

# A Qualitative Study on the Social Determinants of HIV Treatment Engagement Among Black Older Women Living With HIV in the Southeastern United States

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## Abstract

Black older women living with HIV (BOWLH) in the United States are disproportionately affected by HIV infection and poor treatment engagement rates, often caused by multiple social determinants of health. In this descriptive qualitative study, we interviewed 17 BOWLH to investigate the facilitators and barriers to HIV treatment engagement. Data were analyzed using the socioecological framework. Findings demonstrate the positive influences of supportive social networks, perceived benefits, HIV-related knowledge, raising HIV awareness in communities, and impact of HIV state laws. The highlighted barriers were mainly low income, substance use, HIV-related stigma, influence of stereotypes and assumptions about older women living with HIV, and health insurance. Religion, managing comorbidities, attitude toward, HIV disclosure, and caregiving roles had both positive and negative influences on engagement. These findings illuminate factors of HIV treatment engagement that might be culturally founded; disseminating these factors to health care professionals is a critical intervention to support this population.

**Key words:** Black women, geriatrics, health disparities, HIV treatment engagement, qualitative descriptive study, socioecological factors

To effectively manage HIV, successful engagement in the HIV care continuum, which involves timely diagnosis, linkage and receipt of care, and retention in treatment, is critical to achieving viral suppression and minimizing transmission rates (Center for Disease Control and Prevention [CDC], 2019). Evidence reveals low rates of involvement at every step of the HIV care continuum among women living with HIV. In 2018, out of every 100 diagnoses, only 76% of women received some care, 58% were retained in care, and 63% were virally suppressed (CDC, 2021a). Further, for older women living with HIV (ages 55 and older), the rates of

infection remained stable from 2014 to 2018, despite a noticeable reduction in rates for their male counterparts (CDC, 2021b). These rates become critical when considering Black women, a population disproportionately affected by HIV (CDC, 2020a). Black women in the United States comprised as much as 57% of new diagnoses among women living with HIV in 2018 (CDC, 2021c). A critical factor placing older women at risk for HIV infection and suboptimal treatment is the assumption that they are not engaging in sexual activity, which research has shown to be false (Durvasula, 2014; Villegas et al., 2020). Such assumptions for BOWLH may be further aggravated by stereotypes and biases about their race, socioeconomic status, and gender-based factors within intimate relationships (Warren-Jeanpiere et al., 2014), which may further hinder effective treatment engagement.

Of the several measures of HIV treatment engagement in the literature, the most robust are those that consider attitudes of medication adherence, medical appointment visit adherence, and an intrinsic motivation to seek care. There exists a paucity of research on the incidence and prevalence of HIV treatment engagement among BOWLH, as well as on the facilitators and barriers that influence successful treatment. Most studies have focused on a general population of people living with HIV,

*Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.*

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*Supplemental digital content is available for this article. Direct URL citations appear in the printed text and in the HTML and PDF versions of the article at [www.janacnet.org](http://www.janacnet.org).*

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*<http://dx.doi.org/10.1097/JNC.0000000000000299>*

with no specific focus on age or gender. Among these studies, the focus was limited to antiretroviral therapy (ART) adherence and retention in care (Abara et al., 2014, 2016; Warren-Jeanpiere et al., 2014). One study examining adherence to ART reported a 32% adherence rate and found that older women (compared with older men), residents of rural areas, and people with comorbid conditions were significantly less likely to adhere to ART (Abara et al., 2016).

The commonly cited barriers to HIV treatment engagement among older women include difficulties with dealing with comorbidities (Warren-Jeanpiere et al., 2014), social isolation, discrimination, stigma (Sangaramoorthy et al., 2017a, 2017b), including from medical providers (McDoom et al., 2015), and stereotypical/societal views of age or ageism (Durvasula, 2014), loneliness, depression, and substance use (Rubtsova et al., 2017). For BOWLH, these risk factors are further aggravated by several socioeconomic and socio-contextual factors that increase their susceptibility to HIV morbidity and mortality, such as poverty, poor education/health literacy, high unemployment rates, racial segregation in poor neighborhoods prone to gangs, gun violence, drug dealings, and prostitution (Sharpe et al., 2012). In one study of African American women with HIV living with comorbid conditions, such as diabetes and hypertension, the major deterrent to effectively managing their health was related to poor social and economic backgrounds, including poor income and/or medical coverage, rigid work routines, and social isolation (Warren-Jeanpiere et al., 2014).

Although there are numerous barriers, there are some notable facilitators of HIV treatment engagement for older women living with HIV. These include social support from family and intimate partners; a focus on caring for the body and mind; using strategies to alleviate stress, depression, loneliness, and anxiety; activism in the community; and social and religious groups to help themselves and others (DeGrazia & Scrandis, 2015; Grodensky et al., 2015; Psaros et al., 2015; Siemon et al., 2013). In a focus group study by Warren-Jeanpiere et al. (2014), Black women ( $n = 23$ ) with caregiving roles were more motivated to seek care to stay healthy and effectively care for their dependents, grandchildren, and significant others. In another study, a majority of women reported social roles as mothers and grandmothers, which motivated them to successfully manage their HIV (Webel & Higgins, 2012). In relation to ART adherence, one study on Black and Hispanic older women living with HIV found that women felt encouraged to take their medications because it helped with relieving psychosocial issues and improving overall well-being (Cianelli

et al., 2020). Another study found that having comorbid conditions facilitated timely ART initiation due to the severity of the combined conditions (Abara et al., 2014).

Despite these facilitators and barriers, older women living with HIV are rarely involved in the discourse concerning HIV treatment and management (Durvasula, 2014). For BOWLH, the importance of exploring such factors becomes critical in understanding possible influences and/or intersections in race, age, gender, social status, and disability that might have an impact on effective treatment adherence. Given the paucity of research in this area, the purpose of this study is to address this gap by exploring the facilitators and barriers of HIV treatment engagement among BOWLH.

## Theoretical Framework

The aforementioned facilitators and barriers to HIV treatment engagement among older women are not solely medical or health system-focused; instead, they are mostly socioecological in nature. These social determinants of health are the conditions in which people are born, grow, live, work, and age (World Health Organization [WHO], 2020), and if these conditions are poor, they can negatively affect health. To investigate the social determinants of health capable of influencing HIV treatment engagement for BOWLH, this study used a socioecological framework (McLeroy et al., 1988). The socioecological model (SEM) investigates the relationship between persons and their environment, two metaparadigms of the nursing discipline (Fawcett, 1996), and this relationship is grouped on the different levels of the ecosystem: the microsystem, mesosystem, exosystem, and macrosystem. From proximal to distal, each level of the SEM, namely, the intrapersonal, interpersonal, community, and societal/public policy levels, incorporates larger, structural, and sociocontextual factors capable of influencing behaviors. For this study, the researchers explored facilitators and barriers at all four levels of the SEM.

## Methods

### Design

We used a descriptive qualitative approach (Sandelowski, 2000) to explore the facilitators and barriers to treatment among older women living with HIV. This descriptive qualitative study addresses several of the objectives of a larger study aimed at investigating the health needs of minority older women living with HIV (Grant no. RWJF-ENF-71968). Institutional review board approval was obtained from the University of Miami (MOD00027622)

and the Jackson Health System Office of Research (201610).

### **Sample and Setting**

Participants were recruited at an ambulatory care center/HIV clinic at a hospital in South Florida, USA, using a purposive sampling approach to identify cases deemed information rich for the purposes of the study (Creswell & Poth, 2018; Patton, 2015). The recruitment was conducted face-to-face in waiting areas of the clinics and by health care provider referrals. Flyers in English and Spanish strategically placed within the community were also used to reach potential participants. Black older women living with HIV were recruited if they (a) self-identified as Black, (b) were age 50 years or older, (c) spoke and read in English, and Spanish, and (d) self-reported living with HIV. Based on prior studies with this population (Cianelli et al., 2020; Rubtsova et al., 2017; Villegas et al., 2020; Warren-Jeanpiere et al., 2014) and the CDC's (2020c) classification of older persons living with HIV, age 50 years was used as the reference point for older adults. Also, based on recommendations for qualitative inquiry, we aimed for a sample of 20 women (Creswell & Poth, 2018). We relied on the notion of concept redundancy to ensure data saturation, described as the point wherein no new information was obtained from interviewing more participants, and repetition in the nature and substance of themes was noted (Creswell & Poth, 2018). For this study, saturation was obtained once a sample size of 17 women had been interviewed.

### **Data Collection**

Data were generated through face-to-face in-depth interviews with BOWLH from April to October 2017. Participants were informed of the study's purpose and screened for inclusion. Those meeting inclusion criteria provided written consent before their interviews. They were also informed of their rights to confidentiality and anonymity, and they could withdraw from the study if they wished to do so at any point. Members of the research team were trained on qualitative data collection, and interviews were conducted by bilingual researchers and a doctoral student, all of whom had previous experience with qualitative data collection. Each participant was interviewed in their preferred language. The in-depth semistructured interviews lasted 45 to 60 minutes and were audio-recorded and conducted in a private space of the health care clinic wherein participants received HIV-related care.

The research team developed the interview questions based on the literature and experience working with BOWLH. Open-ended questions were developed to explore HIV treatment engagement and all its related intrinsic and extrinsic influencers within the environment. These questions were piloted and deemed understandable by three volunteer older women fitting the selection criteria. The team ensured consistency by using the same interview guide for all participant interviews. Also, the open-ended nature of the questions ensured that participants' responses were not restricted and were without bias, allowing for novelty and robustness of emerging themes (see Appendix 1, <http://links.lww.com/JNC/A21>, for sample interview questions). All audio-recordings were transcribed verbatim and stored in a locked office, with digital files saved in password-protected computers.

### **Data Analysis**

To address the aim of this article, two research team members inductively synthesized (Patton, 2015) the transcripts and deduced meaning from them using a directed content analysis approach (Hsieh & Shannon, 2005). Researchers use this type of content analysis when guided by constructs, models, or a theoretical framework (Hsieh & Shannon, 2005). These research team members conducted the analysis of the transcripts manually using a codebook and code sheet that were developed using constructs of the SEM as the overarching themes (Hsieh & Shannon, 2005). The researchers independently identified codes by analyzing the transcripts line by line and then grouped similar codes into subthemes under the predetermined themes of the SEM (Hsieh & Shannon, 2005; Patton, 2015). On completion, the research team compared the results and discussed the subthemes and quotations until reaching 90% consensus. A third member of the research team participated in this process to help reach consensus, thus ensuring the rigor and quality of the data analysis (Creswell & Poth, 2018).

In addition, the following steps were taken to ensure qualitative rigor. Dependability: researchers maintained documentation of the analysis via an audit trail consisting of raw data such as direct quotes from the transcripts, drafts of the subthemes created during the analysis process, a codebook, and a code sheet (Denzin & Lincoln, 2017). Credibility: two researchers independently coded the transcripts first and then reviewed the findings together with a third member of the research team participating in the process (Denzin & Lincoln, 2017). Transferability: the description of

participant demographics provided will facilitate comparisons with other groups of individuals (Denzin & Lincoln, 2017).

The trustworthiness of the study was also enhanced by immersing in the data before analysis and seeking patient feedback to confirm that the researchers' interpretations reflected the participants' intended meanings. Five participants were part of the member check process (Patton, 2015) and received their transcripts and the themes with their own quoted responses. They were asked to provide feedback regarding whether the themes and quotations reflected the key issues discussed during the interview. The participants were called by the principal investigator (PI) of the parent study to discuss the findings. Participants agreed with the study's findings as presented to them by the PI.

## Results

A total of 17 Black women who spoke English were included in the study. Their mean age was 57.4 years ( $SD = 6.13$ ) with an average monthly income of \$1,001.70 ( $SD = \$589.10$ ) and 11.4 years ( $SD = 2.0$ ) of education. Two women (12%) were employed, 16 (94%) had health insurance, 16 (94%) identified with a religion and agreed that their religious views influenced their lives, 12 (71%) were married or in a relationship, 5 (41%) were living with their partners, and 11 (64%) reported having sexual partners in the last 6 months. Women had an average of two partners in the last 6 months and an average of 13 partners in a lifetime. Of those who had health insurance, the majority was through Medicaid ( $n = 13$ , 81%). All women identified the United States as their country of birth.

Through our analysis, we developed 14 themes across the four levels of the SEM (McLeroy et al., 1988). Collectively, these findings (Table 1) speak to the cross-cutting impact of socioecological factors affecting HIV treatment engagement among BOWLH. Herein, we present the themes alongside participant quotes. Participants' names have been replaced with pseudonyms to maintain confidentiality.

### Themes at the Intrapersonal Level

The themes in this level describe the influence of the women's intrinsic characteristics and personal factors on engagement.

**Prevalent poor socioeconomic status and its effects.** Low income was a common deterrent to HIV treatment engagement among women. Some participants described their inability to afford stable

accommodation or sustain employment because of their HIV status. Participants reporting sustainable housing stated that the neighborhoods were unsafe and prone to dangerous activities like gangs, rape, and violence, which deterred engagement in attending medical appointments. Others felt that the houses were often stripped of basic amenities (e.g., light). To address income gaps, women sometimes had to take up additional jobs. Thus, women faced challenges attending their appointments due to time conflicts and/or because they were weary of disclosing their status. One participant stated the following: "It's hard because I get a check for \$735.00 each month. And I have bills to pay. I have food to put in the house. So, it's like I can't pay for the things that I really need. You know"? (Eunice).

**Influence of religion, good or bad?** The practice and principles of religion were frequently cited as affecting HIV treatment engagement. There were several elements of religion, such as spirituality, faith, scriptures, prayer, and miracle, that either served to encourage or deter engagement. As a facilitator, in one instance, a participant recounted how she developed a personal relationship with God, which encouraged her to take her medications.

I developed a spiritual relationship with God. And from that relationship which—which I developed with God, I am who I am today...I know I could deal with it, but the main thing is I know I must take my medication, you know, because the meds do work. I can say that. And it's also I could say through God with my prayer, my faith, and my belief and hope in God. (Edom)

Some women found their religious beliefs satisfied their hopes of recovery. There was a strong belief in healing without medicine or science, as described by this participant: "I just kept it between me and God, and I prayed, and I prayed, and I prayed, and I fed myself life, not death. I spoke life into my—my—my body—into my spirit" (Edom). One participant also recounted a miraculous healing after she had been informed of her poor prognosis.

When I got sick, I reaffirmed my faith, and I hold my faith close to me. I hold strong to my faith because, um, ... They thought that I was going to die, I wasn't going to make it. But some kind of way, I did. Miraculously, I made it. I'm here and I've been here. (Helen)

**Attitudes toward antiretroviral therapy.** Participants recounted their lived experiences with ART. Participants described that some of the factors that encouraged their adherence to ART were foreseeable positive outcomes and observable improvements in psychological health by alleviating stress.

**Table 1. Social Determinants of HIV Treatment Engagement Among Black Older Women Living With HIV**

Socioecological Model Level	Themes	Facilitator	Barrier
Intrapersonal	Prevalent poor socio-economic status and its effects		✓
	Influence of religion	✓	✓
	Positive attitudes toward antiretroviral therapy	✓	
	Dependency on substances		✓
	Perceived benefits on overall health	✓	
	Gained HIV-related knowledge	✓	
	Managing medical comorbidities	✓ <sup>a</sup>	✓
	Caregiving roles, work schedules, and competing demands on time	✓ <sup>b</sup>	✓
Interpersonal	Caregiving roles as extrinsic motivation	✓	
	Support from family, friends, and HIV care providers	✓	
	The effects of HIV status disclosure	✓	✓
Community	Transportation factors	✓	✓
	Stereotypes and assumptions about older women living with HIV		✓
	Raising HIV awareness in the community	✓	
Societal/public policy	Difficulty obtaining health insurance		✓
	The influence of HIV state laws	✓	

<sup>a</sup> Severity of some comorbidities prompted engagement in one instance.

<sup>b</sup> Caregiving roles was a facilitator in some instances.

If you don't take that medication, you be dysfunctional. You—You—You can't think. I—I was stubborn one time, I'd say back in 2010. I was a little pissed off because I got cut—from work...I got depressed. I wouldn't take no medicine. I was mad as hell because I ain't had no work. Frustrated. Argue with people all the time. Cussing. The key is [take] the medication and you won't have to cuss. (Joy)

Women described some of the factors that encouraged ART adherence. These were (a) an intrinsic motivation to live, (b) understanding medication regimen, (c) having easy access to their medications at home, (d) fewer pills to swallow, (e) using reminders like alarm clocks, and (f) following a routine. One participant described her experience of coming to terms with the need to seek treatment:

I wanted to live. I got tired of being sick and tired, and I start looking in the mirror one day and just looked at how my face looked, my body looked. I mean I was always skinny, but I was

just looking very unhealthy, so I decided to get myself together. (Olivia)

Others described a process of learning about *how* to take their medication and developing a new normal to feeling good: "Learning how the medication taken. That's the easiest thing if it makes me feel better. That's the easiest thing. All I got to do is take my medication. I feel good" (Oddie).

Some deterrents to ART participation included coping through dependency on illicit substances, physically debilitating symptoms of HIV, polypharmacy, negative experiences of others, and adverse effects of medications.

The pill was orange, so I woke up one day—and it was later. It was so many years had gone past. My hands were orange. My feet were orange. And I was like, "Oh, my goodness. What is going on? I'm turning orange." And now—and then he took me to three pills again, and it started bothering my stomach. (Edom)

**Dependency on substances.** Women reported dependency on substances (i.e., tobacco, alcohol, and illicit drugs) for comfort while managing HIV. These women noted difficulty with HIV treatment engagement. Women who managed to take ART together with these substances noted an interference with ART potency. One participant described how she used these drugs to self-medicate: “I, um, got on drugs. I stopped taking my medications. I was self-medicating myself with the drugs and drinking. I mean, it seems like I was trying to end my life quickly by using drugs” (Eunice), whereas another participant described how she was adhering to her treatment but also using drugs: “The negative part about it because it [zidovudine] wouldn’t work for me when I was on drugs. The medicine—I was taking it, but it didn’t work. Because I was drinking and drugging...” (Jane).

**Perceived benefits on overall health.** Women reported that engagement in other multidisciplinary aspects of their health spurred engagement in HIV treatment. For example, positive aspects of engagement in substance-use cessation programs, by receiving treatment in a rehabilitation center, by having long-term substance abuse remission, or even having short-term breaks from drug use, helped these women overcome barriers to HIV care engagement:

So, ever since I been like not having to use drugs, I don’t have to worry about going to the hospital for depression. I didn’t have to worry about going to the ER for any kind of chest pains or anything else because I been compliant to what I have to do. (Rosa)

Women who completed these programs were more comfortable receiving HIV treatment and felt better about their overall health.

**Gained HIV-related knowledge.** Some women recounted how having HIV led to an increased knowledge of the disease, as women embarked on their own personal research to learn more about their condition. The attained knowledge helped in dispelling myths, preconceived notions, and biased beliefs they had about the disease and increased their motivation for treatment engagement:

Once I started educating myself and learning more about it, you know, because I was diagnosed in 1993, so a lot of people were dying. And it was the medications and the side effects, and you know, it was scary. You know, I was very scared...I’m always doing research, you know. If like—if there’s a study about it, I try to get into a study so I can learn more about it. This is how I learned about the disease, you know, but it was hard. (Rosa)

Thus, women who reported an increased awareness about the disease and exposure to more HIV-related knowledge were more open to treatment options and engagement.

**Managing comorbidities.** Most women stated they were dealing with physiological and psychological comorbidities, including cardiovascular, metabolic, pulmonary, and renal diseases, bipolar depression, and anxiety, among others. Women reported feeling discouraged from taking ART for fear it would exacerbate symptoms of the other illnesses and expressed fear of dying from a potential exacerbation. The increased need to frequently screen themselves for these comorbidities and the extra pills they had to take, in addition to ART, contributed to HIV treatment disengagement:

I don’t just have HIV. I have other conditions. I have so many pills, and then you have so many, um, you have extra, um, doctors’ appointments instead of more than the regular healthy negative person. And then we have the normal appointments because we are aging. (Helen)

Many participants also reported experiencing mental health challenges. Some already had prior psychiatric history, including depression, anxiety, post-traumatic stress disorder, schizophrenia, and suicidal ideations, whereas others stated having HIV caused their psychological stressors. The added burden of managing these psychological stressors, together with HIV, was a deterrent to treatment engagement.

I suffer from bipolar depression through finding out that I was HIV positive. I mean, all of the stuff—all of the stuff just compounded at one time. So, now I’ve got to not only deal with HIV, I got to deal with depression, too. Because being HIV positive, it can send you in a state of depression, you know, because it’s like, why me? (Rosa)

One exception to the negative influence of additional medical comorbidities were situations wherein the severity of the comorbidities, alone or with HIV, caused women to return to care. One woman had reported not taking her ART for 5 years until she got cancer, which spurred her to return to HIV treatment.

I didn’t take pills for 5 years. I didn’t have to take anything because my body, although I had the virus, my body was good because I took vitamins. So, my body was good. When I started taking them is when I got cancer. So, the doctors made me start taking them. (Shanda)

**Caregiving roles, work schedules, and competing demands on time.** The overwhelming nature of handling paid work, household responsibilities, and other life stressors was reported as a hindrance to engaging in treatment, particularly with attending medical appointments. For example, appointment times conflicting with work schedule, job instability, and caregiving roles all deterred engagement.

And then, you have to still do all the regular stuff everybody else do. All your errands, you know? All your household responsibilities. Then your responsibilities to your social group, like whereas your friends, your family. So, it, gets to be overwhelming. (Helen)

### **Themes at the Interpersonal Level**

These factors relate to the influence of relationships between BOWLH and persons in their immediate environment and social networks, such as family, peer groups, and health care providers, which influenced treatment engagement. The main themes in this level were the influence of caregiving roles and household responsibilities, social support (or an absence thereof), and HIV disclosure, on engagement.

**Caregiving roles as extrinsic motivation.** Some women reported feeling motivated to seek care due to their caregiving roles. Their zeal to stay healthy was motivated by the care they provided their spouses, children, and grandchildren. As one participant stated:

I had to get my life together because of them kids. Especially the first one—the first-born. I had to get my life—I had to change it...My son is about to have a baby—his wife—his girlfriend. (Jane)

**Support from family, friends, and HIV care providers.** Other women received support from family, HIV support groups, and health care providers, which positively influenced engagement. One woman recounts emotional support from her family members:

Yes, my whole family. I told all of them...They all hugged me, and kissed me, and I started crying. And they said, "It's going to be all right, just don't miss your meds." And I don't miss them. I take them. (Divine)

Some women in seroconcordant intimate relationships reported support from their partners, which fostered medication adherence. These women and their partners supported each other with medication reminders. One woman recounts, "So, it's good when you have a partner, you know? You help each other. [They] remind you—'You take your piggy'?" (Daniella). Another woman recounted how she and her partner turned it into a fun contest: "Because my significant other, he takes the medication too, we have a contest" (Rochelle). Participants recounted the positive influences of joining HIV support groups, and learning from the experiences of other BOWLH encouraged and motivated women to keep up with treatment:

I was going to group, and I started meeting and talking to people that was HIV positive and was going through the same

thing that I was going through, and I started realizing I'm not alone, and so, I have other people that's fighting this disease. (Olivia)

Positive relationships with health care providers were described as facilitating engagement. Participants reported openness and trust in their providers, which fostered engagement:

You know—it's a relationship that you have with your doctor. My doctor is everything. I mean, my doctor is good. I can tell him—uh, sit down and tell him my deepest secrets, my deepest thoughts, and he will sit there and listen and—and, you know He's a friend. He's—he's my friend. He's my doctor. You know. (Jennifer)

However, some women reported stigmatizing negative encounters with their providers, which deterred engagement. One participant shared the following experience:

When I was in the hospital... she [the nurse] went and got me some ice, and I was going to hand her the cup back. She reacted, said she didn't want the cup back. She say, "Don't give me that cup." She just froze up, and she was scared. (Helen)

**The effects of HIV status disclosure.** There were benefits and consequences of HIV disclosure cited by the women. In disclosing, some women experienced a stronger bond with the person with whom they shared their diagnosis and, thus, more support from said person, which aided engagement. One benefit of disclosure was developing closeness with family, and friends, which fostered support.

My kids the only one I came out to. Um, I told them my status, and I asked them how they felt about me, because it was very important to me how my kids felt. And my son say it didn't make any difference to him, that I'm still his mother. So, um ... that made me feel good. (Helen)

Some other women recounted instances of discrimination and rejection from their families and friends, which deterred engagement.

So, when she found out that I was sick and I told her, she didn't want to have nothing to do with me. So, I went back to the streets and lived out there. My sisters and brothers—they didn't want to take me. You know, my friend ain't turned her back on me. But my mama did. My sisters and siblings did—two people that turned—three people that turned their back on me. (Jane)

For women who had not disclosed their status due to perceived discrimination, their most cited fear was a confidentiality breach. This hindered engagement, as women feared that, although they might disclose to persons whom they trust to provide support, such persons might share news of their status with others who might not be as supportive in their attitudes toward

them. One participant shared this concern: “If you tell one person—Everybody just talk. You know, when peoples know—you can hear peoples in the background, or everybody looking at you in a special way. You know—So, I’d rather just keep it to myself” (Eve). The fear of discrimination secondary to a confidentiality breach caused this woman to keep news of her diagnosis private, which might have been at the cost of inadvertently curbing supportive networks.

### ***Themes at the Community Level***

This theme addresses the relationship between women and structural infrastructures in their communities. These were mainly related to difficulties with health care access and included issues regarding transportation, negative effects of stigma, stereotypes, and assumptions about BOWLH and HIV awareness within the communities.

**Transportation factors.** Transportation issues were apparent in conversations with the women as influencers of HIV treatment engagement. For example, easy access to a reliable, safe, and comfortable means of transportation was cited as a facilitator: “I have a bus card and I’m sure to come in if I have an appointment” (Rochelle). Conversely, limited access to transportation was described as a major barrier to treatment engagement: “I just don’t feel comfortable going on the bus because I’m not very good with directions. I get lost in... And I’m not gonna go in an area that I don’t know, and I feel I’m gonna get lost” (Helen).

**Influence of HIV-related stigma.** Women reported experiences of perceived or actualized stigma within their communities, because of their HIV, which deterred engagement. These participants avoided being out in their neighborhoods so as not to be recognized by familiar faces from the HIV clinic, and this hindered their ability to attend treatment appointments. One woman recounts her experience: “Especially in my neighborhood, the women—I know a girl, she isolates herself. She doesn’t even like to be seen talking to me because she knows I’m positive because she knew me from the clinic” (Daniella). Another participant recounted her negative experiences living with a friend who refused to help her while she was sick.

When I moved in with her with this virus—she like paper plates, paper spoons, paper cups—everything I had to use paper. And that hurt me so bad that she didn’t want to accept that I was sick and help me. (Jane)

**Stereotypes and assumptions about older women living with HIV.** Women acknowledged that certain

stereotypes held of older women living with HIV may deter adequate treatment and engagement. One such stereotype is that older adults are not willingly engaging in sexual activity, which often hinders their provider’s attention to the presence of a sexual problem or health risk, hence, impeding effective management of HIV. One woman recounts: “Nobody recognizes that older people are still having sex or being forced to have sex or, ‘Because I can’t have babies, I’m not going to get nothing. I can’t get a baby, so I can use no condoms,’ a lot of that kind of stuff” (Daniella).

**Raising HIV awareness in the community.** Women believed that raising HIV awareness in their communities can positively affect treatment engagement by increasing HIV-related knowledge. Women provided suggestions for improving HIV-related knowledge, such as using print and digital media, and roundtable conversation, among others. One woman emphasized the importance of education provided by fellow older women, “You need older people to talk to older people. Okay? Um—Older people are afraid...So, you need older people, people in that age range that could let them know that it’s okay” (Shanda).

Further, some women acknowledged the difficulties in reaching out to certain vulnerable populations and involving them in HIV treatment programs.

In prevention?—It’s hard to get, in this Hispanic community, and in African American communities too, it’s hard to get them to come in and learn how to keep from getting sick. For me, it’s educating someone who doesn’t have it, saying, “Let me tell you, anybody can get this. Anybody.” (Daniella)

### ***Themes at the Societal/Public Policy Level***

The social determinants of HIV treatment engagement within this level were related to public laws and policies. These included health insurance policies, HIV as a reportable crime, and the roles of public service agents.

**Difficulty obtaining health insurance.** Women described difficulty with getting preferred health insurance, especially Medicare, which were all related to daunting policies and bureaucratic processes in applying for them. One woman recounts: “I can’t get Medicare. I have Medicaid now, but I want Medicare too. My friend sitting at the VA, he get Medicare. He gets the right transportation. People with Medicaid don’t get much. I notice that” (Rochelle). Without health insurance, BOWLH faced an extreme challenge to engage in treatment because they were unable to afford medications and medical appointments.



**The influence of HIV state laws.** Women also described encounters with public service agents that facilitated HIV treatment engagement, albeit in an unconventional way. In Florida, it is a third-degree felony to have sex with someone (with a condom or not, virally suppressed or not) without disclosing your HIV status (The Center for HIV Law and Policy, 2020, 2021). Women described encounters with public service agents that incited fear of persecution, which motivated them to be more vigilant about their health.

I actually got arrested for prostitution one time and the judge says if you get another prostitution charge, we're gonna charge you with murder, and that's when I stopped. That's the real truth. If you get arrested for prostitution and you're HIV, that's a—that's a murder charge...And that's the law. I know the system. I know the law very well. (Kelly)

Another woman recounted her doctor's warning from missing medical appointments, which caused her to be more alert in taking care of herself, "Doctor told me, if you don't show, we're calling the police on you" (Rochelle).

## Discussion

Through our study, we identified that HIV treatment engagement among BOWLH is affected, both positively and negatively, by numerous social determinants of health, across the four levels of the SEM. Effective management of HIV and viral suppression can only be achieved when BOWLH are optimally engaged in treatment, thus growing the knowledge base around barriers to engagement is a critical first step. Beyond ART adherence, other aspects of HIV treatment engagement must be considered in the discourse regarding successful treatment and management of HIV. Prior research has established the impact of socioecological and psychosocial factors on the HIV management among older women (Durvasula, 2014; Rubtsova et al., 2017; Sangaramoorthy et al, 2017a, 2017b; Warren-Jeanpiere et al., 2014); however, a paucity of research exists for Black older women. This is the first study investigating a more robust outlook on HIV treatment engagement and using a social determinant of health approach to explore facilitators and barriers on a population—BOWLH—disproportionately affected by HIV, and in a geographic region with one of the nation's highest new HIV infection rates (CDC, 2020d).

At the intrapersonal level, facilitators of HIV treatment engagement included increased HIV-related knowledge and positive attitudes to care. These findings are congruent with literature related to HIV treatment management among older African American women living with HIV, wherein women seemed

tolerant of their treatment regimen, acknowledging the impact of taking it one day at a time (Warren-Jeanpiere et al., 2014) and the impact of self- or physician-initiated HIV-related knowledge (Sankar et al., 2011). Black older women living with HIV in this study recounted feeling intrinsically motivated to seek care motivated by physical factors such as noticeable deterioration in health. Thus, increasing HIV-related knowledge may spur engagement practices among BOWLH. Other facilitators of engagement at the intrapersonal level included: following a routine, using reminders, easy access to and administrations of pills, among others. These findings are consistent with research investigating facilitators and barriers to ART compliance (Sangaramoorthy et al., 2017b) among BOWLH. Perhaps encouraging BOWLH to adopt such practices might improve engagement for those who are disengaged.

The barriers to engagement among BOWLH at the intrapersonal level were mainly related to low socioeconomic status, managing other medical comorbidities, and competing demands on time. Low income as a deterrent to timely initiation of ART and retention in care among BOWLH have been reported in other studies (Sangaramoorthy et al., 2017b; Warren-Jeanpiere et al., 2014). Although managing comorbidities was a burden for some women and deterred engagement in HIV treatment, it inspired engagement for others. These conflicting effects of comorbidities on engagement are present in the literature, wherein having other comorbidities was both a facilitator (Abara et al., 2014) and a barrier to engagement (Abara et al., 2016) among older adults living with HIV. Given the high prevalence and negative influence of medical comorbidities among BOWLH (Warren-Jeanpiere et al., 2014), health care providers should provide thorough assessment of Black older women's confidence and knowledge related to managing HIV and comorbid disease. For patients with low incomes struggling to meet basic needs, transportation and food vouchers may be an important intervention to assist them and encourage their engagement.

We found that managing household responsibilities and having caregiving roles both facilitated and deterred engagement, particularly in relation to attending medical appointments. Similar to the study by Warren-Jeanpiere et al. (2014), women in our study also reported feeling overwhelmed by household responsibilities in managing care when combined with care for other comorbid conditions. Conversely, household responsibilities that involved caregiving roles to significant others were a motivation to seek treatment so as to remain healthy while caring for their loved ones. Studies have reported similar findings of caregiving roles as facilitators (Warren-Jeanpiere et al., 2014; Webel &

Higgins, 2012) for treatment engagement. For the women who encounter barriers to engagement related to time conflicts with their household responsibilities and medical appointments, health care providers should be considerate when scheduling medical appointments with these women. For example, fewer appointments may benefit the more adherent and virally suppressed. Other solutions might consider frequency and duration of these appointments or choosing virtual or telephone appointments when/if possible based on patient's health outcomes, particularly for those traveling from a far distance.

Another social determinant at the intrapersonal level that acted as both facilitator and barrier was religion, which had both a positive and a seemingly negative effect. The positive influence of religion served to strengthen participants' faith and encourage them to seek care. This finding is congruent with research showing the positive impact of religion on the psychosocial health of Black and Hispanic older women living with HIV (Cianelli et al., 2020). As a barrier, some women became heavily reliant on their faith for cure, neglecting the influence of science and medicine. Providers should be cognizant of these beliefs and educate patients who might be ignoring the role of medicine and science in their treatment. This could be achieved by taking a harm reduction approach, supporting women to engage in their beliefs while also providing support for them to engage in treatment.

At the interpersonal level, the social determinants of engagement for BOWLH were social support and HIV status disclosure to family, friends, and health care providers. The role of social support as a facilitator for BOWLH for HIV treatment cannot be underestimated. Literature highlights the importance of having supportive social networks and relationships on health outcomes of older women living with HIV (Grodensky et al., 2015; Psaros et al., 2015; Rubtsova et al., 2017), particularly Black women (Sangaramoorthy et al., 2017a, 2017b; Warren-Jeanpiere et al., 2014). Social support is one of the direct positive influences of HIV disclosure. Women feel comfortable engaging and sharing their treatment plans to supportive family members and friends to whom they have disclosed their status. As seen in this study, women may stray from acts of engagement so as not to unknowingly divulge their status to unsupportive others in their social networks. Providers should be cognizant of BOWLH's sources of support and, when none is present, refer them to social workers, peer support groups, or HIV peer counselors.

Some participants reported that HIV disclosure led to discrimination from support people and, in certain instances, within the health care system. These reports are

congruent with literature findings of stigma and discrimination as a deterrent of engagement among BOWLH (McDoom et al., 2015; Sangaramoorthy et al., 2017a, 2017b). Evidence exists on the presence of social isolation among BOWLH (Cianelli et al., 2020; Durvasula, 2014) resulting from stigma, discrimination, and shame because these women hold important positions of prominence in their social circles that might be attributable to culture (Gallant et al., 2010). At the community level, acts of discrimination were mainly driven by HIV-related stigma. Some women reported not wanting to be seen at clinics or with certain doctors known to be HIV care providers in the community. HIV-related stigma is often a result of limited knowledge and awareness about the disease, leading to preconceived negative judgments of people living with HIV, as seen in this study. Studies in the literature have buttressed this point equally, especially among Black women (McDoom et al., 2015; Sangaramoorthy et al., 2017a, 2017b). Black older women living with HIV should be provided continuous support and education concerning the disease and ways it can be managed. Thus, the findings emphasize the importance of developing HIV peer groups within the community and in health care systems, which can provide support at the inter/intrapersonal and community levels.

Stigma and discrimination may also lead to non-adherence with ART. BOWLH tend to be caregivers to important others (e.g., families, friends, social networks; Gallant et al., 2010; Warren-Jeanpiere et al., 2014), particularly children and grandchildren who often cohabitate with them, as seen in this study. This might prompt reasons for women who have not disclosed their status to be discreet with medication administration. Thus, health care providers ought to be cognizant of these family-related barriers and provide education and/or counsel where needed.

At the public policy level, health insurance policies and their influences on obtaining coverage may be a barrier to optimum HIV treatment engagement for some women. Studies have highlighted this finding among BOWLH (Sangaramoorthy et al., 2017b; Warren-Jeanpiere et al., 2014). Also, state laws regarding HIV were described as a facilitator of engagement, albeit in an unconventional way that incited fears and distress in persons who did not engage in treatment. Women who were informed that they could face felony charges for engaging in sex work or other acts of risky sexual behaviors were more likely to engage in HIV treatment. This finding is new among the population of BOWLH literature and shows the influence of justice on HIV treatment engagement.

These findings illuminate certain HIV treatment engagement practices that might be culturally founded among BOWLH. Future interventions should consider that older Black women tend not to utilize professional health services and choose to cope with problems in other ways. Spirituality is frequently described as a common coping mechanism (Ward et al., 2014). Interventions should address several other issues, such as intimate partner violence, gender inequality, and partner deception (Sangaramoorthy et al., 2017a, 2017b), which BOWLH often confront and which can affect their treatment and maintenance of a healthy lifestyle. Also, stigmatizing attitudes from partners and family members can lead to shame, guilt, anger, distress, and self-hatred, all of which can have a negative impact on BOWLH treatment (Sangaramoorthy et al., 2017a, 2017b).

### **Limitations**

This study has a few notable limitations. First, the sample was recruited from a specific geographic location, limiting the generalizability of results to BOWLH in other geographic settings. The study is also limited by recall bias. Some of these women were diagnosed with HIV decades ago, and their responses might have been impeded by difficulties in recalling those memories. In addition, social desirability bias could have affected participants' responses. To avoid this, anonymity was reminded before the interview, leading questions were avoided, and word choice for questions was kept neutral.

### **Nursing Implications**

This study has implications for nursing education, clinical practice, research, and policy. Several BOWLH acknowledged the positive influence of HIV-related knowledge on treatment engagement. Participants stated they were unaware of HIV before their diagnosis. However, the intrinsic motivation to recover and regain their lives led them to learn about the disease. In increasing knowledge related to treatment engagement for BOWLH, curricula changes in nursing courses should focus on health disparities and social determinants that negatively influence health outcomes for BOWLH. Certain stereotypes and assumptions held of older women living with HIV, particularly those alluding to an inactive sex life, should be addressed in these courses. The considerations are especially important for Black women who might be more prone to living in racially segregated regions and unsafe neighborhoods and have potential for exposure to risky sexual behaviors in these neighborhoods (Sharpe et al., 2012).

In incorporating this study's findings to the clinical setting, nurses play a pivotal role because they spend a significant portion of their time in direct patient care (Kakushi & Evora, 2014). Nurses could provide phone call reminders to BOWLH struggling with treatment engagement. Home visits by the nurses might also be worth considering when protocols and resources allow, particularly for women who have been lost to care for long periods. Health care providers should be flexible and accommodate changes to their patients' appointments when such extenuating needs arise. For BOWLH managing comorbidities, the knowledge of pharmacology becomes very important. Nurses should be able to provide education on polypharmacy with specific focus on drug interactions, side effects, and overall nursing management of other medical comorbidities. Nurses can also emphasize the importance of ART in treating HIV in the context of their faith or religious beliefs. Finally, nurses should promote holistic well-being among BOWLH by encouraging healthy dietary and sleep practices, physical activity, involvement in the community, and engagement in other aspects of their physiological (dental and eye care) and psychosocial health (e.g., substance use cessation programs).

### **Conclusion**

Findings from this study illuminate factors to HIV treatment engagement for BOWLH and have implications for research. We found that BOWLH facing multiple structural vulnerabilities (e.g., low income, struggling to meet basic needs, low HIV-related knowledge, living in communities prone to stigma, and living with comorbidity) might be at increased risk of disengagement from HIV treatment. More research is needed to support these results and, thus, develop effective interventions to eliminate these barriers and encourage engagement in treatment for this population. Screening tools could be developed to identify patients likely to disengage from treatment, thereby stratifying those who are most at risk and need the most support and resources to engage in treatment. Such women could be proactively identified with the use of screening tools and adequate interventions put in place to avoid disengagement from treatment.

### **Disclosures**

The authors report no real or perceived vested interests related to this article that could be construed as a conflict of interest.

### **Author Contributions**

All authors on this article meet the four criteria for authorship as identified by the International Committee of

Medical Journal Editors (ICMJE); all authors contributed to conception and design, acquisition of data, or analysis and interpretation of data; drafting the manuscript or revising it critically for important intellectual content; providing final approval of the version to be published; and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Specifically, using the CRediT taxonomy, the specific contributions of each author is as follows: Conceptualization: E. Ojukwu. Methodology: E. Ojukwu, R. Cianelli, N. Villegas, G. De Oliveira, and V. Kalu. Formal analysis: V. Kalu and E. Ojukwu. Funding acquisition: R. Cianelli. Writing—original draft: E. Ojukwu and V. Kalu. Critical review for intellectual content: R. Cianelli, N. Villegas, and G. De Oliveira. Writing/revising—E. Ojukwu, V. Kalu, R. Cianelli, N. Villegas, and G. De Oliveira.

### Key Considerations

- Black older women living with HIV (BOWLH) have additional caregiving roles to their grandchildren, social networks, and other work responsibilities. Better management of the disease should include treatment appointments and regimens that accommodate these needs and are less time-consuming.
- Many BOWLH have additional medical comorbidities, and effective education must be provided to effectively manage those, in addition to HIV.
- BOWLH suffer greatly from socioeconomic hindrances. Thus, interventions that enhance adherence, such as providing them with travel and food vouchers, and less bureaucratic health insurance options may encourage engagement.
- Some BOWLH continue to engage in sexual activities and use substances. Education on safe sex and substance use cessation are highly recommended for this population to encourage effective treatment.
- BOWLH may be unaware of HIV state laws and may benefit from reminders provided by their health care providers.
- The study illuminates certain HIV treatment engagement practices that may be culturally founded among BOWLH, such as spirituality, gender inequality, and stigmatizing behaviors from intimate partners and family members.

### Acknowledgments

This study was funded by the Robert Wood Johnson Foundation (RWJF-ENF-71968; R. Cianelli, PI) grant. The authors would also like to acknowledge Kristen Haase, PhD, RN, for her assistance in peer revision of the manuscript.

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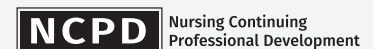
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