"Walk a Mile in My Shoes:" African American Caregiver Perceptions of Caregiving and Self-Care

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Abstract

African American Alzheimer's disease and related dementia (ADRD) family caregivers are understudied in intervention research with discrepant evidence existing on their mental and physical health outcomes. The stress toll of ADRD caregiving, coupled with the well-documented health disparities for African Americans, place these caregivers at higher risk for morbidity and mortality.

Objectives: The purpose of this study was to explore African American ADRD family caregivers' perceptions of caregiving and self-care.

Design: Qualitative descriptive study based on individual, one-time, semi-structured interviews from a purposeful sample of current/former African American ADRD community-dwelling family caregivers. Participants agreed to either face-to-face or telephonic interviews between 60–90 minutes in length.

Results: Twenty-one caregiver interviews were conducted with primarily adult children (mean age = 62.61 (SD=12.88); 81% completed college; 57% women). Content analysis yielded three major themes: Stressors, Resources, and Coping. The results demonstrate a complex interaction of sociocultural and environmental stressors and perceptions of resources that influence the coping strategies adopted by caregivers to navigate their caregiving experience.

Conclusions: These findings suggest a broadened perspective to further inform the development and testing of interventions to address the health outcomes and caregiving needs of African American ADRD caregivers.

Keywords

African American; Family Caregivers; Alzheimer's/Dementia; Caregiving; Qualitative Descriptive; Socio-environmental

African American Perceptions of Family Caregiving and Self-Care

Alzheimer's disease is the third most costly disease in the United States with projected national expenditures expected to more than triple by the year 2050 (Alzheimer's Association, 2019). Most individuals with Alzheimer's disease and related dementias (ADRD) reside in their communities, and 75% of their care comes from unpaid family caregivers (Alzheimer's Association, 2019). Considerable and well-documented mental and physical health costs are incurred by family caregivers in terms of their stress, depressive symptoms, and poor general health (Fonareva & Oken, 2014; Trivedi et al., 2014; Gilhooly et al., 2016). Given that family caregivers spend over $9 billion in additional health care costs for their own health (AARP, 2015; Alzheimer's Association, 2019), numerous interventions have been developed to improve the health outcomes of caregivers (Maslow, 2012; Gitlin, Marx, Stanley, & Hodgson, 2015).

Despite these interventions, limited understanding about the health and self-care of African American ADRD caregivers remains. For example, some studies suggest that African American caregivers have worse self-reported physical health, more unhealthy behaviors, and no change in self-care in comparison to Non-Latino White ADRD family caregivers (Dilworth-Anderson, Goodwin, & Williams, 2004; Haley at al., 2004; Belle et al., 2006). Other studies with mental health outcomes have had mixed results. To illustrate, some studies have reported better mental health for African American caregivers, including lower rates of depressive symptoms (Belle et al., 2006; Glueckauf et al., 2012, Kally et al., 2014), lower anxiety (Haley et al., 2004), greater life satisfaction (Haley et al., 2004), and greater well-being (Czaja, Loewenstein, Schulz, Nair, & Perdomo, 2013; Haley et al., 2004). Alternately, other studies have reported either no change or worse mental health after the intervention with higher rates of depressive symptoms (Burgio, Stevens, Guy, Roth, & Haley, 2003; Czaja et al., 2013; Elliott et al., 2010; Gitlin et al., 2003; Williams, 2005) and lower quality of life (Belle et al., 2006) in comparison to non-Latino White and/or Latino ADRD caregivers.

One possible reason for the discrepancy in intervention results may be attributed to an under-appreciation of the specific experiences that African American ADRD family caregivers have in the caregiving role – how they experience the caregiving process and how they manage their health during the process. Given that African Americans are understudied in ADRD caregiving research with discrepant results regarding the effects of interventions on the mental and physical health outcomes of these caregivers, significant gaps remain in understanding how caregiving affects the health of African American caregivers. Further examination of this population's experiences with caregiving and perceptions of self-care will help explain inequities in their health outcomes. In turn, this will further inform interventions tailored to meet this population's specific needs. The purpose of this study was to explore the experience and perceptions of African American caregivers of individuals with ADRD with regards to their self-care.

Materials and Methods

This was a qualitative descriptive study based on guided, semi-structured individual interviews with African American caregivers of family members with ADRD. Each caregiver was interviewed to explore his/her perceptions of caregiving and self-care. Qualitative description draws upon naturalistic techniques that allow a phenomenon to emerge but provides a comprehensive overview through an "everyday language" presentation of facts, which results in easier researcher consensus and descriptive validity (Sandelowski, 2000, 2010; Sullivan-Bolyai, Bova, & Harper, 2005).

Sample and Setting

A purposeful sample of African American community-dwelling, current or former ADRD family caregivers was recruited from a large Midwestern city and surrounding suburbs. Inclusion criteria for participants were: (1) English speaking, (2) self-identification as African American, (3) present/former ADRD caregiver, and (4) willingness to participate via telephone or an in-person interview.

Study Procedures

Institutional Review Board approval for interviews was obtained through the study institution. Fifty-three African American caregivers of individuals with ADRD from a completed randomized clinical trial (Etkin, Farran, Barnes, & Shah, 2012; Farran et al., 2016) who agreed to be contacted for further research opportunities were mailed a one-page flyer describing the study. The original purpose of the randomized clinical trial was to test the effectiveness of a physical activity intervention in comparison to a caregiver skill building intervention to increase physical activity among dementia family caregivers, using community-based outreach methods. For the current study, community-based outreach approaches were also used to recruit additional caregiver participants (i.e., snowball referral, churches, community talks, a university associated Alzheimer's disease memory clinic, or "word-of-mouth"). The flyer: (a) briefly described the parent trial, (b) included a description of the current study purpose, and (c) included a phone number to contact the principal investigator (PI)/interviewer with interest and/or questions.

After prospective participants initiated a phone call, participants provided verbal agreement over the phone, and consent was obtained in writing during the face-to-face interviews. For telephone interviews, consent forms were mailed to caregivers, and caregivers were encouraged to contact the PI with any questions prior to signing. When signed consent forms were returned, telephone interviews were scheduled according to the caregiver's preference.

Participants answered questions either in-person or by telephone according to their preference to allow for choice/convenience associated with the demands of caregiving. Face-to-face interviews were recorded with participants' permission on digital recorders to ensure accuracy. Telephone interviews were recorded with the participant's permission via a study-designated phone line in the PI's office and a 2-way attachment between the digital recorder and the hand-held telephone. Participants agreed during consent to be re-contacted by telephone to clarify points from the interview as needed. The questions were focused

on the caregiving experience/perceptions of caregiving and self-care. The PI conducted all interviews.

Data Collection Methods

Caregiver questions were developed by the PI based on the literature to generate a discussion about the perceptions, experiences, and self-care practices of African American family caregivers. One semi-structured, open-ended 60 – 90-minute interview was conducted with each participant, which included built-in flexibility to extend interviews beyond the allocated time. Two major questions guided the interviews: (1) *How is your experience as an African American caregiver unique?* and (2) *What do you do to take care of yourself while caregiving?* Probing questions were asked to deepen the understanding of caregivers' responses. Some probing questions were: *What is/was it like being a caregiver? How did you become a caregiver? Is there anything that makes caregiving easier/harder? How do you view your health? What do you do for yourself?* The majority of caregivers shared freely without prompting, and few needed probing questions. Data collection occurred January 2015 through August 2015.

Data Analysis

A professional HIPAA-certified service was used for interview transcription. Data was entered into Dedoose© (Sociocultural Research Consultants, n.d.) software for organization, management, reduction, coding, and categorization. Using qualitative descriptive content analysis, researchers (FAC, OP) independently reviewed transcripts line-by-line in their entirety and then across transcripts by question to identify and compare major themes (Sullivan-Bolyai et al., 2005). Due to a limited foundation of literature surrounding 'perceptions of caregiving' and 'self-care' for African American caregivers, we incorporated content analysis to help interpret relationships between themes (Hsieh & Shannon, 2005; Le Navenec & Hirst, 2012).

For inter-rater reliability, a doctoral student (SS), who was not involved in data collection, independently reviewed and coded transcripts to identify themes and subthemes. All coauthors compared and discussed the similarities and differences of the themes and subthemes, determined relationships between themes, and sorted and collapsed underlying meanings until 100% agreement on major themes and subthemes was reached (Sandelowski, 2000, 2010).

Results

Overall Description

A total sample of 21 African American family caregivers of individuals with ADRD completed the interviews. Most of the caregivers (71%) were recruited from the parent trial. Seventeen participant interviews were conducted in-person, and four were conducted by phone. The average interview length was 105 minutes (ranging from 35 to 200 minutes) depending on the interview type with phone interviews being shorter. Most caregivers were female (57%), primarily adult children (mean age = 62.61, SD = 12.88), had completed college (81%), and were not working (62%). Caregivers reported an average length of six

years caregiving (ranging from 1 to 17 years), and several caregivers had prior caregiving experience for another relative (e.g., parent, spouse, sibling, aunt/uncle, or grandparent). Table 1 provides additional characteristics of the sample.

Major Themes

Content analyses yielded three major themes based on participants' described individual experiences: Stressors, Resources, and Coping. *Stressors* included factors that contribute to difficulty or challenges in the caregiving process. *Resources* included interpersonal and community level factors that influence the caregiving process, and *Coping* included self-care strategies caregivers adopted while navigating the caregiving experience. Table 2 presents the major themes with definitions and examples.

Initially, some caregivers did not identify their experience as being unique to African Americans as they felt that caregiving was a lonely, stressful experience for anyone caring for a person with dementia. As one adult daughter caregiver stated,

> It seems to be across the board when you get to this point where you're thrown into that caregiver role, we're all along even keel…. I don't think there's a whole lot of difference [as African American caregivers] cuz at the end of the day, we wanna' see 'em safe… clean… loved…, getting their medicine, keeping their doctors' appointments.

Other experiences not viewed as unique to African American caregivers included public embarrassment from unanticipated "accidents," care recipient behaviors, change in role identity, and watching the progressive cognitive/functional decline of a family member. Nevertheless, as the interview sessions progressed, caregivers began to describe unique stressors that contributed to challenges in their caregiving process.

Stressors—Several caregivers described stress in their caregiving role, or described themselves as being stressed, without consistently, or explicitly, using the term "stress." As one caregiver eloquently stated,

> It's like the walls were closing in… walk a mile in my shoes, then maybe you can understand what I'm saying, but if you've never walked a mile in my shoes… or [been] in the storm or on the bridge, however you want to look at it… because it is a storm, you know? You're in some sort of storm because all of these things are coming at you.

Although caregivers were aware of the importance of managing stress and caring for themselves, many admitted that the ongoing demand of providing care for their family member superseded their own care and contributed to the stress of caregiving.

> I had broken my ankle years ago… and there's some plate and some screws in there, and it hurts a lot now because one of the screws is probably next to a nerve and is kind of sticking out, but again I can't have that surgery and have that fixed because I wouldn't be able to really take care of her…

Additional experiences perceived as stressors specific to African American caregivers emerged. One salient aspect that caregivers highlighted included the description of

experiences, or perceptions of racism/discrimination, in the context of caregiving. For instance, in one caregiver's description of a referral visit to a specialist:

> When you walked in his office, he had all these Confederate flags and everything. It was like mm… I just needed to know, with all the Confederate stuff, I needed to know-how [me and] my mom would be treated. Because we were African American, I just needed to know…. because of what the Confederate flag, what it stands for. That whole implication of racism.

Another caregiver described,

> …most of the people… doctors and things, I come in contact with they are Caucasian people. I sort of steel myself against some of that… I don't have to do that with [Dr.] by him being Jewish… he know what it is to be outside looking in...

Caregivers also highlighted the conflict between valuing African American cultural norms balanced against acknowledging the value of healthcare and research recommendations. As one caregiver highlighted about religion/spirituality,

> In African American families a lot of the reliance and importance in the home is religion. [We] rely more heavily on church…. I think they [non-African Americans] don't understand how [we] could rely more heavily on the church than on the medical or the research or the-they don't understand, "Well, we'll pray on that."

Another caregiver discussed how in addition to pamphlets or traditional aspects of information/content delivery, African American caregivers are receptive to other methods which are an important aspect of culture and often dismissed by the health professional community:

> The entertainment aspect of our culture and recognizing that we are big [on] entertainment and – it gets our attention… That recognition may not have been as easily accepted by the health care industry or health care professionals. They… have been more adamant about, "Well, yeah, but we've got – this has been proven… this is the way you do this, and this is the way you're most effective."

Still, other caregivers highlighted putting "family first," and the expected tradition of caring for family members at home juxtaposed with a resistance to place family members in long-term care.

> …That's still the core of our culture, is bringing mama home, bringing daddy in, bringing uncle so-and-so in, to live with us, because he can no longer take care of himself…. if we can help it, we're not going to put them in a nursing home – we're not gonna put them away to pasture… we're taught to take care of our own.

In fact, resistance to placement was so deeply entrenched that caregivers also described strong dissent from family members when attempting to circumvent expected norms:

> 'Everybody saying you shouldn't take her there [nursing home], you shouldn't do this with her, you shouldn't do that…'

For several caregivers, cultural norms surrounding family were a strong influence, even as they described simultaneously providing care for children, grandchildren, or another parent.

> You've got a job. You try and have a life of your own and you take care of a parent. You come in, you get up, and you get everybody else out. You go to work. You work all day. You come home. You've still got to do homework with kids. At least say hi, to whomever, feed everybody, care for your parent, and still get ready to do it all over again the next day.

In addition, caregivers described the impact of adhering to cultural norms where prior experiences of providing care for another family member influenced the experience of caregiving for an individual with dementia. As one caregiver commented,

> Question is, would I do it again? Nope. I wouldn't do it again. I've done it. I've been a caregiver [for] three different people. I had an uncle… He stayed with me… Then, his sister… which is my mother… I'm taking care of her upstairs and taking care of him downstairs. I'm caregiver to two people at the same [time] simultaneously. Then she [mother] died. Then she [wife with Alzheimer's] came in…. It's not just one person I [was] caregiver to. It was always two at the same time.

Caregivers also consistently highlighted gender role expectations as part of the cultural norms inherent to African American families as additional stressors:

> 'They think females should take care of their parent… For me, whoever can [do it] needs to take care of their parent.'

Financial concerns were another set of stressors expressed in terms of "how to make ends meet," being the primary source of support for other family members, and out-of-pocket expenses, even if care recipients had "good insurance" or the benefit of pensions/social security. One caregiver described the financial challenge of rehabilitation after her mother experienced a fall:

> 'After they've [insurance company] taken the pension and social security and all of that, there's still this outstanding bill, every month to be paid… Literally, I'm looking at $1,000-$1,500 coming out-of-pocket.'

The caregivers simultaneously discussed having to give up work or the necessity of an early retirement/resignation as a result of caregiving demands, which contributed to their financial concerns.

> 'I quit my job in 2001 because early on she was able to kind of still be at home by herself. Then, as time went on, it got worse. So, I quit my job…'

In more than one situation, retirement or resignation became necessary if the work environment was not flexible to the changing needs of the caregiver.

> '…I was also the person who was most accountable for being on time. I'd be late for work… I got written up for being tardy. I got put on probation… I had developed this pattern of tardiness that I couldn't control…'

Finally, caregivers also highlighted environmental safety as a concern for themselves and their family members.

> To think of our mom at a currency exchange [cashing a pension check], getting, I don't know, $4,000, you know what I mean, by herself, and just having – just the thought of a guy seeing all of that, hanging out, with all the crime and all this craziness…

Resources—Besides stressors, caregivers also described their experiences with resources, which played a unique role in their caregiving process by mitigating or aggravating their experiences. For African American caregivers, their experiences with resources, particularly their perceptions of benefits and challenges, had an impact on their caregiving role. Formal resources included a variety of paid organized services offered through agencies, hospitals, or organizations to support caregivers in their role. Some examples included home health care, adult daycare, hospice, and support groups. Not all caregivers used these services, and those who did identified mixed experiences. In particular, one common reason given by caregivers for not using formal resources was the lack of access, either through being unable to physically get to them and/or being unable to have resources come to them. As one caregiver described:

> 'When I got that list from the Alzheimer's Association – a lot of things up north… a lot of things in the suburbs. Not that much here on the Southside of Chicago or in our area that you can rely on.'

Another caregiver noted:

> 'I think certain things African Americans don't get and maybe certain people are scared to come out to visit us, when you find out it is African American.'

In addition to accessibility barriers to formal resources, caregivers also identified types of experiences, both positive and negative, for those who attempted to use formal resources and opted not to continue, and for caregivers who were currently using formal resources. Positive experiences included the benefit as well as the experiences with a trusted resource, or invaluable service.

> '[She-homemaker] was a nice lady. [She] would cook all the holiday dinners like Christmas and Thanksgiving… she was good and on time. You could depend on [her] to be here at 8 in the morning…'

Alternatively, and more commonly, word-of-mouth exchanges that reflected the experiences of others, quality of facilities, limited/inconvenient hours, age and gender composition of support groups, or poor personal interactions with staff were negative. As one caregiver described,

> 'This particular one [homemaker]… I don't know how she pulled it off, but somehow, she connected herself to mama's gas bill and my mama was getting a bill for our address and her address…'

Despite the negative experiences, most of the caregivers continued to provide care in the absence of adequate support/help, while acknowledging the disparity in resources:

> Not that it's fair, but sometimes – I've always been taught that – as an African American, this is just as simple as this. You may have to take that local road… where you stop at every stoplight where somebody else may be able to take that expressway. You going to the same place, but you may have to take the slower route to get there… You just gotta be prepared to be able to endure it, to be stronger…

Informal resources represent the unpaid support for caregivers often provided by family members, friends, or religious organizations/faith communities. Experiences with informal resources were generally perceived/described positively, helping the caregiving experience and included information sharing, support groups, "being there," and other support offered by friends or religious organization/faith community leaders and/or members. One caregiver described her church members:

> '…They tried to be a buffer, and to talk to her… They came every two weeks and they were very supportive. They would call if it was just really stressful. They would call and say, "Hey, how you doing?" … Just verbal support.'

Another caregiver discussed coworkers:

> 'I had some very supportive coworkers who were African American. They were very supportive. They would ask me, "How's your mom?" and if I needed to leave, "Don't worry about it. We got you covered," and all that.'

Some of the experiences with informal resources were also perceived/described negatively as barriers to caregiving, such as unsupportive or unavailable leaders or members of religious organizations/faith communities, unreliable or unavailable family members, and lack of emotional or physical support from family members. One caregiver noted a lack of emotional support,

> 'My sister never wanted to talk about it [mother's dementia], even to this day she doesn't talk about my mom. She doesn't talk about it. A lot of times I do wanna talk about it.'

Other caregivers described a lack of general support from family or their faith community,

> …the bottom line is my brother does what he wants to do… He knows I cannot leave this house, and particularly since my mother's been on oxygen... I'm sure it's very hard to see the way she's deteriorated, but it's like everybody thinks it's okay with me?

> …While mama was well they loved her… but when she got ill, there were a few people that came by to see her… but it wasn't as much as I thought it should be as far as the support from them, especially our pastor… he did not step up as I thought he should.

Further, long-standing, unresolved conflict or misunderstandings exacerbated by the disease progression or withdrawal and denial within families highlighted a lack of communication, estrangement, ostracism, or generally challenging family dynamics that contributed to the absence of resources and exacerbated the stress of caregivers. One daughter described becoming a caregiver:

> My mom was never sweet. I was never her favorite… She divorced my father who was physically abusive. I was his child, so she didn't like me much, but I ended up being her caretaker in the end… even though my sister was the one that [she] felt closer to…

Another caregiver described the deterioration of a relationship:

> 'Well, we started off as a team. It's been three years this year, my brother and I got into a physical fight. We've been nemeses ever since, so it's just me taking care of my mother… it's like having no one there...'

Coping—Caregiver descriptions of experiences with stressors and resources highlighted how various self-care or coping strategies were used to navigate the caregiving process. Many caregivers emphasized prayer as a critical practice to continue in the caregiving role. One caregiver observed,

> I prayed for God to keep me in good health so I could help him [and] He did. He brought me through. I mean, I was crippled in the end, but He brought me through. He didn't break me down where I would end up in the hospital, thank God, but I was whipped down.

Other caregivers mentioned ignoring their own needs or isolating themselves as a result of being totally immersed in the caregiving role.

> 'It is hard because the caregiver, you start caring for someone else and you forget to care about yourself, the most important person…. I let my asthma get bad. You know, even, I didn't go take my physicals like I should.'

Still, other caregivers fell along a spectrum of self-care to sustain their caregiving role, from taking/refilling medications to engaging in activities. One caregiver described,

> 'I take my meds and that's about as best as I can do… I do take my medicine. I am, at least, religious about that.'

Another caregiver described the significance of appointments and medication,

> 'I take care of myself. One because knowing what the family history is I just refuse to go out like that. Two, I know if anything happens to me, then day-to-day, mom is totally dependent on my brother. I ain't going out like that either.'

Caregivers who engaged in physical activities, such as line dancing, bike riding, going to the gun range, or playing tennis, or contemplative activities, like reading the Bible, knitting, or painting, verbalized the importance of their health to maintain caregiving.

> I pretty much just started continuing to do my exercising… I'm in a walking group and try to do stuff to keep myself sane because even my husband had noticed. I'm trying to get balance back in my life cuz at one point I had pretty much just came to work and managed her. Then I realized I needed to get balance because I could see it was impacting me health-wise.

Finally, accepting limitations as a form of self-care, usually after experiencing a health scare or hospitalization, was discussed:

…I just learned it the hard way, about maybe I just had too much on my plate….
You've gotta take you with you on this journey, and realize that she'll be better, or
he'll be better off, if you're good. I don't know why it took me so long to think
about that.

Discussion

The purpose of this study was to explore the perceptions and self-care practices of African
American caregivers of individuals with ADRD to further inform the design of culturally
tailored interventions. Caregivers' descriptions of their experiences were reflected in three
major themes: Stressors, Resources, and Coping. Our findings extend what has been
previously highlighted in caregiving literature (Gilhooly et al., 2016), and demonstrate
a complex interaction of sociocultural and environmental stressors and perceptions of
resources that influence the coping strategies caregivers adopt to navigate their caregiving
experiences. Complex stressors go beyond the progressive functional/cognitive decline and
behavioral changes of the care recipient. Experiences with racism/discrimination, cultural
norms, financial concerns, and environmental safety contribute to a uniquely stressful
experience for African American ADRD caregivers. Further, the perceived benefits and
challenges with formal/informal resources appeared to simultaneously influence the stress of
caregiving, thereby contributing to the coping strategies adopted by caregivers.

Racism/discrimination has a long history in the African American community and is
a unique stressor to African Americans with particular linkages between perceived
discrimination, adverse health outcomes, and trust building (Goosby & Heidbrink, 2013;
Paradies et al., 2015; Williams, 1999). Caregivers in this study described navigating
interactions within the health care system and accessibility and quality issues with formal
resources where structural discriminatory practices, including housing, employment, and
education, can have residual effects (Allard & Small, 2013; Mezuk et al., 2010). A lack
of formal resources in the community, lower quality resource options, or even negative
perceptions can influence health outcomes and contribute to the unmet needs of caregivers
(Desin, Caban-Holt, Abner, Van Eldik, & Schmitt, 2016).

Cultural norms also contributed to the stressors experienced by caregivers, including the
importance of religion/faith communities, maintaining family members in the home, and
gender role expectations. For African American caregivers who rely on their faith and value
prayer, balancing cultural beliefs against interactions with providers who did not recognize
or acknowledge the significance of their beliefs was a challenge. In health care interactions,
a lack of sensitivity or tailored approaches can inadvertently influence health outcomes and
create barriers to help-seeking behaviors/health care access (Kreuter, Lukwago, Bucholts,
Clark, & Sanders-Thompson, 2003; Napoles, Chadiha, Eversley, & Moreno-John, 2010).
Further, caregivers in our study articulated the supportive role of religion/spirituality or faith
communities, which is consistent with current literature (Epps & Williams, 2018). However,
caregivers also expressed negative and distressing aspects of the informal social support
offered by religious organizations/faith communities when members or leaders did not offer
support in expected ways, which exacerbated the stress of caregiving and could influence
health outcomes.

The expectations that family members would remain in the home and that female family members would assume the caregiving role were also stressful, especially when caregivers articulated the added complication of having insufficient support to maintain the caregiving role. Although caregiving literature has highlighted the reliance on family among African Americans (Dilworth-Anderson & Gibson, 2002) many of the caregivers in this study described family dynamics/dissension regarding decisions, and a deterioration of family relationships that limited the amount of family/social support while they cared for a person living with dementia at home. In a study that examined racial differences in the program evaluations of caregivers, interventionists who made phone calls to African American caregivers were likely perceived as social supports in the absence of traditional family supports (Cothran, Paun, Farran, & Barnes, 2016). Further, the inherent expectation and perception of caregiving as gendered has implications for women, particularly African American women, placing them at-risk for health outcomes (Baker, Buchanan, Mingo, Roker, & Brown, 2015).

Financial expenses, particularly out-of-pocket costs for medications and home needs, associated with caregiving are not an uncommon stressor (National Academies of Science, 2016). Nevertheless, for African American caregivers, who are predominantly women and disproportionately heads of households, financial expenses and the challenges of maintaining work roles with the increasing needs of caregiving at home, created additional stress with implications for health (Cothran et al., 2015). In particular, the inability to meet ongoing and progressive caregiving demands while working for employers who were not sensitive to the changing needs of caregivers often led to employment termination, resignation, or early retirement. African American caregivers, compared to non-Latino White or Latino caregivers, are more likely to quit working (Covinsky et al., 2001), yet African Americans generally delay retirement due to financial challenges (Mermin, Johnson, & Murphy, 2007). Therefore, with African American adult children more commonly fulfilling the role of caregivers, after the care-recipient's death, their future earning potential will be affected by early workforce separation (Covinsky et al., 2001; Dilworth-Anderson et al., 2002).

Caregivers also highlighted concerns about the safety of their environment for themselves and for the care recipient as being stressful. For a person living with dementia, maintaining familiarity is important (Son, Therrien, & Whall, 2002) and moving is not always an option. The literature highlights how the persistence of structural racism and under-resourced environments perpetuate crime/violence (Gee & Ford, 2011). The impact of race and place in relation to health outcomes, particularly environmental stress and health, cannot be overemphasized (Braveman & Gottlieb, 2014). Nevertheless, in the presence of inequitable resources or challenging experiences, caregivers in this study were resilient in navigating caregiving as best they could. Yet, for African American caregivers, long-standing resilience in the presence of adversity/environmental stressors has implications for long-term health.

Caregivers in this study used various strategies for self-care or coping. Prayer was prominently highlighted, which is not uncommon in the literature; however, using prayer as a self-care strategy is an emergent theme (Epps, Skemp, & Specht, 2016). As mentioned earlier, prayer is a strong cultural value for African American caregivers, and in this context,

prayer was a means to keep going even at the expense of self-neglect (Dilworth-Anderson et al., 2004). Caregivers spoke about how they managed the stress of caregiving and how they navigated limited/insufficient resources or social support with a variety of self-care activities. Interestingly, while caregivers used various coping strategies, these strategies were used as a mechanism to maintain the caregiving role, thus demonstrating participants' commitment and resilience (Wilks & Croom, 2008).

Caregivers also incorporated various forms of physical activity that differed from what has been previously reported in caregiving literature (Castro, Wilcox, O'Sullivan, Baumann, & King, 2002; Farran et al., 2016). While the focus of this study was not to explore physical activity in depth, the variety of physical activities that African American caregivers engaged in is noteworthy. In a study that included African American and non-Latino White caregivers, African American caregivers did not engage in the same amount of physical activity as non-Latino White caregivers over time (Cothran et al., 2017). While time and other factors should be considered for this finding, incorporating individual preferences into a broad range of activity to promote health behaviors among caregivers should be evaluated in future research.

The value of understanding self-care in African American caregivers is gaining momentum in the literature. We extend the existing body of literature by highlighting sociocultural and environmental aspects influencing African American caregivers, particularly in relation to self-care, and include a sample of male African American caregivers (n = 9). In light of these strengths, we recognize the limitation that this was a purposeful sample from a single geographic area where a large proportion of the participants had completed a randomized controlled trial. It is possible that prior participation in the parent physical activity trial could have introduced potential self-selection bias. However, this study purpose focused on an in-depth exploration of caregivers' perceptions of caregiving and self-care instead of physical activity. In addition, caregivers from the clinical trial and the current study were recruited using community-based outreach approaches. Another limitation is the use of mixed mode interviews – face-to-face and telephone –which could have led to stronger 'interviewer effects.' However, participants had the option to select their mode of interview and we respected their preference based on their time and other obligations.

Despite these limitations, this study provides insight into the experiences, perceptions, and self-care practices of African American caregivers. In addition, the findings offer insights into the possible tailoring of interventions to mediate stressors, resources, and coping strategies based on caregiver preferences. The optimal health of caregivers is important due to the rapidly growing population affected by Alzheimer's disease, and African Americans face greater risks than the rest of the population (Barnes & Bennett, 2014). African Americans in general are disproportionately affected by health disparities, including diabetes, cardiovascular disease, cancer, and obesity (CDC, 2015; Healthy People, 2015). Chronic stress from caregiving, plus the burden of health disparities, creates a double jeopardy for poor health outcomes, including morbidity and mortality, among African American caregivers (CDC, 2015).

Implications for Research and Practice and Policy

The caregiving role is important to many African American caregivers wherein they make decisions related to their own care and persevere through multiple challenges for the benefit of the care recipient. Overall, for African American caregivers, additional stressors and resources that encompass environmental and sociocultural factors influence the caregiving process and coping strategies in the caregiving process. Considering the dynamic process of caregiving, we contend that the stress process model, and various adaptations (Knight & Sayegh, 2010; Knight, Silverstein, McCallum, & Fox, 2000; Pearlin, Mullan, Semple, & Skaff, 1990), which guided considerable caregiving literature and numerous interventions (Gilhooly et al., 2016; Gitlin, Marx, Stanley, & Hodgson, 2015) be expanded to incorporate environmental and sociocultural influences. A framework such as the NIA Health Disparities Framework (Hill, Perez-Stable, Anderson, & Bernard, 2015) would provide a perspective that further contextualizes our findings and broadens the approach to address the health outcomes and caregiving needs of African American caregivers.

African American caregivers experience significant stressors in caring for family members where the complex interaction of sociocultural and environmental features and the perceptions of resources influence their coping strategies. Indeed, stressors may influence the health of African American caregivers more than has been previously reported. Within an intervention, stressors may manifest across environmental and sociocultural domains with a greater impact on African American caregivers and the intervention outcomes.

Future intervention research should incorporate greater attention to the environmental and sociocultural nuances unique to African American caregivers in the design and implementation phases. By identifying and understanding the perceptions and experiences of African American caregivers, interventions/health outcomes research may be tailored to meet the specific needs of African American family caregivers. Currently, a gap exists in responding to the needs of caregivers. Prioritizing the environmental and sociocultural context provides an opportunity to better understand trends that could otherwise be overlooked by health care and other service providers as well as policymakers.

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Table 1

Caregiver Demographics

Characteristic	N	%
Gender		
Female	12	57%
Male	9	42%
Parent study participant		
Yes	15	71%
No	6	28%
Education *missing (5)		
High school or less	3	19%
College	5	31%
Graduate/Professional	8	50%
Relationship		
Child	15	71%
Spouse	5	21%
Other	1	.05%
Employment		
Yes	8	38%
No	13	62%
	M	**SD**
Age at time of interview (years) *missing (8)	62.61	12.88
Length of Caregiving (years)	6.6	4.2
Interview Length (minutes)	104.62	42.62

Table 2

Outcomes of Analysis

Category	Definition	Example
Stressors Racism/ Discrimination	Factors that contribute to the difficulty or challenges in the caregiving process	*"Because of what the Confederate flag – what it stands for. That whole implication of racism."*
Cultural Norms		
Religion/ Spirituality		*"A lot of the reliance and importance in the home is religion…"*
Entertainment		*"We are big on entertainment, and it gets our attention."*
Family		*"That's the core of our culture … is bringing mama home, bringing daddy in, bringing uncle so-and-so in to live with us because he can no longer take care of himself…"*
Gender Role		*"They think females should take care of their parent…"*
Financial Concerns		*"There's still this outstanding bill, every month to be paid…"*
Environmental Safety		*"Just the thought of a guy seeing all of that, hanging out, with all the crime and all this craziness…"*
Resources Formal	Interpersonal and community level factors that influence the caregiving process	*"A lot of things in the suburbs. Not that much here on the Southside of Chicago or in our area that you can rely on."*
Informal		*"Or if it was a totally difficult day and I couldn't get her to eat anything… they were supportive."*
Coping Prayer	Self-care strategies caregivers adopted while navigating the caregiving process	*"I prayed for God to keep me in good health so I could help him, and He did."*
Neglect		*"You start caring for someone else and you forget to care about yourself, the most important person."*
Activity		*"I'm in a walking group and try to do stuff to keep myself sane."*
Accepting Limitations		*"We just have to learn how to deal with it and not be so hard on yourself."*