

Caregiving Among Older Black Same-Gender-Loving Women During the COVID-19 Pandemic: Findings From Qualitative Research

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Abstract

Background and Objectives: Few data on caregiving during the coronavirus disease 2019 pandemic use an intersectional lens to attend to how multiple social categories, such as gender, age, race, and sexual orientation, shape caregiving experiences. This analysis sought to explore caregiving experiences of aging Black same-gender-loving women.

Research Design and Methods: Sixteen focus groups were conducted with 4–8 participants each ($N = 102$) from across the United States. Audio-recorded discussions lasted for approximately 90 min and were transcribed verbatim. Two analysts coded transcripts for discussions related to caregiving and used content analysis to identify themes.

Results: Participants engaged in caregiving for children, parents, family, friends, and neighbors. They provided physical, economical, instrumental, and/or secondary caregiving; and sometimes received care themselves. The pandemic heavily affected their stress level and mental health as well as their intimate partner relationships. Discussions mostly offered descriptions of increased caregiving difficulty caused by the pandemic. However, a few participants identified ways the pandemic made caregiving easier; changed caregiving without making it easier or harder; or thwarted their ability to provide care.

Discussion and Implications: Older Black same-gender-loving women described some pandemic caregiving experiences that diverged from the existing literature, demonstrating the importance of considering how gender, race, age, and sexual orientation affect caregiving experiences during a pandemic fraught with health inequities. Ensuring the multiply marginalized caregivers have access to the practical and emotional support they need is critical for advancing health equity and preparing for future pandemics.

Keywords: African American, Focus groups, Intersectionality, Sexual minority

Background and Objectives

Caregiving has been defined as providing care to another person who needs assistance with social or health needs, including daily living activities, chronic illness, emotional support, or disability (CDC, 2019). It is estimated that 1 in 5 (21.3%) adults in the United States provide unpaid care to someone experiencing sickness or disability (AARP & NAC, 2020). Informal caregivers have been described as the backbone of the care system (CDC, 2019)—contributing an estimated \$470 billion (Reinhard et al., 2019) in unpaid physical, emotional, economic, and instrumental support to nearly 53 million people per year in the United States (AARP & NAC, 2020).

In the United States, the role of caregiver is more pivotal to the identities of women than men (Williams et al., 2017). In a systematic review of studies exploring informal caregiving,

Zygouri & colleagues (2021) concluded “gender ideals of the feminine nurturing role” influenced how women viewed, navigated, and coped with caregiver roles (p. 1). Women were more likely than men to view caregiving as a normative part of their family life. Correspondingly, in the United States, an estimated three in five women (65%), in comparison to two in five men (39%), provide unpaid care to someone in their lives (AARP & NAC, 2020).

Black adults account for 24.3% of caregivers in the United States, of whom most are Black women caring for a parent, spouse, or grandparent (AARP & NAC, 2020; CDC, 2019). Crenshaw’s (1990) intersectionality framework provides a way to conceptualize how history, culture, social determinants of health, and place shape the caregiving experiences of Black women (Dilworth-Anderson et al., 2020; Walton & Boone, 2019). Further, Naqvi et al. (2020) contend “identities like sex and race interact multiplicatively, creating distinct

experiences of advantage and disadvantage for each subgroup”; and thus should always be considered when examining the circumstances of Black women (p. 70). Although most caregivers experience both emotional distress and psychological benefits in relation to their caregiver role (Roth et al., 2015), Black women consistently perceive caregiving more positively than their White counterparts (Fabius et al., 2020), despite typically experiencing lower household incomes and higher burdens of care (AARP & NAC, 2020).

Bowleg (2008) theorized sexual identity as inseparable from other identities (e.g., race/ethnicity, gender), and inhabiting multiple marginalized social positions influences life circumstances. Lesbian, gay, bisexual, transgender, and queer (LGBTQ) adults experience more concern about unmet care needs than non-LGBTQ adults (Fredriksen-Goldsen et al., 2011) and may rely more heavily on informal systems of support due to having no children (Brennan-Ing et al., 2014; Orel, 2017) or to avoid experiencing discrimination from intolerant formal caregivers (Choi & Meyer, 2016; Putney et al., 2018). In a qualitative exploration of familial support among Black lesbian couples, Glass & Few-Demo (2013) found that Black lesbians may adapt their identity expressions to maintain functional relationships with their familial and community (e.g., church) networks. Black lesbians may navigate familial and community homophobia by limiting contact between LGBTQ social supports and their families.

There is an unequivocal need for more research on the lives of aging Black lesbians (Adams & Poteat, 2016; Fredriksen-Goldsen et al., 2017), including caregiving (Schwartz et al., 2021). In this study, we used a qualitative approach to explore caregiving among aging Black same-gender-loving women during the coronavirus disease 2019 (COVID-19) pandemic.

Research Design and Methods

We conducted an inductive content analysis (Faria-Schützer et al., 2021) of focus group discussions (FGDs) with Black cisgender (i.e., someone whose gender aligns with their assigned sex at birth) same-gender-loving women as part of a community-engaged participatory study involving the University of North Carolina School of Medicine (UNC) and ZAMI NOBLA: National Organization on Black Lesbians on Aging. The parent study aimed to broadly explore the COVID-19 experiences of aging Black same-gender-loving women and inform future programming by ZAMI NOBLA. Inductive analysis was used to draw broader interpretations from the FGDs. The study team met biweekly during data collection, coding, and analysis for peer debriefing and data validation.

Criterion sampling (Moser & Korstjens, 2018) was used to identify cisgender Black same-gender-loving women across the United States. Participants were recruited via the ZAMI NOBLA Facebook page and listserv. Participants were encouraged to recruit others within their social networks. We conducted 16 FGDs using HIPAA-compliant Zoom videoconferencing software between July and December 2020. FGDs were organized using a semi-structured guide, audio-recorded, and transcribed verbatim. Each FGD included 4–8 participants, 1 facilitator, and 1–2 notetakers.

Eligibility criteria included age \geq 40 years; female sex assigned at birth; identity as a Black or African-American woman; identity as lesbian, gay, same-gender-loving, bisexual, pansexual, or queer; and residence in the U.S. FGDs lasted 90 min, and participants were remunerated with \$50. After

their FGD, each participant completed a brief online survey with demographic information (Table 1).

Reflexivity

FGDs were led by a cisgender Black lesbian, and both note-takers identified as cisgender Black lesbians. All coauthors, including coinvestigators and analysts, identify as cisgender women. Four of the coauthors are Black; however, neither coder identifies as Black. Five coauthors are sexual minority women. During biweekly study team meetings when coding and analysis were discussed, coders and coinvestigators reflected on how their identities and social locations contributed to data interpretation.

Ethics

The Institutional Review Board at UNC provided ethical approval for this study. Each participant ($N = 102$) provided verbal informed consent prior to the start of the discussion, and names were changed to numbers prior to participants' entry into the Zoom room to promote confidentiality. Funding was provided by the Urgent Action Fund for Women's Human Rights and the National Institute on Aging, which played no role in the collection, interpretation, or presentation of the data.

Analysis

Each transcript was coded in ATLAS.ti Windows (2022) by two independent analysts using *a priori* codes related to caregiving (Section A in the Supplementary Material). We defined caregiving as providing support without remuneration. The FGD guide did not include specific questions about caregiving. However, upon reviewing the transcripts, the study team identified caregiving as an emergent topic. Coders met regularly to discuss and expand codes and to debrief with the larger study team, including the FGD facilitator and note-takers. Inter-coder reliability was 0.782 using Krippendorff's c - α -binary. Data were explored across and within codes to identify patterns and themes (see analytic matrices in Section B in the Supplementary Material). Memos were used to organize the analytic process. To enhance credibility, regular debriefings were held with the data analysts, ZAMI NOBLA, and other community leaders in LGBTQ aging and/or caregiving. Feedback from these meetings informed the study results. The steps of data analysis are outlined in Figure 1.

Results

The average participant age was 57 years. Most participants had a master's (41%) or bachelor's degree (29%), and most were employed (44%) or retired (31%). Almost half (46%) were single, and 26% were married. Their households included partners (43%) and children (21%); only 11% shared a household with a parent. Additional participant characteristics are in Table 1. Identified themes are summarized in Table 2 and described later. Some themes offered context, although others were topics related to the experience of caregiving.

Contextual Theme 1: Care Recipients

Care for parents and children was most commonly described. Participants who provided parental care, did so most often for their mothers. Participants also cared for school-age and

Table 1. Demographic Information for Focus Group Participants (*N* = 102)

Characteristic	Category	Result
Age in years	Min	40
	Max	80
	Mean	57
		<i>n</i> (%)
Race	Black or African American	100 (98.03%)
	Prefer not to answer	1 (0.98%)
	Missing	1 (0.98%)
Sexual orientation ^a	Lesbian	88 (86.27%)
	Queer	12 (11.76%)
	Same-gender-loving	10 (9.80%)
	Gay	8 (7.84%)
	Bisexual	3 (2.94%)
	Another identity not listed	2 (1.96%)
	Pansexual	1 (0.98%)
	Gender ^a	Female or women
	Another identity	4 (3.92%)
	Gender nonbinary or genderqueer or genderfluid	3 (2.94%)
Education	Master's degree	42 (41.17%)
	Bachelor's degree	30 (29.41%)
	Doctoral	10 (9.8%)
	Some college	6 (5.88%)
	Associates degree	5 (4.9%)
	Other	4 (3.92%)
	Professional degree (e.g., MD, JD)	4 (3.92%)
	Missing	1 (0.98%)
Employment	Employed	45 (44.11%)
	Retired	32 (31.37%)
	Self-employed	13 (12.74%)
	Unemployed	8 (7.84%)
	Other	6 (5.88%)
	Part-time employed	6 (5.88%)
	Receiving unemployment	1 (0.98%)
Current relationship structure	Single	47 (46.07%)
	Married	27 (26.47%)
	Other	18 (17.64%)
	Widowed	1 (0.98%)
	Missing	9 (8.82%)
Household composition	Partners	44 (43.31%)
	Children	21 (20.58%)
	Friends	12 (11.76%)
	Parents	11 (10.78%)
	Other	10 (9.8%)
	Siblings	10 (9.8%)
	None of the above individuals live in my household	37 (36.27%)

^aPercentages do not sum to 100% because participants were able to select more than one response.

adult children as single parents, coparents in separate homes, and/or stepparents.

Participants discussed adjustments they had to make although caring for children during the pandemic. Some participants found it challenging to balance their own online work with children's online school and to find a space in their homes for children to attend school online. Some participants

faced challenges of coparenting in separate homes and expressed concern that sending children between homes would increase the risk of acquiring COVID-19. Participants mentioned the need to find ways to keep the children engaged during the pandemic when they could no longer meet with friends indoors and described the labor involved in teaching children to protect themselves from COVID-19.



Figure 1. Process of thematic qualitative analysis of focus group discussions.

Participants who provided care for their mothers discussed a variety of situations that required their care, including dementia, illness, and/or disability. Participants described joy in caregiving as well as challenges and frustrations. Several participants described the need to be especially careful so as to protect their mothers from COVID-19. Some participants described ways in which their sexual orientation impacted their experience of caregiving. For example, one participant stated:

Being a lesbian, I noticed in my straight family, my social life is not as important as my brothers and sisters, who are married to the opposite sex. So, the validity of me having a relationship isn't important, you know, so my job is to

take care of my mother, period. And so, my life is not important as theirs are. So that's real for me...I'm tired. I go to the store, I'm shopping, I'm cleaning, I'm fixing, and I'm taking care of two houses and a dog and I have a girlfriend, so, you know, I need to show up for those things... lesbians are basically killed in an invisible place as far as our real personal feelings are concerned. And don't get the accolades or the 'you've done such a great job.' No, they'll do anything in my family to not recognize my sacrifices. (Participant 100, FGD 2020.11.30)

Participants provided care for other kin, including siblings, in-laws, nieces, and grandchildren, in a variety of ways. One participant described using her retirement money to buy a

Table 2. Topical and Contextual Themes

Type	Topic	Themes
Contextual	–	1. Care recipients: caregiving is provided to a range of recipients, including children, parents, family, friends, and neighbors.
	–	2. Types of caregiving: caregiving was physical, economical, instrumental, and/or secondary.
	–	3. Care received: Black same-gender-loving women were not always caregivers but also at times recipients or engaged in mutual caregiving.
Topical	Impacts	1. Stress and mental health 2. Intimate partner relationships
	Changes	1. More difficult 2. Less difficult 3. Not more or less difficult 4. Thwarted

guesthouse for her niece to stay during the height of the pandemic. Another participant allowed her sister-in-law to come to her house to access the internet—despite concerns about COVID-19. Most participants described family caregiving as their responsibility and readily made adjustments to provide the care needed.

Caregiving for nonkin took a variety of forms. For example, one participant described efforts to provide COVID-19 education for her friends. Others picked up food boxes and delivered them to people in their communities. One participant shared the financial benefits she received with other people in need, “I’ve just felt that so many people were suffering worse than I am. And, matter of fact, when it first started happening, I had benefits. I gave half of everything I took in to other people” (Participant 95, FGD 2020.11.30).

Contextual Theme 2: Types of Caregiving

Participants discussed economic, instrumental, and physical caregiving. Most participants who provided economic caregiving noted the need to provide more support since friends/family/community had lost jobs or other sources of income due to the pandemic. Some participants provided care over the long term, generally for partners or family to whom they felt kinship obligations. Others provided short-term care or a one-time donation—generally for nonkin. Participants providing one-time or short-term care described feelings of empathy and were pleased to be able to offer this support. However, providers of long term, economic support often described financial and psychological stress due to the pressures to support both themselves and those for whom they provided care.

Instrumental caregiving included allowing family members to move in during the pandemic for safety or to access services. One participant ran all errands for the household because her partner had conditions that increased her vulnerability to COVID-19. Only two participants discussed physical caregiving, which included conducting blood tests on their mother (Participant 6; FGD 2020.07.06) and needing to physically carry her mother out of bed, around the house, and to medical appointments (Participant 113; FGD 2020.12.12). Both noted that these were new roles they had taken on since the start of the pandemic.

Secondary caregiving was also discussed. Despite not being the primary caregiver, participants noted concern about the

welfare of other caregivers and those being provided care by other informal caregivers. When their partner was the caregiver, participants expressed concern about inadvertently exposing care recipients to COVID-19. For some, this led to a shift in their behaviors, such as practicing more stringent isolation. One participant stated: “I understand that this is precious time with her mother at this age and would never do anything to jeopardize that” (Participant 54, FGD 2020.09.19). Participants who expressed concern that the primary caregivers may be behaving in ways that put the care recipients’ safety at risk, usually referred to other family members who were primary caregivers.

Contextual Theme 3: Care Received

Receipt of economic and/or instrumental care was also discussed. Participants described receiving a one-time monetary donation or help accessing health care. They also described receiving sustained support, such as food assistance, via mutual aid or social service organizations. However, support received from organizations was sometimes unacceptable:

Then another thing I noticed is that some of the support that they do offer us, YOU have to make them adapt for yourself, you know what I mean?...They’ve offered me Meals on Wheels. You know, no ethnic foods? No, you know what I mean? None of that. So I refuse it, you know. (Participant 104, FGD 2020.12.09)

Sustained care from loved ones often took the form of mutual caregiving. For example, several participants indicated that living with a partner made coping with the pandemic easier because each person was less isolated, provided emotional support to one another, divided errands and chores, and got to know one another better. Other participants noted similar mutual benefits from living with family members. Some participants who lived alone described giving support to and receiving support from their neighbors. Although taking care of her sick mother, one of the participants indirectly received emotional care as well:

Hospice teaches that you have to take care of yourself in the process of taking care of them. So, I just focus more now on her comfort in her emotional wellness, and I give it back to myself at the same time. (Participant 83, FGD 2020.11.08)

Topical Theme 1: Impacts

Stress and mental health

Many caregivers described the added stress the pandemic brought to their lives, whether they were already providing care for others or started providing care during the pandemic. Although discussions of caregiving stress were common, the stress of caregiving for parents and/or children was raised most frequently.

Caregivers expressed fear of acquiring COVID-19 and jeopardizing the health of their loved ones. They discussed the extra effort involved in trying to minimize that risk. For example, one participant described self-imposed isolation, “[I don’t] allow people in my space because I’m taking care of my mother and she’s ill” (Participant 83, FGD 2020.11.08). Another participant shared her experience confronting someone who tried to get too close to her.

I’ve seen people walk up to me. A man walked up to me at Walmart, threw his arms around me, talk[ing] in my face, and said ‘Don’t be afraid. I don’t believe in it anyway.’ I pull back and I said I take care of [my] mother. You know, it’s not about me. It’s about my mother. You can’t give me something I could take home to her. (Participant 100, FGD 2020.11.30)

These efforts took a toll. One participant described the following experience of returning from a trip:

I got back and I felt concerned, and I actually went and was tested because of it, because not only was I concerned about myself, my mother, who’s 88, lives with me, and I was really more concerned [about] what I may have brought home to her. So, my casualness then turned to stress. (Participant 6, 2020.07.06)

Participants discussed the impact on their mental health and stress levels due to pandemic-related changes in household composition and duration of time spent in the home together. One woman described the impact on her partner in this way:

I think the stress of [her son] being home with her for so many months, 24 hours a day, seven days a week, really escalated her drinking. And then her mom moved in. And I think that really impacted and escalated her drinking. (Participant 85, FGD 2020.11.15)

Another participant noted: “My mental health actually plummeted after COVID, because my daughter was going through a lot mentally, because she wasn’t at school” (Participant 51, FGD 2020.08.16). A participant who lived with her wife and two children described the impact of pandemic restrictions this way:

Thinking about what the dynamics are going to look like in the house now that everybody was in the house, that was a whole another other and trying to adjust to just the energy because it was impacting all of us in different ways. So that is the way in which mental health has impacted me. (Participant 31, FGD 2020.07.18)

Another participant described the difficulties of managing her daughter’s school and her job:

I always wanted to work from home, but I never thought, like, under these circumstances, where they’re here all day with me, so just seeing how we’re going to manage that. Yeah, so that’s a new concern. I’m glad I have the option, though, but just seeing how that’s gonna go, that comes with a different kind of stress. (Participant 33, FGD 2020.07.20)

Another participant noted: “So, it’s like my wife, my mother, my adult daughter is here and she was working as well. So, it was like a lot of added stress and pressure because everybody’s working, everybody’s doing something” (Participant 32, FGD 2020.07.18).

Participants who were not the primary caregivers described concerns about the behaviors of other caregivers. For example, one participant discussed concerns about the behavior of her cousin, who provided care for her grandfather. She was worried about her grandfather’s health and infuriated by her cousin’s choice to go to parties, thereby exposing himself and therefore her grandfather to the risk of acquiring COVID-19: “I lost it. I stayed calm I didn’t call him right away. I sat on it for two days, but it turned out well, but I had to have that talk with him” (Participant 16, FGD 2020.07.13).

Other participants experienced stress and negative mental health effects from facing resistance to their efforts to educate others about the pandemic. One participant described this experience of trying to convince her friends to stock up on food during the pandemic:

I was telling them, ‘Make sure you have two to three weeks of food in your house’ and they were like, ‘Yeah, yeah. You’re overreacting.’ In terms of my mental health, I think that kind of has had an effect on me.” (Participant 2, FGD 2020.07.06)

Caregiving for people with dementia presented specific challenges. One participant described caring for her brother with dementia this way:

He knows sometimes to wear his—you know, he can still wear his mask. And he’s kind of aware of this corona stuff. But it hasn’t kind of locked into his head. I mean, you can tell him one day, ‘Oh, because of corona.’ And he’s like, ‘What are you talking about?’ But then he’ll say something, you know, ‘Oh, I gotta wear my mask’ or something...I worry about people with dementia, people who don’t really have an understanding because, you know, it’s just hard anyway, but then this is just another extra level. (Participant 60, FGD 2020.09.19)

Another participant whose mother has dementia described the challenges of trying to explain why her mother could no longer go to daycare to see her friends: “She’d been wanting to go out and not understanding and she also has dementia. And trying to explain all of that, that has been quite, quite, quite difficult” (Participant 32, FGD 2020.07.18).

Intimate partner relationships

Caregiving burden often increased stress in relationships where partners lived together. For example, one woman described exhaustion from caring for her mother and stated, “I don’t have energy to be intimate when I get home at the end of a day. And, and I’m tired. Turn on the TV, I don’t want

to talk” (Participant 100, FGD 2020.11.30). One participant described the impact of her partner caring for her mother who lived with people who did not follow pandemic precautions: “That caused some turbulence between my partner and I that we just had to have some talks and some excess couples counseling to get through” (Participants 11, FGD 2020.07.11). Another participant noted that her partner’s child “never takes precautions. And I can’t keep... You know, you don’t want to keep talking to somebody about their child over and over again. Because then that becomes stressful” (Participant 85, FGD 2020.11.15).

Partners who did not live together sometimes avoided in-person visits to reduce the risk of transmitting COVID-19 to the people—typically parents—for whom they provided care. For example, one participant described precautions taken with her partner who was providing care for her mother: “[She] would come to the parking lot and we’d mask up and we’d wave... I understand that this is precious time with her mother at this age and would never do anything to jeopardize that” (Participant 54, FGD 2020.09.19). Although participants saw these precautions as necessary, they also limited the quality and duration of time spent with their partners.

Participants who engaged in mutual caregiving with their partner sometimes described a strengthening of their relationship, particularly if this mutual support was emotional. One participant stated: “My relationship with her, it’s kind of morphed, really. It’s almost like we’re doing some kind of like mutual caretaking and lifting each other up” (Participant 25, FGD 2020.07.18). Some participants expressed gratitude for having a partner with whom to face pandemic challenges. One woman stated, “during this whole troubling time, I’m not alone, and I have a wonderful love in my life. So, my whole mental state is, is quite positive” (Participant 95, FGD 2020.11.30).

Topical Theme 2: Changes in Caregiving

The pandemic caused notable changes in how participants provided care. They discussed changes caused by children always being at home as well as precautions taken to protect vulnerable family members from COVID-19. Discussions were usually about the increased difficulty of caregiving during the pandemic, however, some participants found it to be easier. A few participants noted that caregiving changed during the pandemic in ways that were neither easier nor harder, just different. Participants also discussed situations in which their desire to provide care was thwarted by the pandemic.

Caregiving became more difficult

Some participants took on new roles during the pandemic by providing care that was no longer available elsewhere or by beginning to care for loved ones who previously did not require it. For example, a participant described taking on an unwanted medical role although caregiving for her mother: “I’ve become like her nurse. I have to give her blood tests, and she doesn’t like it, and I don’t like it either because I don’t know anything about medicine” (Participant 6, FGD 2020.07.06).

The pandemic exacerbated the challenges of caring for family members with dementia. The person with dementia experienced increased isolation with concomitant increases in agitation and confusion. Therefore, caregivers had to navigate the heightened emotions of the family member as well as maintain higher levels of vigilance to ensure that person took

COVID-19 precautions. One participant who cared for her brother noted:

When he comes home every night, he’s got some dementia, so I’ve got to always make sure that he knows to take his—to not wear the same clothes twice, not to wear his clothes around the house too much... I worry about people with dementia, people who don’t really have an understanding because, you know, it’s just hard anyway, but then this is just another extra level. (Participant 60, FGD 2020.09.19)

The challenges of coparenting in separate homes were also exacerbated by the pandemic. Participants expressed concern about maintaining everyone’s safety although their children navigated multiple households. One participant stated:

It’s the actual coparenting that has created issues in terms of how do we take safe measures for ourselves individually, and also for a child who goes between two homes. And then she is also remarried, and so has a stepdaughter who also goes between two homes. So, you have then three homes that are negotiating and trying to figure out not only what is safe for our families individually, but then the notion of collectivity and health takes on a whole different sort of dimension. (Participant 84, FGD 2020.11.15)

Caregiving became less difficult

Although less commonly discussed, some women found that the pandemic made caregiving easier due to the ability to work from home. This flexible working arrangement allowed them more free time and rest. For example, one participant, referring to working from home although caring for her mother: “This has given me that opportunity to rest. I think I actually feel better physically than I have because my body has gotten a chance to rest because it has not for decades now” (Participant 6, FGD 2020.07.06).

Caregiving not more or less difficult

Some participants found that caregiving changed but did not become easier or harder. For some, the pandemic alleviated certain stresses (e.g., commuting to work) but generated new ones (e.g., managing a child at home during online school), leading to similar levels of stress, but from different sources than prepandemic. Others noted that the dynamics of caregiving had shifted; however, they felt able to readily adjust to this new landscape.

Caregiving was thwarted

Some participants noted that their ability to serve a desired caregiving role was thwarted by the pandemic. For instance, some no longer felt safe seeing family members whom they had cared for and/or supported prior to the pandemic. Others were thwarted by the inability to travel during the lockdown to visit family members. One participant stated:

I’m also very far away from my blood family right now... And my daughter was laid off her job. It was just a very stressful time, and I just felt kind of helpless. I felt like I couldn’t really do anything for anybody. (Participant 11, FGD 2020.07.11)

Some participants who had provided care to family members who were incarcerated or in hospital prior to the pandemic noted that pandemic restrictions prevented both physical access to their family members as well as limited the knowledge they could acquire about how care was being provided in their stead. One participant stated, “My son is incarcerated. And there’s the stress and you know, ill feelings around his health has been just overwhelming. Knowing that they are definitely not getting the attention that they need” (Participant 97, FGD 2020.11.30). Another participant described concerns about the needs of loved ones not being met in the hospital:

I’ve also lost friends from other things, and I had to assist. And during this pandemic, you cannot go to the hospital and see people... You couldn’t care for them in the hospital. You had no idea if they had their needs met, if they were taken care of. You just had to go on blind faith. (Participant 45, FGD 2020.08.11)

One participant described the challenges of getting funeral care for a loved one who had died:

It was a very emotional and horrendous experience because they passed and I could not even get a funeral director after calling like 25 funeral homes, you could not even get anybody to even consider picking up the body. And the nursing home said that they were going to, you know, put the body in a truck and I said, Oh, no, you don’t. Don’t even go there. I just had to work until I was able to really get someone to pick up the body. (Participant 111, FGD 2020.12.12)

Discussion and Implications

This study explored how aging Black same-gender-loving women discussed their caregiving experiences during the first year of the COVID-19 pandemic. They provided multiple types of care to a range of recipients, and some received care themselves. The pandemic increased stress and presented challenges to their mental health and intimate partner relationships. Although many found caregiving to be more difficult during the pandemic, a few found it easier or simply different, although yet others found that caregiving desires were thwarted by pandemic restrictions.

A recent systematic review of qualitative studies on the experiences of informal carers during the COVID-19 pandemic (Bailey et al., 2022) identified increased caregiving demands, heightened fear, and uncertainty related to the pandemic, as well as decreased social support as common themes. Likewise, a recent scoping review of the impact of the pandemic on family carers in the community (Muldrew et al., 2022) identified four key themes: (a) decline in psychological wellbeing; (b) concerns about personal health and wellbeing; (c) practical and logistical concerns, and (d) removal or uncertainty of support.

Themes identified in our current analysis both overlap with and diverge from existing literature in salient ways. Our theme of increased difficulty of caregiving during the pandemic is consistent with the existing literature. The participant narratives also provide insights into the specific ways in which intersectional social categories play a role in that burden. For example, one participant clearly articulated the

ways in which her family’s expectation that she shoulder the caregiving burden was a manifestation of how her life as a Black lesbian was devalued as well as a manifestation of the gendered expectations of caregiving.

Although not the most common theme, our study did identify situations in which the pandemic simply changed the nature of caregiving or made caregiving easier. These “positive deviations” have not been attended to in prior literature. Identifying these neutral and positive experiences during the early pandemic provides important information about social structures that need to be in place to avoid excess caregiver burden. For example, one caregiver noted that working from home provided opportunities for rest that were not available to her when juggling commuting to work and providing care. This suggests that providing respite care for caregivers may be an important strategy for reducing caregiver burden.

Notably, lack of support was not a major theme among Black same-gender-loving caregivers in this study—in contrast to other published studies and despite the similar theme of increased caregiving burden. Although it is possible that this absence of discussions about loss of social support may be because participants had and retained adequate support for caregiving during the pandemic, this interpretation is not consistent with participant narratives. Consistent with the “Strong Black Woman” (SBW) cultural archetype, it is most plausible that participants were simply so used to shouldering burdens without support that it did not occur to them to discuss it. The SBW trope compels Black women to put forward a guise of self-reliance, selflessness, and psychological, emotional, and physical strength—an image at odds with seeking or expecting social support (Baker et al., 2015). Creating an infrastructure to provide both instrumental (e.g., home health aides) and emotional (e.g., counseling) for all caregivers that does not require requesting assistance could be an important way to ensure that the most marginalized carers receive the support they need.

We found discussions of stress and worsening mental health to be common, including fear of acquiring and transmitting COVID-19, similar to prior studies of caregivers. A nationally representative study conducted early in the pandemic found that caregivers were significantly more likely to have symptoms of depression and anxiety, increase substance use to cope, and seriously consider suicide (Czeisler et al., 2020). Even before the pandemic, Black lesbian and bisexual women reported poorer mental health than both Black and White heterosexual women (Yette & Ahern, 2018). The SBW archetype may not only present a barrier to Black same-gender-loving women caregivers seeking respite care, but it may also worsen mental health (Abrams et al., 2019) and preclude seeking mental health services (Hall et al., 2021). Culturally responsive, trauma-informed, community-based, integrative mental health services have been identified as key to addressing the mental health needs of Black women and may be even more relevant for caregivers (Matthews et al., 2021).

Data on the impact of COVID-19 pandemic and associated restrictions on intimate partner relationships is limited. The national COVID-19 Family Life Study of U.S. cohabitating couples reported that overall relationship satisfaction declined slightly during the pandemic (James et al., 2022). However, sub-analyses by race indicated that relationship satisfaction remained stable for Black participants; and analyses by gender found that it decreased for women. No data were reported on sexual orientation nor were analyses conducted

by both race and gender. This study not only provides relationship data on a population invisible in the existing literature but also highlights the complexity of how relationships were impacted, with some relationships strained by caregiving responsibilities and others strengthened by mutual caregiving.

This study provides important insights into the experiences of pandemic caregiving among aging Black same-gender-loving women—a population often invisible in health literature. The gradual shift of many health care responsibilities (e.g., drawing blood) to unpaid family members was accelerated by the COVID-19 pandemic and has affected caregiver's mental health and intimate partnerships. Contextual and topical themes highlight the invisible burden of caregiving borne by marginalized women and the unmet need for culturally tailored instrumental and psychosocial support. An intersectional lens helps us to place this unpaid burden in historical and current political contexts. The United States is a country whose wealth was built on chattel slavery, including the caregiving labor of enslaved Black women. Persistent wage gaps and financial insecurity rooted in historical and ongoing intersectional discrimination in the labor market mean that Black same-gender-loving women have fewer resources for assistance, such as home health aides (Elliott & Walker, 2022).

This analysis was limited by the lack of direct questions and probes specific to caregiving experiences. However, the emergence of such rich caregiving discussions without prompting speaks to the salience of this topic for our study population. The study is also limited by the focus group format of data collection that may have prevented some participants from sharing potentially sensitive information about their experiences.

Even with limitations, this study provides important data on older Black same-gender-loving women's pandemic caregiving experiences and demonstrates the importance of considering how multiple marginalization affects caregiving experiences, especially during a pandemic fraught with health inequities. Ensuring the multiply marginalized caregivers have access to the practical and emotional support they need is critical for advancing health equity and preparing for future pandemics. Future research is needed on effective interventions to reduce caregiver burden among Black same-gender-loving women.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None.

Data Availability

We acknowledge that this study was not pre-registered, and original transcripts are not available to other researchers because we are unable to effectively blind the data, and the

authors are conducting additional analyses using these data. However, the qualitative codebook and analytic matrices are available in the Online Supplementary Material.

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Author Contributions

T. Poteat (Formal analysis [Equal], Funding acquisition [Equal], Methodology [Equal], Supervision [Equal], Writing – original draft [Equal]); P. Hall (Conceptualization [Equal], Investigation [Equal], Writing – original draft [Equal]); M. A. Adams (Conceptualization, Funding Acquisition, Validation, Writing-review & editing); D. S. Gautam (Formal analysis [Equal], Writing – review & editing [Equal]); R. Ashenden (Data curation [Equal], Formal analysis [Equal], Writing – review & editing [Equal]); J. Horn (Conceptualization [Equal], Validation [Equal], Writing – review & editing [Equal])

References

- AARP & National Alliance for Caregiving. (2020). *Caregiving in the United States 2020*. doi: [10.26419/ppi.00103.001](https://doi.org/10.26419/ppi.00103.001).
- Abrams, J. A., Hill, A., & Maxwell, M. (2019). Underneath the mask of the strong Black Woman schema: Disentangling influences of strength and self-silencing on depressive symptoms among U.S. Black Women. *Sex Roles*, 80(9-10), 517–526. doi: [10.1007/s11199-018-0956-y](https://doi.org/10.1007/s11199-018-0956-y)
- Adams, M. A., & Poteat, T. (2016). ZAMI NOBLA: Preserving history and fostering wellness in Black lesbians. *Generations*, 40(2), 80–82. EID no.: 2-s2.0-84981298759. <https://www.jstor.org/stable/26556211>.
- ATLAS.ti Scientific Software Development GmbH [ATLAS.ti 22 Windows]. (2022). <https://atlasti.com>
- Bailey, C., Guo, P., MacArtney, J., Finucane, A., Swan, S., Meade, R., & Wagstaff, E. (2022). The experiences of informal carers during the COVID-19 pandemic: A qualitative systematic review. *International Journal of Environmental Research and Public Health*, 19(20), 1345510.3390/ijerph192013455
- Baker, T. A., Buchanan, N. T., Mingo, C. A., Roker, R., & Brown, C. S. (2015). Reconceptualizing successful aging among Black women and the relevance of the strong Black woman archetype. *Gerontologist*, 55(1), 51–57. doi: [10.1093/geront/gnu105](https://doi.org/10.1093/geront/gnu105)
- Bowleg, L. (2008). When Black+ Lesbian+ Woman≠ Black Lesbian Woman: The methodological challenges of qualitative and quantitative intersectionality research. *Sex Roles*, 59(5), 312–325. doi: [10.1007/s11199-008-9400-z](https://doi.org/10.1007/s11199-008-9400-z)
- Brennan-Ing, M., Seidel, L., Larson, B., & Karpiak, S. E. (2014). Social care networks and older LGBT adults: Challenges for the future. *Journal of Homosexuality*, 61(1), 21–52. doi: [10.1080/00918369.2013.835235](https://doi.org/10.1080/00918369.2013.835235)
- CDC. (2019, July 20). *Caregiving for family and friends—A public health issue*. <https://www.cdc.gov/aging/caregiving/caregiver-brief.html> (2023, February 9, date accessed).
- Choi, S. K., & Meyer, I. H. (2016). *LGBT aging: A review of research findings, needs, and policy implications*. The Williams Institute.
- Crenshaw, K. (1990). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, 43, 1241. doi: [10.2307/1229039](https://doi.org/10.2307/1229039)
- Czeisler, M., Lane, R. I., Petrosky, E., Wiley, J. F., Christensen, A., Njai, R., Weaver, M. D., Robbins, R., Facer-Childs, E. R., Barger, L. K., Czeisler, C. A., Howard, M. E., & Rajaratnam, S. M. W. (2020). Mental health, substance use, and suicidal ideation during the COVID-19 pandemic—United States, June 24–30, 2020. *MMWR*.

- Morbidity and Mortality Weekly Report*, 69(32), 1049–1057. doi: [10.15585/mmwr.mm6932a1](https://doi.org/10.15585/mmwr.mm6932a1)
- Dilworth-Anderson, P., Moon, H., & Aranda, M. P. (2020). Dementia caregiving research: Expanding and reframing the lens of diversity, inclusivity, and intersectionality. *Gerontologist*, 60(5), 797–805. doi: [10.1093/geront/gnaa050](https://doi.org/10.1093/geront/gnaa050)
- Elliott, D., & Walker, F. (2022, November). *Centering Black Women in income and wealth policymaking*. Urban Institute. <https://www.urban.org/research/publication/centering-black-women-income-and-wealth-policymaking>
- Fabius, C. D., Wolff, J. L., & Kasper, J. D. (2020). Race differences in characteristics and experiences of Black and White caregivers of older Americans. *Gerontologist*, 60(7), 1244–1253. doi: [10.1093/geront/gnaa042](https://doi.org/10.1093/geront/gnaa042)
- Faria-Schützer, D. B., Surita, F. G., Alves, V. L. P., Bastos, R. A., Campos, C. J. G., & Turato, E. R. (2021). Seven steps for qualitative treatment in health research: The clinical-qualitative content analysis. *Ciencia & Saude Coletiva*, 26(1), 265–274. doi: [10.1590/1413-81232020261.07622019](https://doi.org/10.1590/1413-81232020261.07622019)
- Fredriksen-Goldsen, K. I., Kim, H. J., Emler, C. A., Muraco, A., Eroshova, E. A., Hoy-Ellis, C. P., Goldsen, J., & Petry, H. (2011). *The aging and health report*. Seattle, WA: Institute for Multigenerational Health.
- Fredriksen-Goldsen, K. I., Kim, H. J., Shui, C., & Bryan, A. E. B. (2017). Chronic health conditions and key health indicators among lesbian, gay, and bisexual older US adults, 2013-2014. *American Journal of Public Health*, 107(8), 1332–1338. doi: [10.2105/AJPH.2017.303922](https://doi.org/10.2105/AJPH.2017.303922)
- Glass, V. Q., & Few-Demo, A. L. (2013). Complexities of informal social support arrangements for Black lesbian couples. *Family Relations*, 62(5), 714–726. doi: [10.1111/fare.12036](https://doi.org/10.1111/fare.12036)
- Hall, J. C., Conner, K. O., & Jones, K. (2021). The strong Black woman versus mental health utilization: A qualitative study. *Health & Social Work*, 46(1), 33–41. doi: [10.1093/hsw/hlaa036](https://doi.org/10.1093/hsw/hlaa036)
- James, S., Ben Brik, A., Jorgensen-Wells, M., Esteinou, R., Acero, I. D. M., Mesurado, B., Debeljuh, P., & Orellana, O. N. (2022). Relationship quality and support for family policy during the COVID-19 pandemic. *Family Relations*, 71(4), 1367–1384. doi: [10.1111/fare.12705](https://doi.org/10.1111/fare.12705)
- Matthews, K., Morgan, I., Davis, K., Estriplet, T., Perez, S., & Crear-Perry, J. A. (2021). Pathways to equitable and antiracist maternal mental health care: Insights from Black women stakeholders. *Health Affairs (Project Hope)*, 40(10), 1597–1604. doi: [10.1377/hlthaff.2021.00808](https://doi.org/10.1377/hlthaff.2021.00808)
- Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *The European Journal of General Practice*, 24(1), 9–18. doi: [10.1080/13814788.2017.1375091](https://doi.org/10.1080/13814788.2017.1375091)
- Muldrew, D. H. L., Fee, A., & Coates, V. (2022). Impact of the COVID-19 pandemic on family carers in the community: A scoping review. *Health & Social Care in the Community*, 30(4), 1275–1285. doi: [10.1111/hsc.13677](https://doi.org/10.1111/hsc.13677)
- Naqvi, J. B., Helgeson, V. S., Gary-Webb, T. L., Korytkowski, M. T., & Seltman, H. J. (2020). Sex, race, and the role of relationships in diabetes health: intersectionality matters. *Journal of Behavioral Medicine*, 43(1), 69–79. doi: [10.1007/s10865-019-00057-w](https://doi.org/10.1007/s10865-019-00057-w)
- Orel, N. A. (2017). Families and support systems of LGBT elders. *Annual Review of Gerontology and Geriatrics*, 37(1), 89–109. doi: [10.1891/0198-8794.37.89](https://doi.org/10.1891/0198-8794.37.89)
- Putney, J. M., Keary, S., Hebert, N., Krinsky, L., & Halmo, R. (2018). “Fear runs deep”: The anticipated needs of LGBT older adults in long-term care. *Journal of Gerontological Social Work*, 61(8), 887–907. doi: [10.1080/01634372.2018.1508109](https://doi.org/10.1080/01634372.2018.1508109)
- Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019). Valuing the invaluable 2019 update: Charting a path forward. *AARP Public Policy Institute*, 146, 1–32. doi: [10.26419/ppi.00082.001](https://doi.org/10.26419/ppi.00082.001)
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *Gerontologist*, 55(2), 309–319. doi: [10.1093/geront/gnu177](https://doi.org/10.1093/geront/gnu177)
- Schwartz, K., Beebe-Dimmer, J., Hastert, T. A., Ruterbusch, J. J., Mantey, J., Harper, F., Thompson, H., Pandolfi, S., & Schwartz, A. G. (2021). Caregiving burden among informal caregivers of African American cancer survivors. *Journal of Cancer Survivorship: Research and Practice*, 15(4), 630–640. doi: [10.1007/s11764-020-00956-x](https://doi.org/10.1007/s11764-020-00956-x)
- Walton, Q. L., & Boone, C. (2019). Voices unheard: An intersectional approach to understanding depression among middle-class Black women. *Women & Therapy*, 42(3-4), 301–319. doi: [10.1080/02703149.2019.1622910](https://doi.org/10.1080/02703149.2019.1622910)
- Williams, L. A., Giddings, L. S., Bellamy, G., & Gott, M. (2017). “Because it’s the wife who has to look after the man”: A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life. *Palliative Medicine*, 31(3), 223–230. doi: [10.1177/0269216316653275](https://doi.org/10.1177/0269216316653275)
- Yette, E. M., & Ahern, J. (2018). Health-related quality of life among Black sexual minority Women. *American Journal of Preventive Medicine*, 55(3), 281–289. doi: [10.1016/j.amepre.2018.04.037](https://doi.org/10.1016/j.amepre.2018.04.037)
- Zygouri, I., Cowdell, F., Ploumis, A., Gouva, M., & Mantzoukas, S. (2021). Gendered experiences of providing informal care for older people: A systematic review and thematic synthesis. *BMC Health Services Research*, 21(1), 1–15. doi: [10.1186/s12913-021-06736-2](https://doi.org/10.1186/s12913-021-06736-2)