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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JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE, Vol. 28, No. 4, July/August 2017, 518-531
http://dx.doi.org/10.1016/j.jana.2017.03.003

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