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HIV Stigma, Retention in Care, and Adherence Among Older Black Women Living With HIV

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Stigma is recognized as a barrier to the prevention, care, and treatment of HIV, including engagement in the HIV care continuum. HIV stigma in older Black women may be compounded by preexisting social inequities based on gender, age, and race. Using semi-structured interviews and survey questionnaires, we explore experiences of HIV stigma, retention in care, and antiretroviral therapy (ART) adherence in 35 older Black women with HIV from Prince George’s County, Maryland. Study findings indicated that older Black women experienced high levels of HIV stigma, retention in care, and ART adherence. Findings suggest that experiences of HIV stigma were intensified for older Black women due to multiple stigmatized social positions. Participants also reported experiences of marginalization in health care that hindered retention in care and ART adherence. Interventions aimed at improving HIV prevention, care, and treatment outcomes should incorporate HIV stigma reduction strategies as core elements.

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Key words: adherence, aging, Black women, HIV, stigma, women’s health

HIV is a major public health concern that disproportionately affects older Black adults. Black adults represent the largest proportion of those older than 40 years of age living with HIV (40%; Centers for Disease Control and Prevention [CDC], 2015a). They have the highest HIV prevalence rates of all racial and ethnic groups, a rate that is 2.3 times that of older Hispanics/Latinos and 6.5 times that of older Whites. Older Black women have been particularly affected by HIV and represent the majority (60%) of new HIV infections among all women older than 40 (CDC, 2015a). Moreover, racial disparities in the HIV care continuum—the progression from diagnosis to receiving optimal treatment—observed in the overall U.S. epidemic persist in older age groups (CDC, 2015b). Racial disparities in HIV-related treatment outcomes continue to exist for Black adults due to unequal insurance coverage, lack of access to medical services, uneven receipt of and adherence to antiretroviral therapy (ART), suboptimal patterns of health care utilization, existence of other serious comorbidities, and HIV stigma (Earnshaw, Bogart, Dovidio, & Williams, 2013). But very little is known about the unique challenges experienced by older Black women, especially related to their experiences.

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with HIV stigma, retention in care, and ART adherence.

Stigma is recognized as a critical barrier to the prevention, care, and treatment of HIV (Mahajan et al., 2008). HIV manifests in individuals as a highly stigmatized attribute (Duffy, 2005). HIV stigma, in turn, can interfere with effective treatment and viral suppression for people living with HIV (PLWH; Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013). Moreover, research has indicated that experiences of gender, age, and racial discrimination compound and intensify HIV stigma for older adults, women, and racial minority populations (Logie, James, Tharao, & Loutfy, 2011). Some researchers have called this phenomenon “intersectional stigma,” the ways in which multiple interdependent social identities—based on gender, age, race/ethnicity—lead to various experiences of discrimination and opportunity (Bowleg, 2012). HIV stigma may be intensified for older Black women due to their multiple stigmatized social positions and may negatively affect retention in care and ART adherence.

Much of the extensive literature on HIV stigma has focused separately on differences based on gender, age, race, and other demographic and social categories, overlooking the unique experiences and impact of stigma for those with multiple socially stigmatized positions such as older Black women. For instance, research on HIV stigma in women has highlighted the role of gender discrimination in compounding HIV stigma for women, while neglecting to consider how racism or ageism may also intensify stigma experienced by older or racial and ethnic minority women (Carr & Gramling, 2004; Sandelowski, Lambe, & Barroso, 2004). Likewise, studies that have examined racial and ethnic differences in HIV stigma among PLWH often did not attend to the unique issues that may arise for racial and ethnic minority women or older adults (Rao, Pryor, Gaddist, & Mayer, 2008). Finally, research has indicated that HIV stigma and ageism are significant concerns for older PLWH, but overlooked how older women or older adults from racial and ethnic minority populations experience and perceive stigma (Emlet, 2006). Studies employing an intersectionality framework have led to greater insights about the overlapping layers of stigma and oppression that function to shape differential experiences of HIV within marginalized groups (Caiola, Docherty, Relf, & Barroso, 2014; Earnshaw, Bogart, et al., 2013; Logie et al., 2011). More research is needed to understand the unique experiences of HIV stigma for those with intersectional identities, especially older Black women.

Using a social ecological approach that characterizes stigma both as a social process contingent on the social context and as a phenomenon experienced at the individual level, we explored how older Black women perceived and experienced HIV stigma, retention in care, and ART adherence (Link & Phelan, 2001; Parker & Aggleton, 2003). Research specific to how older Black women experience stigma and the potential impact of stigma on the management of HIV may help health care providers better develop optimal standards of care for a growing population of those aging with HIV. The purpose of our study was to explore HIV stigma, retention in care, and ART adherence in older Black women. Specifically, we used (a) semi-structured interviews to explore older Black women’s experiences of HIV stigma, retention in care, and ART adherence over the life course; and (b) a survey questionnaire to measure HIV stigma, retention in care, and ART adherence in our participants.

Methods

Setting

Prince George’s County (PGC), located between Baltimore, Maryland, and Washington, DC, benefits from a higher-than-average median household income and a low percentage of children in poverty. The majority of PGC residents also identify as Black (65%; U.S. Census Bureau, 2015). While this suggests a relatively positive economic situation and reflects a diverse population, PGC is an understudied, medically underserved area with some of the worst health outcomes in the state. PGC has the second highest number of HIV cases in Maryland behind Baltimore City. The Washington, DC HIV epidemic, ranked first nationally, also crosses the jurisdictional border into PGC, as the majority of HIV cases in PGC occur in areas adjacent to DC. With rates that are 5 to 20 times higher than those of White adults, Black
adults are disproportionately impacted by HIV in Maryland (Maryland Department of Mental Health and Hygiene, 2015). In Maryland, heterosexual transmission of HIV is slightly higher than homosexual male-to-male transmission, accounting for 35% of PLWH (Maryland Department of Mental Health and Hygiene, 2016). In addition, approximately a third of those who acquire HIV heterosexually (35%) are not aware of their positive status in Maryland (Maryland Department of Mental Health and Hygiene, 2016). The majority of women living with HIV in PGC are Black (90%). Older Black women represent 57% of all HIV-infected women in PGC (Maryland Department of Mental Health and Hygiene, 2015). Moreover, engagement in care is suboptimal for PLWH in PGC. Only 68% of PLWH are linked to care, while less than half (47%) are retained in care (Maryland Department of Mental Health and Hygiene, 2015). Fewer still (40%) are on ART and only 35% have achieved viral suppression (Maryland Department of Mental Health and Hygiene, 2015).

Participants

A total of 35 women were interviewed over a period of 13 months, from September 2014 to October 2015. Participant eligibility criteria included women who (a) self-identified as Black, (b) were 40 years of age or older, (c) had documentation of HIV seropositive status, and (d) had a primary residence in PGC. We used a purposive sampling technique to recruit participants from local HIV service organizations, county public health clinics, and federally qualified health centers. Participants then referred us to neighbors, friends, and colleagues. Case managers and outreach workers also identified potential participants and referred them to the research team.

Although 40 years is chronologically defined as middle-aged, definitions of aging can differ widely from traditional or community definitions of when a person is older (Cohen, 1994). Key stakeholders in our study setting, including the participants, reported that women ages 40 years and older should be considered “older adults” to mark the end of reproductive age. This age classification has been further specified in literature on Black women (Geronimus et al., 2010) and, for the purpose of our study, older women were denoted as being ages 40 years and over.

Design

We used semi-structured interviews and survey questionnaires to provide measurable evidence of HIV stigma, retention in HIV care, and ART adherence, and to deepen our understanding of how and why stigma manifested itself in older Black women. We chose to read the survey items aloud to participants to avoid issues with low literacy, as some women had less than a high school education and limited English proficiency. We used a semi-structured interview guide to expand on survey data and to explore older Black women’s experiences with HIV stigma, HIV care, and ART adherence (Table 1). The interview guide was developed

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sample Interview Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV stigma</td>
<td>• How are HIV and AIDS seen in your community?</td>
</tr>
<tr>
<td></td>
<td>• Do people make remarks in your presence that indicate that they are aware of your HIV status?</td>
</tr>
<tr>
<td></td>
<td>o Probes</td>
</tr>
<tr>
<td></td>
<td>• What kinds of remarks?</td>
</tr>
<tr>
<td></td>
<td>• How do these remarks make you feel?</td>
</tr>
<tr>
<td>Medication adherence</td>
<td>• How is your disease treated?</td>
</tr>
<tr>
<td>Retention in care</td>
<td>• How do you feel about taking HIV medications? Why?</td>
</tr>
</tbody>
</table>

Table 1. Sample Interview Questions
through discussions with HIV stigma experts, and was based on previous experiences of the authors and the relevant literature. Interviews lasted 45 to 90 minutes, with an average duration of 60 minutes. Participants were compensated $25 USD for their time, in accordance with community norms. Participants provided written consent prior to participation. All study procedures were approved by the University of Maryland’s Institutional Review Board. All interviews were conducted by the first and third authors (Table 1).

Measures

Sociodemographics. Information on gender, age, race and ethnicity, education, income, current employment status, and marital status was collected.

HIV stigma. HIV stigma was measured using a 27-item stigma scale adapted from the Multidimensional Measure of Internalized HIV Stigma Scale. The original measure was validated with a diverse sample of PLWH and designed to measure four key domains of stigma: HIV stereotypes, HIV disclosure concerns, social relationship stigma, and self-acceptance (Sayles et al., 2008). We modified this scale by omitting a single item to reduce redundancy. Similar to the original scale, all items were coded on a 5-point, Likert-type scale (i.e., none of the time, a little of the time, some of the time, most of the time, or all of the time), such that higher scores indicated more internalized HIV stigma across all four domains. In our modified scale, the four key domains were represented as subscales in the measure. The HIV stereotypes subscale included 11 items with possible scores ranging from 11 to 55; the reliability coefficient of the HIV stereotypes subscale was $\alpha = 0.89$. The HIV disclosure concerns subscale included five items with possible scores ranging from 5 to 25; the reliability coefficient for the disclosure concerns subscale was $\alpha = 0.87$. The social relationship stigma subscale included 7 items with possible scores ranging from 7 to 35; the reliability coefficient for the social relationship stigma subscale was $\alpha = 0.91$. The self-acceptance subscale included four items with possible scores ranging from 4-20; the reliability coefficient for the self-acceptance subscale was $\alpha = 0.73$. Total possible scores for the total stigma scale, therefore, ranged from 27 to 135, with an overall internal reliability score of $\alpha = 0.94$. We additionally calculated scores for each subscale by anchoring each item’s rating scale at zero, and dividing the subject’s subscale total by the range of possible scores for that subscale, which made it possible to directly compare scores across domains despite each relying on a different number of items (Emlet, 2007). The scale scores were as follows: HIV stereotypes, 0.6; disclosure concerns, 0.5; social relationships stigma, 0.4; and self-acceptance, 0.6. These scores indicated that, with this sample of women, although HIV stigma was high across all four subscales, HIV stereotypes and self-acceptance were of particular concern to these women (see Table 2).

Retention in care. Retention in care was measured using two indicators: (a) the number of HIV-related care visits scheduled in the past year and (b) number of kept visits of the total scheduled visits for HIV-related care. These questions captured the number of missed appointments and the proportion of appointments kept.

Table 2. Sample Stigma Measures

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Sample Survey Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV stereotypes</td>
<td>● People assume I have done something bad to get HIV.</td>
</tr>
<tr>
<td></td>
<td>● Society looks down on people who have HIV.</td>
</tr>
<tr>
<td></td>
<td>● People assume I slept around because I have HIV.</td>
</tr>
<tr>
<td>Disclosure concerns</td>
<td>● I am concerned if I go to the HIV clinic someone I know might see me.</td>
</tr>
<tr>
<td></td>
<td>● I am concerned if I have physical changes from the HIV medications people will know I have HIV.</td>
</tr>
<tr>
<td>Social relationships</td>
<td>● People treat me as less than human now that I have HIV.</td>
</tr>
<tr>
<td></td>
<td>● I feel abandoned by family members because I have HIV.</td>
</tr>
<tr>
<td>Self-acceptance</td>
<td>● I feel ashamed to tell other people that I have HIV.</td>
</tr>
<tr>
<td></td>
<td>● I am comfortable telling everyone I know that I have HIV (reverse code).</td>
</tr>
<tr>
<td></td>
<td>● It is important for a person to keep HIV a secret from co-workers.</td>
</tr>
</tbody>
</table>
ART adherence. ART adherence was measured using four questions: (a) Do you ever forget to take your HIV medication?; (b) If you feel worse, do you stop taking your medication?; (c) Did you not take any of your HIV medications over the past weekend?; and (d) What is the total number of missed doses in the past 7 days? The first three were measured dichotomously (Yes/No) and the final question was a continuous measure. Self-report data for ART adherence have been confirmed as a valid measure when compared to other indirect indicators of adherence including viral load and pill counts (Simoni et al., 2006).

Analysis

Semi-structured interviews were audio-recorded and transcribed. For qualitative data, we used analytic methods from grounded theory, including open and axial coding, development of core themes, and memo writing (Greene, Caracelli, & Graham, 1989). We used QSR NVivo 11 (QSR International, Melbourne, Australia, 2016) to code the transcripts using a thematic approach to data analysis (Steckler, McLeroy, Goodman, Bird, & McCormick, 1992). Major themes from the interview guides were used to conduct initial broad coding. New and emergent ideas were also captured at this stage. Data were analyzed a second time so that the initial broad codes could be further detailed into sub-codes. Examples of broad codes included stigma, experiences with retention in care, experiences with ART adherence, and changes over the life-course. Examples of sub-codes for stigma included public silence, HIV stereotypes, and avoidance and rejection. Examples of sub-codes for experiences with retention in care and ART adherence included facilitators and barriers and comorbidities. A finalized codebook of 52 unique codes was developed and discussed by the first and second authors; all transcripts were then recoded by the second author. The analysis process by the first and second authors employed the constant comparative method, following an iterative process of coding, analysis, and recoding based on inductive reasoning (Glaser & Strauss, 1968). Coded excerpts were then incorporated into written memos, expanding upon and further developing emergent themes.

Quantitative data were analyzed using SAS 9.3 (SAS Institute, 2011, Cary, NC). Descriptive statistics, including mean, range, frequency distributions, and percentiles were determined for all variables. We created an HIV stigma score by summing the total responses to the 5-point Likert scale. There were a total of 34 skipped questions out of 945 total responses (3.5%) on the stigma scale. Missing data were replaced with mean scores from appropriate subscales. Mean scores for each of the four subscales were calculated, and overall mean scale scores were calculated by averaging the four mean subscale scores. Analyses also included an inspection of item response rates. For reliability analyses, we derived internal consistency coefficients (alpha, $\alpha$) for the entire sample. We also created dichotomous measures of HIV-related stigma as 0 = none of the time and 1 = a little of the time/most/or all of the time. Those coded 1 were considered to have any experience with stigma for that subscale. From the dichotomous measures, we calculated the proportion of women reporting any experience with stigma.

Results

Sample Description

Women in our study ranged in age from 40 to 71 years, with a median age of 52, and included native-born African American ($n = 28$) and foreign-born, Black African participants ($n = 7$). Forty-three percent of the sample had a high school diploma, while only 9% had obtained an associate’s degree or higher. Approximately a third of our sample reported annual household incomes of less than $5,000 (USD; 31%) and more than $25,000 (USD; 33%). The majority of participants reported that they were mothers (86%), with an average of two children, and living with their children (46%). Equal numbers of women reported that they were single, never married (40%), or were separated/divorced (40%). The majority of participants had been diagnosed with HIV for more than a decade (78%), with many having lived for more than 20 years with HIV (Table 3).
Table 4 presents the summed HIV stigma and sub-scale scores. HIV stigma scores ranged from 29 to 127, with a mean of 70.3 (SD = 25.3). Eighty percent of the sample reported any experience with HIV stereotypes; 71% reported any experience with HIV disclosure concerns; 74% reported any experience with stigma related to negotiating social relationships; and 91% reported any experience with self-acceptance stigma.

Retention in care was high (Table 5). The women reported between 2 and 12 annual appointments for HIV care, with an average of four appointments (SD = 2). The 2014 Guide for HIV Clinical Care recommended that HIV-related laboratory blood work be performed every 3 to 6 months to check the CD4+ T cell count and viral load (Health Resources and Services Administration, 2014). The standard of care is determined by the health of the patient, with sicker patients requiring more frequent visits. Thirty women reported attending all scheduled HIV-related appointments, while five women reported missing only one appointment.

ART adherence was also high in the sample (Table 5). Thirty-three of the 35 women were actively taking prescribed medication. One woman reported never having met the medical threshold to begin ART and another woman reported discontinuing ART, despite her physician’s urging, and followed an alternative therapy called “Product B.” For the 33 women on ART, self-reported adherence was high, with 69% reporting that they were fully adherent in the previous week. Only 26% of women reported missing a dose in the previous week, and no one reported missing more than a single dose in that time. Additionally, only 17% of the women reported ever skipping medication when they felt worse.

### Theme 1: HIV Stigma

Public silence. For participants, HIV continued to be a stigmatized and stigmatizing subject in their communities. Despite increased public awareness of HIV, participants reported that public silence had remained fairly constant over their lifetimes. A participant noted, “Where I live, people are becoming more aware of it, but still not very comfortable with it.” Another participant stated, “No matter how much we progress on the medical side, it’s still dinosaur age as far as just the human part.”

Negative stereotypes. Participants also discussed the pervasiveness and consistency of HIV stereotypes within their communities, which continued to focus
on immoral or stigmatized behaviors. A participant explained:

I think people with HIV are still seen negatively. I think a lot of people really don’t look at the person singularly and how they came about and what happened, because we’re not all drug users, we’re not all screwing everybody, we’re not all doing this and that.

Participants also reported that HIV stigma continued to be pronounced for them due to negative stereotypes about Black women with HIV that had existed since the beginning of the epidemic. A participant recounted, “If you’re a Caucasian female, people are like ‘I’m so sorry!’ But if you’re a Black female, they’re like ‘Drug user ... prostitution.’” Such stereotypes were described as part of the ongoing struggle experienced by Black women within their communities. A participant stated:

When it comes to Black women, it’s just a part of what we go through. It adds to the burdens we

Table 4. HIV-Stigma Scores

<table>
<thead>
<tr>
<th>Subscale</th>
<th>N = 35</th>
<th>Subscale</th>
<th>N = 35</th>
<th>Subscale</th>
<th>N = 35</th>
<th>Subscale</th>
<th>N = 35</th>
<th>Subscale</th>
<th>N = 35</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Stereotypes</td>
<td></td>
<td>Disclosure Concerns</td>
<td></td>
<td>Social Relationship Stigma</td>
<td></td>
<td>Self-Acceptance</td>
<td></td>
<td>Total HIV-Stigma Scale Score</td>
<td></td>
</tr>
</tbody>
</table>
| Mean score (SD)               | 32.4 (10.9) | 11.3 (6.4) | 13.9 (7.9) | 12.5 (4.8) | 70.3 (25.3) 
| Range of observed scores      | 13-55  | 5-25  | 7-34  | 4-20  | 29-127  
| Range of possible scores      | 11-55  | 5-25  | 7-35  | 4-20  | 27-135  
| Index score                   | 0.6    | 0.5    | 0.4    | 0.6    | 0.5    

Table 5. Retention in Care and Adherence

<table>
<thead>
<tr>
<th>Frequency</th>
<th>N</th>
<th>Percent</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retention in Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many scheduled visits have you had in the past year?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-3</td>
<td>10</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>4-5</td>
<td>21</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>6 or more</td>
<td>4</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Of the scheduled visits over the past 12 months, how many were you able to keep?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All</td>
<td>30</td>
<td>86</td>
<td></td>
</tr>
<tr>
<td>Nearly all (1-2 missed)</td>
<td>5</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Adherence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you ever forget to take your HIV medications?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>17</td>
<td>48</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td>2</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Sometimes if you feel worse, do you stop taking your HIV meds?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>77</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td>2</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Did you not take any of your HIV medications over the past weekend?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>24</td>
<td>69</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td>2</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>What would you say the number of doses you have missed in the past 7 days is …</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>24</td>
<td>69</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>9</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>More than 1</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td>2</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>
already have. It’s just part of a Black woman’s struggle. Being a woman there are cultural issues within your family. It adds more to the burdens.

Avoidance and rejection. HIV stigma also affected our participants’ perceptions of disclosure. Many described disclosure as a major concern, expressing that keeping their positive status from others felt like a constant burden. A participant stated, “I have such a big secret. It takes a toll on me because you want to be honest, especially with close friends.” Another participant described how she kept her status a secret for decades because of the stigmatizing ways others around her talked about HIV, “I kept mine a secret until about a couple of years ago. I didn’t tell people because I listened to people talk about how other people have it.”

Fear and concerns surrounding disclosure stemmed from experiences of rejection from loved ones, colleagues, and health care professionals. A participant described her experiences: “When my mother knew I was positive, when I go to her house, if I used the bathroom I had to clean it. If I ate, I had to use a plastic plate and a fork.” Likewise, many participants recounted how they lost many friends after they initially disclosed their status. They were now very guarded about making new friends. A participant explained:

One time I went to my girlfriend’s house when I first told her. I went in her bathroom. She went in there and sprayed off the toilet. That made me feel really uncomfortable. I haven’t really seen her since and kept to myself.

Finally, some women described experiences of rejection from health care professionals:

It made me feel less than less. It set me up for stigma. You feel if the doctor is going to treat you this way, and they know the medical ins and outs of HIV, what would a normal person do to you? That made me more withdrawn from people. It made me not want to disclose my status. Because if she treats me that way, how would a regular average person treat me?

Such instances of public silence, negative stereotypes, and experiences of avoidance and rejection by family and friends led many participants to feel ashamed and guilty about the infection. A participant told us:

People think I’m a bad person because I have HIV. I don’t want to go visit my family. I just want to be home. Most of the time I’m home. When I work, I come from work and I go home.

Theme 2: Experiences With Retention in Care and ART Adherence

Facilitators and barriers. Participants mentioned that they had no difficulties remembering their appointments, and used calendars, phone alarms, and reminder calls/cards to keep track of appointments or medication times. Many stated that these appointments and medications had, over time, become a regular part of their “lifestyles,” built into everyday routines. The women’s narratives centered on structural challenges such as lack of access, no coordination of care, and routine financial hardship. Most participants had originally been diagnosed or had previously received care in nearby Baltimore or Washington, DC, where they described HIV care as highly coordinated. They depicted HIV care in PGC as “scattered” in comparison. Several women continued to travel long distances or considered moving back to Baltimore or DC because of this perceived difference in care. A participant told us:

Prince George’s County just really sucks in doing anything for anybody with HIV. Because it is like having leprosy or something. They just send you off to the island and just wait for you to die. There is no help for you. In DC and Baltimore, they’ve got these programs, assistance, and stuff free of charge. Us here in the middle? We’re just out, especially ethnic women.

Participants also mentioned financial constraints as a key challenge that prevented them from obtaining consistent HIV care or buying medications. A participant recounted her hardships with getting to appointments due to the high cost of public transportation in PGC and feeling stigmatized by the lack of public welfare programs available to subsidize the cost:

I don’t have the money. I have to get transportation. I’ll call Maryland Medicaid to try to get a
cab. The young lady will tell me that she doesn’t feel that I “need that” because I’ve been catching public transportation, so why can’t I keep catching it? That was another door closed in my face so I just said, “Forget it.” So when I don’t have that money, I don’t go to the doctor.

The additional costs of childcare also prohibited women from regularly attending HIV appointments. Many participants were primary caretakers of their children and grandchildren and couldn’t bring them to appointments. For instance, a participant who did not have enough money for childcare explained that she had not disclosed her status to her young son and worried that he would “see what was happening” at the clinic.

In addition, co-pays presented many challenges for participants. Even in the advent of the Affordable Care Act, participants expressed that the cost was still too prohibitive. For instance, a participant who was newly insured told us:

I have Obamacare now. The co-pay was a little bit high for someone who doesn’t work and I have a lot of doctor appointments. If you don’t be careful, you’re not going to be healthy because you have the co-pays.

To remain in care, the women described prioritizing health costs despite tight budgets, borrowing money from friends and family members, rescheduling appointments until they had money for a co-pay or, in dire circumstances, going directly to ambulatory care centers where they knew they could be treated without payment.

Financial concerns also affected the women’s abilities to stay adherent. A participant described her challenges, “It wasn’t the fact that I didn’t want to take my medicine– I couldn’t afford it!” Another woman described skipping medicine when she didn’t have enough to eat after running out of food stamps:

This week I took my pill and I didn’t eat, oh it made me so sick! It was like the medicine ate my stomach – I was sick. But I didn’t have no food. I said, “Should I take it? Should I not take it?”

The women reported several strategies to remain adherent, including relying on providers and pharmaceuticals to obtain free or discounted medicines, picking up pills in 2-week increments instead of filling an entire 3-month prescription at once, or even opting for HIV medications instead of medications for other chronic conditions.

**Comorbidity.** A key issue for participants was comorbidities. Participants said that, as older women, they suffered from numerous comorbidities that required additional health services. A participant explained:

I’ve had biopsy on my left, biopsy on my right. Right breast cancer with a mastectomy. I’ve had lung collapsed twice on the right. I’ve had a colpotomy twice. I had a scare with cervical cancer, but when they did the biopsy they got it all. My HIV. I have an enlarged heart. I have asthma. I have COPD [chronic obstructive pulmonary disease].

Some participants relied on as many as five different specialists to manage multiple conditions. As a result, many participants reported deep frustrations of feeling like they were “always at the doctor” or stigmatized by the tendency of providers to consistently ascribe all of their health concerns to HIV. A participant told us, “They always say, ‘You’re sick because of your HIV.’ I say, ‘No it ain’t, no it ain’t!’”

Participants said that they had difficulties managing multiple health conditions due to the prohibitive cost of multiple co-pays, the challenges of coordinating travel to see different providers, and complicated treatment plans that often required coordinating communication between different providers and being vigilant about potential drug interactions. A participant explained, “I make sure that my ID [infectious diseases] doctor knows my HIV doctor, my heart doctor, and my OB/GYN [obstetrician/gynecologist] so they can communicate together. I like for everyone to be on the same page.” Another participant noted that she stopped taking her ART while receiving treatment for breast cancer:

Going back and forth with the chemo every day and the radiation … it was too much. My doctor was telling me that it would affect my medication with the chemo, so I was like “You’ve got to take me off of that. When I finish, then you can put me back on.”
Additionally, participants reported feeling distressed having to explain their HIV to other specialists who they felt were not well informed. A participant stated, “I’ve finally found an infectious disease doctor that just handles everything! I think maybe that is all we need. Other specialists, that’s extra money and [they’re] second-guessing because they don’t normally see people with HIV.”

**Theme 3: Changes Over the Life-Course**

Despite persistent experiences and feelings of stigmatization, participants reported that they were more accepting of the infection as they aged and were better able to cope with negative public attitudes. A participant recounted, “Back in the day, it was first and foremost—you’re going to die. You wanted to die. No one’s going to love me. Not now. I’ve got to live my life. I’m so happy in my skin!” Participants expressed that the advent of effective ART, along with the passage of time, aided in their increased self-acceptance.

Participants also described a similar shift in their experiences with HIV care and ART adherence. They noted that during the initial months and sometimes years after receiving an HIV diagnosis, they did not keep regular appointments and frequently missed medication doses due to the stigma of having HIV. A participant recounted:

I was ashamed. I had them in the house and when people came over I had to hide. I had the ones that you had to keep it in the refrigerator. I didn’t want to keep them when the kids come over. I paid the price for that. When I got sick and went to the hospital, I vowed to take my meds every day.

Participants described this transition from being disengaged and distressed about their HIV care to being more committed as being motivated by a major life event such as getting sick or being hospitalized, the birth of a child or grandchild, or a death of a family member or close friend. Other times this choice was related to finding a trustworthy and compassionate provider. Still other women described the change as coming with the maturity of age. A participant explained:

I’ve got to the point in my care where I want to get better. I want to partake and do my part. I think as long as my condition declined, I didn’t want it to be where it is too late, where nothing would help. I think you get a little wiser when you get a little older.

Many participants recalled a past where they frequently felt stigmatized by their providers and unsure about their chances of survival. They now described consistent retention in care and mainly positive relationships with their HIV physicians. They depicted routine medical visits as integral to maintaining health and knowing their bodies. For instance, a participant explained, “I’m very on time with my meetings, my doctor. I don’t play with that, that’s my lifeline. I need to know what’s going on with my body.”

Although the women reported high levels of adherence, ART continued to be a significant dilemma for participants who viewed the drugs as both life saving and a constant reminder of HIV. A participant declared, “I hate them. But I know that I have to take them in order to live.” This dilemma was further compounded, as the women aged, by the realization that taking ART was a lifetime endeavor. A participant noted:

You know when you’re told you have to do it for the rest of your life? Even if it isn’t hard, but sometimes it seems impossible … for the rest of my life? Thinking about it is more of a challenge than taking it.

Women who had been on ART for a decade or more recalled taking dozens of pills and suffering from debilitating side effects, which continued to have a negative impact on their adherence. Participants also described serious concerns about the long-term health effects of taking ART, expressing a desire to eventually stop taking medication.

**Discussion**

We explored HIV stigma, retention in care, and ART adherence among 35 older Black women from PCG using semi-structured interviews and survey questionnaires. Overall, we found that HIV stigma
continued to be a critical issue for older Black women. In semi-structured interviews, participants revealed that despite increased public awareness, community perceptions of HIV and negative stereotyping of PLWH continued to be highly stigmatizing. These perceptions often led to experiences of rejection by family and friends and internalized feelings of shame and guilt.

In our sample of older Black women in PGC, there were also high levels of HIV stigma as measured by our scale and across all sub-domains. Our findings were consistent with the only other study completed to date that measured HIV stigma rates in a diverse sample of older PLWH (Emlet, 2007) and a handful of studies focused on how community-level HIV stigma intensified stigma for HIV-infected Black women of all ages (Black & Miles, 2002; McDoom, Bokhour, Sullivan, & Drainoni, 2015; Rao et al., 2008). However, our findings indicated that older Black women, who increasingly make up a large proportion of those aging with HIV, experienced high levels of HIV stigma.

Our findings also indicated that HIV stigma intersected with and was compounded by multiple forms of marginalization associated with race and gender. Semi-structured interviews revealed that negative stereotypes about Black women with HIV related to sexual promiscuity and drug use intensified our participants’ perceptions of HIV stigma. This suggests the presence of intersectional stigma, stemming from long-held stereotypes of Black adults as hypersexual and deviant (Collins, 2004). Such findings contribute to the growing literature on intersectionality and HIV stigma (Earnshaw, Smith, Cunningham, & Copenhaver, 2015; Logie, James, Tharao, & Loutfy, 2013).

Both qualitative and quantitative findings indicated that participants were highly retained in HIV care and ART adherent. Our semi-structured interviews further revealed that participants developed a renewed interest in their own health and well-being through greater engagement in HIV care and treatment as they aged and lived longer with HIV. The literature on aging and HIV suggests that retention and adherence may improve with increased age because older adults have been found to demonstrate characteristics of successful aging such as self-acceptance, hopefulness, and resilience even as they faced serious challenges with HIV and other comorbid conditions as they aged (Emlet, Tozay, & Raveis, 2010; Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011).

However, our findings demonstrated that the structural context, especially within PGC, hindered retention in care and ART adherence. Older Black women suffered from numerous comorbidities that required complex coordination of care, which was often difficult due to the financial burden of multiple co-pays, coordination of travel for numerous health appointments, and management of sometimes competing treatment plans (Warren-Jeanpiere, Dillaway, Hamilton, Young, & Goparaju, 2014). Our findings also indicated that ART was a significant dilemma over the life course, helping to promote feelings of self-acceptance but also serving as a constant lifelong reminder of HIV.

The emergent themes described in our study provide several important insights for future planning and research agendas related to HIV stigma and older Black women. Because HIV stigma is multidimensional and can be pronounced for marginalized populations, intersectional approaches such as those that consider different types of discrimination and disadvantage that occur as a consequence of the combination of stigmatized identities can inform HIV stigma-reduction interventions for older Black women. Few interventions have been effective in reducing HIV stigma, but among those that are successful, all have been narrowly focused on reducing HIV stigma in a specific population (Sengupta, Banks, Jonas, Miles, & Smith, 2011). Therefore, interventions that focus on intersectional stigma could be particularly helpful for reducing HIV stigma in older Black women.

Additionally, client-centered care with older Black women—engaging older Black women in their own health and health care—should be strongly considered by researchers and service providers, as they may lead to better understandings of resiliency, coping, and disease-management skills employed over the life course. This can help in designing culturally tailored services and treatment programs for a growing population of older adults with multiple comorbidities (Buseh & Stevens, 2007; Emlet et al., 2010). For instance, many women found that having their infectious disease physician provide
comprehensive care was highly beneficial in managing multiple comorbid conditions. This was consistent with findings that indicated that increased attention to comprehensive, coordinated, and economical care, such as targeted case management that included a multi-professional team of providers with HIV expertise as well as care coordinators and other specialists, could facilitate access and retention in care by those who had limited resources but complex physical and behavioral health care needs (Cheng, Engelage, Grogan, Currier, & Hoffman, 2014).

Limitations

This is one of the first studies to explore HIV stigma, retention in care, and ART adherence using semi-structured interviews and survey questionnaires, and it is not without limitations. Social desirability bias and self-report bias may have been a factor in women’s underreporting of HIV stigma or overreporting of retention in care and ART adherence. Utilizing biomarkers or chart review abstractions in addition to self-report data may be important for older Black women. Extended ethnographic investigations are also needed to illuminate how HIV stigma is understood and experienced by older Black women in everyday life and its impact on care and therapeutic interventions. Participants in our study were not selected randomly and their viewpoints may not reflect the perspectives of other older Black women living in PCG. Our study focused specifically on one county in Maryland and their local experiences of HIV stigma. While these findings cannot be generalized to other groups of PLWH, including other older Black women, they can help us understand the role of HIV stigma, particularly intersectional stigma, and its impact on retention in care and ART adherence in other populations facing similar issues.

Conclusion

HIV stigma is a critical issue for older Black women. Perceptions and experiences of HIV stigma by older Black women were often compounded by their multiple marginalized social positions, particularly those based on race and gender. Although the older Black women in our study were highly retained in care and ART adherent, they experienced multiple barriers to engaging with the HIV care continuum, including access to coordinated care in PGC, financial need, and the management of comorbidities. Overall, these older Black women experienced distinct changes over the life course that profoundly impacted their perceptions of HIV stigma, retention in care, and ART adherence. The content and structure of future intervention programming to improve older Black women’s engagement in the HIV care continuum should incorporate intersectional stigma reduction and successful aging strategies as core elements.

Disclosures

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

Key Considerations

- Older Black women with HIV experience high levels of HIV stigma and multiple forms of marginalization associated with age, race, and gender.
- Despite being highly retained in care and adherent to treatment, older Black women with HIV in our study reported experiences of marginalization in health care that hindered experiences with retention in care and ART adherence.
- Older Black women with HIV suffer from comorbidities that require complex coordination of care.
- Interventions aimed at improving HIV prevention, care, and treatment outcomes for older Black women should incorporate HIV stigma reduction strategies and successful aging strategies as core elements.
Acknowledgments

The work presented in this manuscript was supported by a seed grant from the University of Maryland NSF-ADVANCE Project. It was also supported through the National Institute of Drug Abuse (RO3 DA03713101; principal investigator [PI]: Dyer) and National Institute on Minority Health and Health Disparities Loan Repayment Program (PIs: Sangaramoorthy and Dyer). The findings and conclusions of this manuscript do not represent the official views or policies of the National Science Foundation or the National Institutes of Health. We would like to express our deepest gratitude and appreciation for the women who participated in this research and shared their stories, experiences, and expectations with our team. We thank the dedicated staff of our community partners including Heart to Hand, Greater Baden Medical Services, and the Prince George’s County Health Department for their assistance with research and data collection. We would also like to thank Emilia Guevara for research assistance. In addition, we thank three anonymous reviewers for their constructive feedback, which led to considerable improvements in this paper.

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