Conclusion

Understanding the experience of Black dementia caregivers during the pandemic is vital in understanding how their experiences are similar to and different from the broader caregiving population. The greater emotional, physical, and financial challenges experienced by Black dementia caregivers are often overlooked (Kasper et al., 2016), leading to missed opportunities for culturally relevant programs and services during a pandemic. This study highlights what resources and support mechanisms are necessary to enhance the experience of this group of caregivers and others in present and future health crises.

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