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Intersectional Stigma Among Midlife and Older Black Women Living with HIV

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Abstract

HIV-related stigma is a barrier to the prevention and treatment of HIV. For midlife and older Black women, the nature and intensity of HIV-related stigma may be compounded by their multiple marginalised social status based on gender, race, and age. We examined the perceptions and experiences of HIV-related stigma among midlife and older Black women living in Prince George's County, Maryland, USA. Between 2014–2015, we conducted semi-structured interviews with a sample of 35 midlife and older Black women living with HIV. Using a modified grounded theory approach, we explored emergent themes related to the manifestation and experience of intersectional stigma and changes in stigma experience over time. Our findings suggest that intersectional stigma is a central feature in midlife and older Black women's lives, with women reporting experiences of intersectional stigma at the interpersonal/familial, community, and institutional/structural levels. Although women acknowledged gradual acceptance of their HIV-positive status over time, they continued to experience negative responses related to gender, race, age, and disease. Our findings indicate that a more robust understanding of the impact of HIV-related stigma requires work to consider the complex manifestations of intersectional stigma among an increasingly aging population of Black women in the USA.

Keywords

Aging; Black Women; HIV; Intersectionality; Stigma

Introduction

HIV-related stigma is a critical barrier to the prevention, care, and treatment of HIV because it impedes effective treatment and positive health outcomes for people living with HIV(PLWH) (Mahajan et al. 2008; Rintamaki et al. 2006). For women, racial and ethnic minorities, and older adults, the nature and intensity of HIV-related stigma may be greater due to pre-existing social inequities based on gender, race, and age (Carr and Gramling 2004; Earnshaw et al. 2013; Emlet 2006). HIV-related stigma intersects with multiple

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interdependent forms of social identities; however, our understanding of the intersectionality of HIV-related stigma remains limited, especially how it manifests and is experienced by those who claim multiple social group memberships such as midlife and older Black women living with HIV.

HIV-related stigma among midlife and older adults can be particularly challenging due to issues related to the loss of social support, management of comorbidities, and ageism (Emlet 2006). Treatment advances have resulted in the rapid growth of those aging with HIV and the majority (72%) of the US population currently living with HIV is 40 years of age and older (Centers for Disease Control and Prevention 2015). The cumulative effect of years of antiretroviral (ART) treatment on bodies and everyday lives is relatively unknown, and combined with the general physical and social effects of aging itself, the context of aging with HIV is complicated but understudied (Deeks, Lewin, and Havlir 2013; Mills, Barnighausen, and Negin 2012).

Moreover, HIV-related racial disparities observed in the overall US epidemic persist in older age groups. HIV is disproportionately high among midlife and older Black adults who represent the largest proportion of those over 40 years of age living with HIV (40%) (Centers for Disease Control and Prevention 2015). Black women are especially affected by HIV, representing the majority (60%) of new HIV infections among all women over 40 years of age (Centers for Disease Control and Prevention 2015). Furthermore, analysis suggests that gender and racial disparities persist at every step of the HIV care continuum (Hall et al. 2013). Of Black women diagnosed with HIV, 81% were linked to HIV care within three months, 51% were retained in HIV care, 51% were prescribed ART, and 40% had achieved viral suppression (Whiteside et al. 2014). These racial disparities in HIV-related health access and outcomes have persisted due to poverty, stigma, discrimination, residential segregation, and lack of access to care (Buot et al. 2014; Earnshaw et al. 2013). Midlife and older Black women, in particular, face a host of co-occurring social and psychological vulnerabilities that increase their risk of acquiring HIV and reduce their ability to be engaged in HIV care continuum (Brawner 2014; Davis and Tucker-Brown 2013; Sharpe et al. 2012).

In this article, we report on qualitative data collected as part of a larger mixed methods study investigating how midlife and older Black women perceive and experience HIV-related stigma (Sangaramoorthy, Jamison, Dyer, forthcoming). We conducted 35 semi-structured interviews with midlife and older Black women to examine experiences of HIV-related stigma to better understand the nature and intensity of HIV-related stigma, with a focus on how HIV-related stigma interacts and intersects with pre-existing social inequities based on gender, race, and age and how experiences of stigma change over time.

Stigma and HIV

Over 50 years ago, Erving Goffman's critical work described stigma as a powerful social phenomenon experienced by individuals who share a deeply discrediting attribute (Goffman 2009). The literature on stigma since Goffman's time has expanded rapidly and has sought to clarify and further develop this often ambiguous concept. Link and Phelan (2001), for instance, describe stigma as manifesting through a set of interrelated components:

identification and labelling of human differences; construction of negative stereotypes against labelled people; categorisation of labelled persons separating “them” from “us;” and outright discrimination of labelled persons leading to disparate social outcomes such as access to education, jobs, housing, and health care. Furthermore, scholars have maintained that stigma is also perpetuated at the institutional and structural levels, limiting stigmatized individuals’ access to social, economic, and political power. Processes and acts of stigmatisation, therefore, are instrumental in producing and reproducing social power relations and maintaining existing social hierarchies (Parker and Aggleton 2003).

Research has shown that stigmatising attributes are not naturally pathological, immoral, or deviant; rather, meanings embedded within culture give rise to, maintain, and alter such stigmatising attributes depending upon different historical and cultural contexts (Alonzo and Reynolds 1995). For instance, disease and illnesses, on their own, are not considered discrediting, but characteristics of disease as deviant and abnormal are culturally founded and propagated (Scambler 2009). HIV, in particular, presents the potential for unique and debilitating forms of multiple intersecting stigmas as a result of societal reactions to those most impacted by the disease. Research has shown that a significant component of the US public’s stigmatising position toward HIV is their negative attitudes toward gay men, people who inject drugs, and sex workers (Devine, Plant, and Harrison 1999; Fife and Wright 2000; Herek and Capitanio 1999). A large body of work also has illustrated that women, racial and ethnic minorities, and older individuals may experience higher levels of HIV-related stigma (Lekas, Siegel, and Schrimshaw 2006; Sandelowski, Lambe, and Barroso 2004). In these ways, stigmatisation and discrimination toward those living with HIV work to reinforce social inequality through both distancing and exclusion (Parker and Aggleton 2003).

More than negative attitudes and actions directed towards sufferers, HIV-related stigma is also internalised by those with HIV as feelings of shame, guilt, anger, distress, and self-hatred, and has been shown to negatively impact the way individuals approach their illness and the choices that they make about seeking treatment and care (Earnshaw et al. 2013; Lee, Kochman, and Sikkema 2002). Internalised or felt HIV-related stigma increases the stress associated with HIV, adds to secondary psychological and social morbidity, and affects the quality of life and physical health of those living with HIV (Fife and Wright 2000). Additionally, nondisclosure, as a result of stigma, diminishes the personal resources for health, mental, and social services, and limits treatment options for those living with HIV (Overstreet et al. 2013; Smith, Rossetto, and Peterson 2008).

Intersectionality and HIV

Proposed by feminists of colour as a lens through which multiple interdependent social categories could be understood and interpreted, intersectionality challenges singular conceptions of social identities and underscores how gender, race, ethnicity, class, age, sexual orientation, and other social formations interact and are mutually constituted in everyday life (Crenshaw 1991; King 1988). An intersectional approach makes visible these multiple dimensions of social identity and highlights the need to understand interrelated social dynamics as co-constitutive and relational rather than as a summation of independent constructs such as gender or race. Scholars from multiple disciplines have conceptualised

intersectionality as a framework for research, policy, and practice (Bowleg 2012; Choo and Ferree 2010). They have promoted intersectionality as a theory of social relationships and power dynamics, a methodology for understanding how individual experiences are shaped by broader structural and systemic inequalities, and a political imperative to build social coalitions and promote social justice issues. Furthermore, an intersectional perspective attends to the relational nature of power, where individuals and groups can simultaneously experience privilege and oppression (Weber and Parra-Medina 2003).

Much work on health treats social categories as separate or additive, and contributing to a cumulative effect on health. This approach overlooks the existing intersections of multiple social identities. However, intersectionality approaches to health-related research are growing, providing an innovative framework for examining intersections of social memberships and structural inequities and their impact on adverse health outcomes (Bauer 2014; Dworkin 2005; Hankivsky 2012). The nascent literature on intersectionality and HIV likewise has provided increased focus on HIV disparities and the development of culturally-relevant intervention strategies for vulnerable populations. For instance, researchers have argued for adequately addressing issues such as the cumulative effects of discrimination based on gender, race, ethnicity, immigration status, sexuality, and poverty within HIV research and resulting programmes so that this work is relevant to communities themselves (Bowleg et al. 2013; Caiola et al. 2014; Collins, von Unger, and Armbrister 2008; Logie et al. 2011; Oliver et al. 2015; Watkins-Hayes 2014). Those applying an intersectional approach to HIV research have also highlighted the need for research and policy to focus on issues of intersectional stigma and discrimination at the interpersonal, community, and structural levels (Logie et al. 2011). Given the complex nature of intersectional stigma, we aim to contribute to the literature by examining how stigma manifests among midlife and older Black women living with HIV.

Methods

Data Collection

Between September 2014 to October 2015, a total of 35 women were interviewed by the first and third authors using a semi-structured interview guide developed from discussions with community partners, HIV-related stigma experts, and authors' previous research. Interview questions explored domains related to experiences of living with HIV, relationships with providers, facilitators and barriers to care, social relationships and support, and everyday experiences of gender, racial, and age discrimination; interviews also documented how perceptions and experiences related to these domains changed over time, from the moment of diagnosis to the present day. Interviews lasted between 45 and 90 minutes, with an average duration of 60 minutes. Participants were compensated \$25 for their time. All study procedures were approved by the University of Maryland's Institutional Review Board.

Participants were eligible for the study if they self-identified as Black or African-American, were 40 years of age or older, had documentation of HIV seropositive status, and had a primary residence in Prince George's County, Maryland. Both purposive and snowball sampling techniques were used. We first recruited participants from local HIV service

organisations, county public health clinics, and federally qualified health centres, and these interviewees then referred us to neighbours, friends, acquaintances, and colleagues. Direct service staff such as case managers and outreach workers also identified potential participants and referred them to the research team.

Data Analysis

We employed a modified grounded theory approach, engaging in an iterative process of analysis and theory-building that allowed us to explore major themes related to intersectional stigma as they emerged from our data (Charmaz 2014; Glaser and Strauss 1967). All interviews were audio-recorded, transcribed, and entered into QSR NVivo 11 for qualitative data analysis. We engaged in multiple rounds of thematic coding, following the constant comparative method of coding, analysis, and re-coding based on inductive reasoning (Glaser 1965). First, we used open codes to identify broad themes, guided by the topics from the interview guide, but also incorporated new themes from the data. This was followed by axial coding, to refine and focus on themes that emerged specific to HIV-stigma, racism, sexism, and ageism. We used selective coding to group these themes into broader categories that assisted with theory development and organisation. Before and after each successive round of coding, the first and second authors met to debrief, discuss emergent themes, address discordant codes, and develop memos to expand upon new ideas. Our final codebook included a mix 52 in vivo and descriptive codes, built around three major themes: manifestations of intersectional stigma, experiences of intersectional stigma, and changes in stigma experiences over time. Through this process, we identified intersectionality as a lens through which to view and understand the multiple, overlapping levels of stigma that were voiced in interviews.

Results

Participant Characteristics

Our sample of women ranged in age from 40 to 71 years, with a median age of 52. Both native-born African Americans (N=28) and foreign-born, Black African participants (N=7) participated in the study. Of the sample, 76% had a high school degree or higher and approximately one third (33%) of our sample reported annual household incomes of more than \$25,000. The majority of participants were mothers, with an average of two children, and lived with their children at the time of the interview. Equal numbers of women reported that they were single, never married or were separated/divorced. The majority of participants were diagnosed with HIV over 10 years ago, with many women having lived for more than 20 years with HIV (Table 1).

Manifestations of Intersectional Stigma

Women's narratives highlighted the inextricability of gender and race in discussions of HIV-related stigma. Their social position as Black women in particular structured their perspectives and experiences of HIV-related stigma. For midlife and older Black women, HIV-related stigma manifested predominantly as prevailing stereotypes of who is likely to get HIV, stemming from common public misconceptions of how the disease is spread and its direct association with risky behaviours and marginalised groups. Participants reported that

manifestations of HIV-related stigma were often framed through negative stereotypes of Black women living with HIV. Toni, a 54-year-old married woman living with her husband and children, explained that these stereotypes were not new, and that they had been in existence since the beginning of the epidemic, “Then it was of course, if you were a Caucasian female, ‘I’m so sorry!’ but if you’re a Black female, ‘drug user... prostitute.’” Roberta, 47-year-old African immigrant and mother of two, summed up her perceptions of how others saw Black women living with HIV, “They see dirty. Very dirty. They’ll put your life down.” Moreover, HIV was described as just one stigma amongst many for Black women, “I had stigma before I was diagnosed. Just being Black is a problem. Being a Black woman with HIV, that’s another” (Annette, 56 years of age).

Unlike gender and race, women perceived age as a protective factor from HIV-related stigma. Shelia, 47 years of age, explained, “Being young, that’s a stigma in itself. Thank God I was older. Fifteen, 16, 17, they’ll have HIV. Imagine that. The trauma, the mental, and the stigma. Your friends knowing. They don’t know how to deal with that.” But age was also described as contributing to stigmatisation, particularly due to heightened feelings of defenceless and helplessness. Rita, a 52-year-old woman, recounted her struggles with relying on increasingly younger social workers:

I’m not going to open up my heart and talk to anyone younger than me. I tell them to give me a counsellor or a caseworker my age. I’m not going to tell no child my business because they can’t benefit me. I’m not going to pour my heart out to a child. I have children age 22 to 35. I might as well set my sons down and talk to them.

Experiences of Intersectional Stigma

Manifestations of intersectional stigma for midlife and older Black women living with HIV operated at multiple levels— from the interpersonal/familial to the broader community to institutional/structural contexts.

Interpersonal/Familial Experiences—For midlife and older Black women living with HIV, some of the more salient experiences with stigma occurred at an intimate level, among family and friends. Their HIV diagnosis had the most significant impact on their role as women as they were forced to renegotiate their roles as daughters, sisters, mothers, girlfriends, and wives. Their HIV-positive status also introduced new forms of stigma related to gender roles. For instance, participants described how their social role within the family, as daughters and sisters, intensified their experiences of HIV-related stigma. Sylvia, who was 53 years old, stated, “It is hard because I’m the only girl and I’m the oldest. My brothers, they’ve never done anything wrong. They’re looking like thinking, ‘Well, what did she do?’”

Women felt further stigmatised by their decisions to have children or to remain childless. Jennifer, a 40-year-old new mother, told us, “People said that I didn’t deserve to have children all the time when I was pregnant.” Lori, who was 50 years of age, explained that this stigma comes from the associations between immoral behaviour and HIV, “It’s because people think you’re using drugs or you sleep around. You can’t be a good parent if you do

those things—having men coming in and out, which I don't. Or using drugs, which I've never done." Several women discussed how they regretted not having children due to HIV-related stigma. Tracy, childless at 50 years of age explained, "I think the worst part of it all—the one thing I do wish—is because I always wanted children." She continued, "If people would have told me when you take your medicine that there was still a possibility, I think I would have just to know that there was a chance that I could have my own child."

Women also internalised this stigma as mothers due to the pressures of being a "good" mother: concern over providing resources for children, worry about becoming financial and health "burdens" as they aged, disclosure, and provision of care for their HIV-positive children. For instance, 50-year-old Lori described often feeling overwhelmed by guilt as a mother, wanting to be open with her young son while protecting him from HIV-related stigma, "It makes me wish I could be another way so he wouldn't have to deal with it. I know he's not a person that really wants to sit down and talk about it, deal with it, and accept it. I just wish he didn't have to. I wish his mum didn't have it." Nicole, a 47-year-old mother whose son was also HIV-positive, explained the complexity of managing her own health while focusing on her son's well-being, "My concern is as a mother. I could care less about me. I would do whatever it takes to protect him."

In addition, women described how HIV-related stigma kept them from pursuing romantic or intimate relationships. Women often discussed their fears of disclosure due to potential rejection from men. Rose, a 52-year-old woman who had never married, stated, "I'm not there to open up with them because men get scared and run away from you." Women also reported internalising feelings of shame and sexual undesirability as well as being stigmatised by romantic partners. Toni, who was 54 years of age, explained her relationship, "I'm married, but our relationship is like&now who is going to want me? I feel like I'm all used up. A dirty vagina. Ain't nobody going to want somebody like me. He even said that to me one time, 'No one wants somebody like you.'"

HIV-related stigma and fear of disclosure further complicated intimate relationships as it created new avenues for manipulation and control. Many women recounted feelings of betrayal by male sexual partners who they felt infected them with HIV knowingly. Mary, a 56-year-old widow said, "I had a husband—that's who gave it to me. I didn't know and he didn't tell me. I found out when I was pregnant." Another woman, 61-year-old Gloria, described how she found out about her own HIV-positive status after the death of her husband, "I'm not a drug user. I couldn't figure it out. I just dealt with the issue, then I found out when my husband died in the prison and on his death certificate, it said complications due to HIV." A few women also discussed how their partners or husbands deceived them into taking ART, telling them that they were antibiotics or vitamins in order to get them to take treatment unknowingly, or abandoned them altogether after finding out their HIV-positive status.

Furthermore, women discussed how men often used HIV-related stigma to exert control over the relationship or engage in gender-based violence. Mary, who was 56 years of age, explained:

I told him my status before marriage but whenever he gets mad at me, he decides to go around and tell everyone, “Well she got a drawer with all those pills” or “She’s diseased.” I’m steady, denying him. I’m a Christian having to make people think that it’s not true, when it really is true. It’s like I’m a liar. I get depressed about this because I want to be normal and do normal things. I have to keep smiling to keep from crying. People don’t know how bad you feel or what you’re going through.

Monica, a 47-year-old African immigrant, described how she made a decision between an abusive partner and a family that constantly stigmatised her for being HIV-positive, “This is how I ended up marrying the abuser. It was better than living in my family house. I had to get out. HIV is a disease but that the violence is always there. I wouldn’t say HIV causes [violence]. It just adds to it.” Similarly, 40-year-old Jennifer discussed why she left an abusive relationship, “I was beginning to feel like I didn’t want to take my medications. I used to feel like that before but it would be twice a month. But with my abusive husband, I started to feel like that every other day.”

Community-level Experiences—Women described HIV as “not something that people talk about” (Shelia, 47 years of age) or as something discussed “behind the closed door” (Beverly, 59 years of age) within their communities. This community silence stemmed primarily from the stigma attached to HIV. Women described community members as “uneducated” and “judgmental” toward those with HIV, particularly Black women. Toni, a 54-year-old woman, recounted how she was perceived at a community AIDS walk, “This man with the Bible was shaking it at me, saying that I was going to hell. I was upset and angry that I was associated with gays, lesbians, and transgenders. I didn’t get it that way! I’m not a drug addict. I didn’t share any needles.” Angela, who was 41 years of age, explained, “People assume that I slept around because I have HIV. That’s all the time! My own sister felt that I had. I’m a one man woman! I don’t mess around with Tom, Dick, Harry and Joe.” Women also discussed how community perceptions of HIV differed from other diseases disproportionately impacting women such as breast cancer, “I get upset because you see a commercial about breast cancer and women saying ‘I’m a fighter!’ They got their hair cut off. They have the pink bags and pink ribbons. How many people you see on there saying ‘I’m HIV positive, I’m a fighter?’” (Lori, 50 years of age).

Institutional/Structural Experiences—Women explained that negative stereotypes of Black women living with HIV led to further stigmatisation in health or social service settings and in the workplace. Women reported that stigma was highly prevalent in healthcare settings when they were first diagnosed at the beginning of the epidemic. Monica, a 47-year-old woman recounted her experience, “[The nurse] was running around and she got the thing you put on [the doctor’s] head, he had the gloves, he had all the gear on. Like it was the plague. I felt so bad. I felt so messed up about that. I was like, ‘Why are they doing this to me?’” Participants indicated that stigmatisation continues to occur in healthcare due to providers’ assumptions that Black women are using drugs or sleeping around, even when they do not report such risk factors. Grace, who was 57 years of age, recounted the birth of her son, “I had a Caesarean section, and they assumed I was a junkie so they gave me less medication. I was in pain! I had to scream. I felt they gave me less because they assumed I was on drugs.” Toni, a 54-year-old woman, told us, “When I first found out, my

pulmonologist was like, ‘Are you surprised?’ Yeah! Just because I’m a single black female at a military facility don’t make it like I whore around.” Donna, who was 44 years of age, likewise described her experience with a support group, “The speaker started talking about women who were involved with incarcerated men. We’re looking like, ‘Ain’t none of us involved with no incarcerated men! Where did you get this from lady?’ It’s like Black women with HIV are this or that and there is nothing in between. I was with someone for 10 years. I’ve known him since I was young, I trusted him...It’s a whole different thing.”

Stigma in the workplace was a constant source of stress for women in our sample. Women who were not currently working felt strongly that manifestations of stigma occurred in the workplace because they heard stories or knew of people getting fired. For those who were working, they were unwilling to disclose their status or perceived that they had little power to stand-up for themselves against supervisors and co-workers when they felt their privacy was being threatened. Donna, who was 44 years of age, recounted what occurred after her HIV-status was disclosed:

It was stressful. I didn’t realise how stressed out I was. I would wake up in the middle of the night with charlie horses. I must have really internalised a lot of stress. These people were going to give me a heart attack. I believe it was divinely meant for me to get out of there. I don’t know what could have happened to my health if I would have stayed.

Additionally, some women like 61-year-old Gloria felt discriminated against in securing employment due to age, “I wonder why I don’t get the interview half the time. I don’t know about age discrimination but once you get to be a certain age it’s hard for a person to get a job.”

Changes in Stigma Experiences over Time

Despite persistent experiences of stigma and discrimination, women reported that they were better able to cope with stigma and manage their condition as they aged. For many women, overcoming adversity and unfavourable life events, including HIV, increased their feelings of resiliency and competency. For instance, Cheryl, a 62-year-old woman declared, “I think my resilience amazes me more than anything. I’ve come through the fire. I’ve been through the fire. I’m still here! Yeah, it’s rough, but I am.” Women indicated that personal resilience came from the maturity of age, “I think the thing with us older girls—or men—it’s more or less we’re on track about feeling better. We want to be better. We want to do the right thing. We’re not going to be dumb and stupid! Do you want to be in a casket? That’s the reality of it” (Wanda, 52 years of age). Advances in treatment also helped diminish feelings of internalised stigma and increased women’s sense of autonomy. For instance, 50-year-old Lorraine declared, “I have the control! I’m working for this! I have all my medication. I’m taking them every day. My body is in control. I have authority over my body. I’m fighting because of it. I’m on top of it.” Finally, major life events such as being hospitalised, the birth of a child or grandchild, or the death of a loved one triggered women’s increased commitment to self-care. Vera, who was 61 years of age, explained, “I like to stay healthy. I like to keep on living. I’m not trying to leave right now. I’ve got grandkids and they need their grandma.”

Discussion

This study examined perceptions and experiences of HIV-related stigma among midlife and older Black women from Prince George's County, Maryland using qualitative data. Participants were not selected randomly and their viewpoints may not reflect the perspectives of other midlife and older Black women living with HIV in the county. Our study focused specifically on local experiences of stigma. While these findings cannot be generalised to other PLWH, including midlife and older Black women with HIV, they can be helpful in understanding the role of HIV-related stigma, particularly intersectional stigma, among other populations facing similar issues.

Intersectional stigma is a central feature in midlife and older Black women's lives. For midlife and older Black women, manifestations of HIV-related stigma intersected with and was compounded by various forms of inequality rendered through ageism, racism, and sexism, what Patricia Hill Collins (1990) has described as a matrix of oppression. HIV-related stigma reinforced negative stereotypes about Black women living with HIV as hypersexual, drug addicted, and sexual partners of incarcerated men. Older age, while moderating some impacts of HIV-related stigma, also augmented midlife and older Black women's feelings of dependency and helplessness. Such manifestations of intersectional stigma highlight the inextricability of midlife and older Black women's multiple social positions and the subsequent dynamics of marginalisation at the interpersonal/familial, community, and institutional/structural levels.

Sharing a positive HIV diagnosis with family introduced new forms of stigma related to gendered social dynamics, significantly impacting midlife and older Black women's social roles. Many women reported experiences of indifference and rejection from family members, who refused to accept women's HIV-diagnosis or blamed them for their condition, often engaging in acts that rendered midlife and older Black women as polluted, impure, and contagious. Likewise, women's roles as mothers were complicated by HIV. Women found their children and grandchildren to be sources of emotional and financial support, some directly reporting that they maintain their health because of their roles as mothers and grandmothers. But these roles were also sources of stress in terms of providing for children and grandchildren, not becoming a burden, and the challenges of disclosure. Still others regretted their choice to remain childless due to HIV-related stigma. Such findings add to the limited literature on the complex social expectations surrounding HIV and motherhood (Sandelowski and Barroso 2003).

In addition, HIV-related stigma compounds experiences with intimate partner violence (IPV). Women described male sexual partners' behaviours as duplicitous, knowingly infecting them with HIV, deceiving them into taking ART, and abandoning them altogether. Gender-based violence and gender inequality are increasingly noted as important determinants of HIV risk for women; however further research on possible connections is necessary (Zierler et al. 2000). The literature on violence among HIV-positive women has noted that violence and victimisation rates among HIV-positive women are comparable to those for HIV-negative women from similar populations and with comparable levels of HIV risk behaviours, with HIV-positive women potentially experiencing more recurrent and

severe forms of abuse (Campbell et al. 2008; Gielen et al. 2007; Zierler et al. 2000). Our findings show that women reporting IPV described a history of abuse and noted that an HIV-positive status generates additional forms of violence, suggesting that these issues persist into midlife and older age and may be complicated by long-term relationships with a husband or partner. It is crucial that additional research be conducted on the syndemics of violence and HIV, especially that which attends to how knowledge of an HIV-positive status alters relationship dynamics over longer periods of time. Furthermore, it is important that programmes address sexually transmitted HIV and IPV risk reduction simultaneously and target HIV-positive women who may be experiencing IPV.

For midlife and older Black women, community-level experiences of intersectional stigma reflected pervasive public silence regarding HIV for fear of further denunciation, but also underscored the fetishisation of Black women's sexuality (Collins 2004; McCord 2014). Moreover, women expressed that they continued to experience intersectional stigma within broader structural contexts such as in healthcare and workplace settings. For instance, women reported receiving differential medical treatments within healthcare settings due to inherent assumptions by providers that they are using drugs or being promiscuous despite reporting the contrary, and that such manifestations had real consequences for their physical and mental well-being. Previous research has demonstrated that implicit bias in medical settings can impact medical decision-making, compromise quality of care, and potentially lead to systematic race-based HIV treatment disparities (Sabin et al. 2009). While studies have explored discrimination in many areas, no study to date has systematically investigated the unique experiences of healthcare discrimination among Black women living with HIV and its impact on their treatment-related disparities (Wingood et al. 2007). This is a critical gap in the literature that could be addressed through additional research on intersectional stigma within healthcare settings. Similarly, our findings suggest that women feel stress in the workplace due to fears of dismissal or having their privacy violated if they disclosed. Studies on older adults with HIV often fail to discuss workplace stigma, perhaps assuming that older people may no longer be working, and may overlook workplaces as sources of HIV-related stigma.

Finally, aging contributed to shifting manifestations of intersectional stigma among midlife and older Black women living with HIV. The advent of ART, overcoming major life obstacles, and the onset of critical life events lessened the impact of intersectional stigma among midlife and older Black women. Living with HIV over a prolonged timeframe, often decades, increased feelings of autonomy and resiliency among midlife and older Black women. While our findings contribute to the very limited literature on resiliency, coping, and successful aging among midlife and older adults with HIV (Emlet et al. 2016; Emlet, Tozay, and Raveis 2010), they also signal the need for additional research on midlife and older Black women's experiences in navigating employment sectors and public service agencies.

Conclusion

Experiences of stigma are not the result of single distinct factors for midlife and older Black women living with HIV; instead, they are multidimensional and complex. Gender, race, and age are inextricable when considering HIV-related stigma experiences disproportionately

borne by midlife and older Black women, who face unique challenges and obstacles as well as demonstrate high levels of resilience. The emergent themes described in this study provide several important insights for future HIV planning and research agendas.

Currently, stigma-reduction programmes exclusively targeting African American and Black diasporic women are limited. Adapting a globally used HIV-related stigma reduction tool for African American women in the USA, one initiative used role playing and peer social support to help women learn how to successfully navigate stigmatising situations and diminish its emotional effects (Rao et al. 2012); another developed a self-care intervention using nurses to provide therapeutic and emotional support for African American mothers with HIV during home visits (Miles et al. 2003). Both of these initiatives integrated cultural strengths specifically related to African American women, used multiple methods to deliver a variety of intervention components, and were attentive to participant burden and socio-cultural contexts of stigma. However, these initiatives did not sufficiently demonstrate long-term stigma reduction impacts, address other forms of stigma related to gender, race, or age discrimination, or attend to mitigating stigma and discrimination at community, institutional, or structural levels (Loutfy et al. 2015)

More research is needed to develop and evaluate the effectiveness of stigma reduction programmes focused specifically on intersectional stigma and discrimination at the individual, community, and structural levels. For instance, stigma reduction public campaigns along with cultural and structural competency training in workplace and healthcare settings could be useful in positively shifting community and peer norms and reducing negative stereotyping and discrimination faced by midlife and older Black women living with HIV. Likewise, a greater focus on culturally-sensitive, gender-responsive, and age-appropriate HIV programmes should be strongly considered to not only alleviate individual experiences of stigma, but to also potentially reframe prevention to a wellness perspective for an increasingly aging population. Families and communities often set values and norms from early life, and building family wellness as part of HIV intervention programmes could serve as the foundation for combating HIV-related stigma (Rotheram-Borus et al. 2011). Furthermore, programmes should also take direct action to promote gender equality and intimate partner violence reduction, providing critically needed resources for women aging with HIV (Crepaz et al. 2009). Finally, programmes that promote and sustain successful aging may be beneficial to increasing retention and adherence among midlife and older adults living with HIV.

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TABLE 1

Socio-Demographic Characteristics of Midlife and Older Black Women Living with HIV in Prince George's County, Maryland, USA (N=35)

<i>Characteristics</i>	<i>Median</i>	<i>Range</i>
Median age, in years	52	40 – 71
Age categories (N=35)	<i>Frequency N</i>	<i>Percent %</i>
40–49	11	31%
50–59	20	57%
60+	4	11%
Time since diagnosis, in years *	16.6 (6.9)	< 2 – 29
Elapsed time since diagnosis (N=35)		
<10 years	8	23%
10–20 years	15	43%
>20 years	12	34%
Education (N=35)		
Some High School	9	26%
High School	15	43%
Some College	8	23%
Associate's Degree or Higher	3	9%
Annual Household Income		
< \$5,000	11	31%
\$5,000–\$14,999	3	9%
\$15,000–\$24,999	7	20%
\$25,000–\$39,999	4	11%
> \$40,000	8	22%
Marital Status (N=35)		
Single, Never Married	14	40%
Separated/Divorced	14	40%
Widowed	4	11%
Married	3	9%
Children (N=35)		
Yes	30	86%
No	5	14%
Living Conditions (N=35)		
Alone	9	26%
Children	16	46%
Spouse	1	3%
Other Adults	4	12%
Combination of above	5	15%

Note:

* Calculated as time elapsed from date of diagnosis until Jan. 1st, 2015.

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