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Perceptions of Intersectional Stigma among Diverse Women Living with HIV in the United States

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Abstract

Attitudes and behavior that devalue individuals based upon their HIV status (HIV-related stigma) are barriers to HIV prevention, treatment, and wellbeing among women living with HIV. Other coexisting forms of stigma (e.g., racism, sexism) may worsen the effects of HIV-related stigma, and may contribute to persistent racial and gendered disparities in HIV prevention and treatment. Few studies examine perceptions of intersectional stigma among women living with HIV. From June to December 2015, we conducted 76 qualitative interviews with diverse women living with HIV from varied socioeconomic backgrounds enrolled in the Women's Interagency HIV Study (WIHS) in Birmingham, Alabama; Jackson, Mississippi; Atlanta, Georgia; and San Francisco, California. Interview guides facilitated discussions around stigma and discrimination involving multiple interrelated identities. Interviews were audio-recorded, transcribed verbatim, and coded using thematic analysis. Interviewees shared perceptions of various forms of stigma and discrimination, most commonly related to their gender, race, and income level, but also incarceration histories and weight. Women perceived these interrelated forms of social marginalization as coming from multiple sources: their communities, interpersonal interactions, and within systems and structures. Our findings highlight the complexity of social processes of marginalization, which profoundly shape life experiences, opportunities, and healthcare access and uptake among women living with HIV. This study highlights the need for public health strategies to consider community, interpersonal, and structural dimensions across intersecting, interdependent identities to promote the wellbeing among women living with HIV and to reduce social structural and health disparities.

Keywords

Stigma; Discrimination; Intersectionality; HIV; Women; United States; Qualitative research; Health disparities

Introduction

In the United States women bear a substantial burden of the HIV epidemic, representing nearly one-fourth of all Americans living with HIV and almost one-fifth of new diagnoses (Centers for Disease Control and Prevention, 2017). The literature suggests that women have poorer HIV treatment outcomes compared to men, particularly lower antiretroviral therapy (ART) adherence (Lazo et al., 2007), and greater morbidity and mortality. Women of color are at especially high risk of acquiring HIV (Centers for Disease Control and Prevention, 2017), and have worse HIV care outcomes compared to White women (Levine et al., 2007). These risks for HIV acquisition and deleterious health outcomes appear to be grounded in social drivers of HIV such as poverty, racial and gender inequality, and cultural norms that devalue women's identities and limit their opportunities (Auerbach et al., 2011). To adequately address racial and gender disparities in HIV prevention, treatment and related sequelae, it is imperative to understand unique barriers to optimal HIV care outcomes among women.

An intersectionality framework offers a constructive lens through which to contextualize the health inequities faced by women living with HIV. This body of literature posits that the

experiences of “multiply-burdened” groups are obscured by focus on single categories of disadvantage (e.g., class, gender *or* race) and treatment of such social identities as discrete (Crenshaw, 1989, p. 140). Rather, this discourse states that understanding the lived realities of marginalized groups requires taking into account the compound nature of their experiences. Central to intersectionality paradigms are attention to social, economic, political, and other hierarchies that create and maintain inequalities among people with interlocking social statuses (Bowleg, 2012b; P. H. Collins, 2000; Roberts, 1999; Watkins-Hayes, 2014). Research in this area highlights unique challenges such as stigma, discrimination and oppression; as well as distinct opportunities, such as empowerment, resilience and reconstruction, that may surface at the intersection of disadvantaged social statuses (Cole, 2009; Crenshaw, 1991).

Stigma, or negative social devaluation concerning attributes, statuses and behaviors that are perceived as less socially desirable (Goffman, 1963; Turan et al., 2017), is theorized as occurring across socioecological levels. At the structural level, stigma is rooted in norms specific to societies, systems and institutions (e.g., legal, welfare, educational settings, etc.) with power structures that assign and label differences among groups, and allow status loss and discrimination due to differences (Link & Phelan, 2001). Stigma is also perceived, enacted and reinforced at the community level in the context of local and cultural norms and values (Lanier & DeMarco, 2015), and at the interpersonal level in the context of relationships with family, friends, intimate partners, or other close individuals (Fletcher et al., 2016). Notably, the stigma process at these various levels are inextricably linked; whereby stigma within social structures at the macro level shapes group and individual processes at the meso and micro levels, and visa-versa (Hatzenbuehler & Link, 2014). Considering its pervasive impact on the social distribution of life chances for health and well-being, and its influence on various physical and mental health outcomes, stigma is considered to be a determinant of population health (Hatzenbuehler et al., 2013; Link & Hatzenbuehler, 2016).

Extensive literature identifies HIV-related stigma as a barrier to HIV prevention, treatment, and wellbeing among people living with HIV (Katz et al., 2013; Rueda et al., 2016). HIV stigma may be exacerbated in marginalized groups experiencing multiple and converging forms of stigma (e.g., racism, sexism, transphobia, mental health stigma, substance use stigma, etc.) (Earnshaw et al., 2015; C.H. Logie et al., 2011; Orza et al., 2015). Scholars coined the term *intersectional stigma* to explain the synergistic, mutually constitutive associations between social identities and inequities (Berger, 2010; C.H. Logie et al., 2011, 2012). Intersectional stigma is also conceptualized as occurring at multiple levels of influence (including the interpersonal, community, and structural levels), from multiple sources (such as by family, friends, or health care providers), and based upon co-occurring and intersecting identities or conditions (e.g., HIV-status, mental health status, age, race, etc.) (Turan et al., 2017). A meta-study of U.S.-based research from 2009 highlighted the absence of discussion of intersecting categories of difference, particularly gender, class and sexual orientation, in among the published domestic HIV-stigma research among women (Sandelowski et al., 2009).

Women are uniquely subject to historical, societal and cultural normative ideals of womanhood which dictate social expectations for their behavior. Depending on cultural group, social position, and other intersections, women may be stigmatized for deviation from normative expectations around sexual behavior, heterosexual partnership, marriage, motherhood and other values (P. Y. Collins et al., 2008; Fletcher et al., 2016; Sangaramoorthy et al., 2017; Smith et al., 2016). Within the context of HIV-status, poverty and gender identities, for example, lack of social and economic power among women may limit their ability to negotiate power in sexual relationships, access preventive healthcare, and use protective resources around HIV prevention; increasing vulnerability to HIV infection (Watkins-Hayes, 2014). Once living with HIV, fear of stigma related to HIV and assumptions regarding risk practices from providers and others in healthcare settings may serve as a barrier to timely HIV testing, treatment uptake and adherence, and subsequent likelihood of engagement in HIV care among women (Katz et al., 2013; Mahajan et al., 2008).

However, few U.S. studies examine perceptions of intersectional stigma among women living with HIV. Research with HIV-positive Black women in Canada revealed significant associations between racial and gender discrimination and HIV-related stigma (C.H. Logie et al., 2013), and higher racial and gender discrimination among sexual minority women in comparison with their heterosexual counterparts, underscoring the importance of examining intersectional stigma (C.H. Logie et al., 2017). Sexism, homophobia, transphobia and sex work stigma also adversely affects HIV-positive women, as indicated by qualitative research conducted within the same geographic setting (C.H. Logie et al., 2011). This literature additionally brings attention to HIV-positive women's resilience, or capacity and resources to overcome threats to their well-being and health (Earnshaw et al., 2013), despite experiences of intersectional stigma (C.H. Logie et al., 2011). In this literature, women were described as coping with intersectional stigma by exhibiting optimism, tenacity, problem solving, and through use of spiritual or religious practices.

Prior studies to examine intersectional stigma in the context of HIV treatment and prevention within the U.S. primarily do so among HIV-positive and negative minority men who have sex with men (Bowleg, 2012a; Bowleg et al., 2013; Brinkley-Rubinstein, 2015; Dale et al., 2016), and HIV-negative minority women at elevated risk for HIV (P. Y. Collins et al., 2008). Thus, there are knowledge gaps regarding intersectional stigma among women living with HIV in the U.S. In the present study, we sought to answer the research question: How do U.S. women living with HIV perceive stigma associated with their co-existing social identities? Specifically, we analyzed perceptions of diverse and intersecting stigmas (related to race, gender, and income as well as weight and prior incarceration), and resilience despite stigmas, in a large qualitative sample of socio-demographically diverse women living with HIV across four metropolitan areas. In-depth accounts of intersectional stigma and resilience can inform efforts to address disparities in HIV treatment and prevention.

Methods

Ethics statement

All study procedures were conducted with the approval of the Institutional Review Boards at the University of Alabama at Birmingham, University of Mississippi Medical Center, Emory University, and the University of California, San Francisco. Signed informed consent was obtained from all participants.

Study Population

The current study is embedded within the ongoing Women's Interagency HIV Study (WIHS), a multicenter longitudinal cohort study of women at risk or living with HIV. Research procedures for the WIHS are described elsewhere (Bacon et al., 2005; Barkan et al., 1998). The present WIHS sub-study aims to examine the mechanisms and longitudinal effects of stigma on adherence to HIV treatment recommendations among women living with HIV in the WIHS. One aim of this sub-study specifically examines the implications of intersectional stigma for health service utilization and outcomes using an explanatory sequential mixed-methods design. The initial qualitative phase sought to obtain an in-depth understanding of intersectional stigma and to inform later quantitative survey measurement development and analyses.

Sampling and Recruitment

The study team recruited women living with HIV from three WIHS sites located in Birmingham, AL (University of Alabama at Birmingham) and Jackson, MS (University of Mississippi Medical Center), which work together as the combined UAB/UMMC WIHS site; Atlanta, GA (Emory University); and San Francisco, CA (University of California, San Francisco). We determined a target qualitative sample size of 75 to allow for racial, ethnic and income sub-group representation and variation from each site, purposively sampling to reflect the diversity within the population of U.S. women living with HIV (Teddlie & Yu, 2016). In particular, we set quotas to assure inclusion of sub-groups under-represented at the WIHS sites (White women, Latinas, and middle-income women). Considering qualitative methodological precedent (Francis et al., 2010; Guest et al., 2006), we estimated that 25 interviews per site would likely be adequate to reach data saturation (or the point of informational redundancy) (Given, 2008; Saunders et al., 2017).

Recruitment occurred during semi-annual core WIHS visits, where staff verbally presented the sub-study information and a copy of the consent form for women to take home if they wished. The consent form included the following research description: "The main purpose of this sub-study is to learn more about barriers to engagement in HIV care (including adherence to medication and attendance at HIV care visits) for women and the effects of stigma and discrimination in their lives. In particular, we are interested in learning more about how experiences of stigma or discrimination, along with associated stress levels, affect women's overall health and well-being." Eligible participants were women living with HIV, 18 years of age or older, English-speaking, and able to provide written informed consent.

Data Collection

Seventy-six qualitative in-depth interviews of 73 minutes on average were conducted between June and December 2015, each in a private room by experienced qualitatively trained female interviewers (3 Black, 3 White, and 1 mixed race/ethnicity). In addition to discussion of HIV-related stigma, the semi-structured interview guide facilitated discussions around other types of stigma and discrimination using open-ended questions, including: “People experience stigma and discrimination based on many other things besides HIV, including race, sexual orientation, using alcohol or drugs, having mental health challenges, or engaging in sex work. Can you describe any experiences you have with discrimination based on other parts of who you are?” We also asked the study participants about their observations of stigma and discrimination. Questions were designed and interviewers were trained to encourage women to share stories of their experiences, and to allow discussion of intersectionality to emerge naturally. Participants received a \$30 cash incentive, and interviews were audio-recorded and transcribed verbatim.

Data Analysis

Transcripts were coded and analyzed according to Braun & Clarke’s steps of qualitative thematic analysis (2006). A team of seven researchers developed a list of codes and sub-codes after data collection. A priori codes (e.g., RACE, GENDER, INCARCERATION, FINANCIAL INSECURITY, STIGMA_DISCRIMINATION and INTERSECTIONALITY) were informed by intersectionality theory, literature review, the interview guide, and an initial review of the data. Four researchers (WSR, MW, TMN, and AB) coded all transcripts using the qualitative data management software, Dedoose.

Coding was iterative to allow for discussion of changes and clarifications in the codebook and coding process amongst the coding team and larger investigator team. Several codes emerged during this process (e.g., AGE, BODY IMAGE, DISABILITY, STRUCTURAL). Twelve transcripts were double-coded in order to establish agreement on coding definitions and procedure. The team resolved discrepancies through discussion to validate the codebook and maximize coding reliability. After coding, we ran queries to enable thematic comparisons between data tagged with different codes, or combinations of codes. Documents summarizing emerging ideas and concepts and patterns across transcripts were shared among the research team and discussed in group meetings.

Results

Participants were predominately Black (61%), heterosexual (83%), and most had one or more children (68%), as seen in Table 1. Interviewees reported perceiving negative opinions and attitudes by other people regarding their HIV status as well as other aspects of their identities. Alongside HIV-related stigma, participants most commonly discussed stigma related to their gender, race, and socioeconomic status. Other forms of stigma that emerged included stigma related to incarceration history, weight and less commonly stigma attributed to mental health, substance use, sexual orientation, age, disability, and sex work. These intersecting forms of stigma were often discussed by the interviewees in the context of one another, and at other times in isolation. Even when discussed in isolation, participants

reported perceptions and experiences with multiple forms of stigma over the course of the interviews.

Below, we present results by major theme, or salient form of stigma, reported by participants. Each form of stigma is categorized in sub-sections according to the socio-ecological context in which they were discussed - as enacted by institutions and/or systems, by the participants' communities, by individuals. Though we present these forms of stigma and corresponding socio-ecological contexts as separate categories below, we interpret the stigma perceptions and experiences of the interviewees as co-occurring when the results are considered as a whole. Interviewees were given pseudonyms to ensure confidentiality.

Sexism

Structural Discrimination

The study participants commonly described the historical and current context as one in which men hold greater social power. Several participants shared perceptions that they were required to exert more effort to attain a similar social status as male counterparts in many contexts, including in schools. Nicole (Black Participant, Age 36 – 45, San Francisco, CA) reflected upon her formative and present experiences:

... females were always looked at as the bottom and guys were at the top. If you wanted to go from the bottom to the top you either had to sleep your way to the top, work like a slave, get an education...you always had to be better than the guy. Even [though] y'all got the same education, you needed to be a step above him in your GPA. You needed to be at the top of the class where maybe he was in the top five... you need to be the top two. You need to do extra work. It's like being a woman you always have to do extra to compete in a man's world.

Despite efforts to even the playing field, participants shared perceptions that they are undervalued in educational and employment systems due to their gender. When asked whether there are aspects of her identity for which she felt she experienced discrimination in the past, Amy (White Participant, Age 36 – 45, Jackson, MS) reflected upon gender discrimination in prior job search experiences:

I apply for what's available but my first choice was always like stock and receiving. Hard work, honest work, not that easy stuff. But I'd always get stuck with some cashier, door greeter, waitress, some crap like that.... Just because I was a woman, [employers] think I couldn't do something....

Community Stigma

The women in our study shared perceptions that the cultural values within their communities assign greater domestic power to men. In sentiments echoed by many other participants, Teresa shared (Hispanic/Latina Participant, Age group 46 – 55, Atlanta, GA):

...the culture is a man does what he does, as long as he brings in the money. The men can do what they do and the women shut their mouths and take it.... I see it in

my own culture. As I got older, different cultures aren't too different. With the Indians and Arabics, women have no say-so.

Participants also reported perceptions that women are subject to different community-based standards for social judgment than men. Women shared that there are different expectations regarding sexuality by gender and different assumptions regarding sexual practices for women as compared to men. Melissa (White Participant, Age 36 – 45, Jackson, MS) elucidated that social judgments regarding women's sexual practices are present in and outside of the HIV context:

It's not so bad for [men] to have many sex partners but it's horrible for a woman to have that many...And she's a whore and all the other words... But it's OK for him. That existed before HIV and it's still in play now...Some dirty woman gave him [HIV] ... and they're the bad person —and then the women ... you got it because you was sleeping around.

Interpersonal Stigma

Participants across geographic and other contexts also described their interpersonal relationships as ones in which men “downgrade” women and don't consider women's needs and preferences. In a reflection upon both sexism and HIV-stigma, Mary (Black Participant, Age 36 –45, San Francisco, CA) stated:

The B word, I hate that. [Men] don't call us by our name... They be like, “Oh, look at that bitch. That bitch got that shit. I don't want that bitch around me.” Just really negative, whether we're HIV-positive or not, we still are human, and we still have feelings and they are very much valid.

Multiple women in our study also shared perceptions that close acquaintances (i.e., partners, co-workers, friends) viewed them as less than others due to their gender. In Jennifer's words (Hispanic/Latina Participant, Age 36 – 45, San Francisco, CA), this is evident not only in the attitudes of family, but also in the way that families choose to distribute resources:

... [parents] make [women] feel they are not worth that much like the men. Parents who have properties ... always give them to the boys, ... because they believe women has to have money or houses ... or anything through your husband, Here my mother and my father and their family are talking about giving the properties to my brothers and not to me because I was a woman. That really made me feel very bad.

Poverty Stigma

Structural Discrimination

Interviewees across settings relayed perceptions of negative treatment during interactions with public programs for people who have limited resources, such as subsidized housing, food assistance, and other welfare programs. Multiple women also described enacted poverty stigma by service providers in healthcare, including HIV care, and other public services. The women in our study discussed perceptions that poverty stigma contributes to

inequitable access to healthcare as well as poorer quality of care, as shared in the following statement:

...a person that has insurance [is] going to be at the front of the emergency room and a person that doesn't have insurance, they will be there for five to six hours at a time.... I feel as though [the rich] do have a better chance at everything. I feel like if they had a cure, [rich people] would be the first [to get the cure] ... It's all in what you have, who you know, the power you have (Brittany, Black Participant, Age 26–35, Jackson, MS)

Many women shared that patient privacy concerns for persons living with HIV are different compared to more socioeconomically advantaged individuals. Specifically, participants perceived that the structure of the facilities in which women seek care differs based upon socioeconomic status. As such, Nicole (Black Participant, Age 36–45, San Francisco, CA) explained:

The rich women ... you wouldn't know they were sick and the poor women ... you know because ... [poor women] have to go to the public clinic ... and you would see them. The rich women...they go to Dr. Whoeverman in his private office. There is sight discrimination only because rich women have more privacy in their medical care...

Community Stigma

Participants shared the notion that their communities think of “poor” women with less compassion than women who are socioeconomically advantaged, regardless of HIV status. Along those lines, participants described social judgment within their communities at the intersection of socioeconomic status, sex work and drug use, as Barbara (Black Participant, Age 46 – 55, Atlanta, GA) articulated:

There's almost like a low expectation of women that are of a certain economic standing, a certain income level. There's – she ain't got no money, she might trick off [have transactional sex] to get her bills paid or you know she got all them children, she might get stressed out and use drugs or she probably dating a dude that sells drugs or is on drugs and all these negative connotations...

Interviewees discussed perceptions that stigmatizing attitudes about women in poverty are closely related to attitudes regarding social responsibility for those in poverty. Donna (Multiracial Participant, Age 46 – 55, San Francisco, CA) voiced a perception that women in poverty are viewed as expendable, and added that this was particularly salient for HIV-positive women:

They're just waiting [for poor women] to die. I mean, I think they're easy to write off.... No one's going to miss them. If you fucking go bury somebody, no one's going to come looking for a while, and I especially feel like that about the HIV thing.

Interpersonal Stigma

Participants perceived that women in poverty are repeatedly burdened by others' negative perceptions of them. As Lisa (Black Participant, Age 36–45, Jackson, MS) stated:

... [people] just [talk] down on the poor women, and the rich ones, [people] are just sorry that [HIV acquisition] happened and then are off to another subject. The poor ones, [people] are just constantly beating them up. [Poor women] already feel bad about [their HIV status], but they constantly just are being reminded.... It is a battle.

When asked whether she'd experienced stigma based upon income level, Nancy (Black Participant, Age 56–65, Jackson, MS), who works within the healthcare setting described statements made by co-workers about poor White women at work, "Oh, yeah. 'Poor trash, poor trash. Trailer trash,' I hear that a lot. 'Oh, poor trailer trash White woman in there getting on my nerves... ain't got no money, ... ain't got no insurance'".

Racism

Structural Discrimination

Participants discussed perceptions that employment and healthcare systems and other structures judge or treat them poorly based on their race. When asked whether there are differences in how women of color are treated, as compared to white women, Brittany (Black Participant, Age 26–35, Jackson, MS) stated:

I feel like it all boils down to racism, it hasn't went anywhere and it's not going anywhere. It's just in a different light. They wearing white collars and that's just what it is. I feel like they think that sometimes, even when I go to the doctor's office I feel like it's a lot of racism.

Several participants in mixed race relationships, and separately, those who had multiracial children reflected upon observations or experiences of racial discrimination. Tonya (Multiracial Participant, Age 46–55, San Francisco, CA) shared about witnessing her former partner being discriminated against in a place of public accommodation:

I had a Black boyfriend for five years. I would watch him walk into a store and the person behind the counter would come out from behind the counter, keep their eye on him, stare at him, and then see me walk up to him. They would go back behind the counter. It's disgusting... they're treated differently. There's no way to look around it... I assume that with HIV they're treated differently too. My eyes opened up wide to the differences, the racist activity that goes on in the world.

Community Stigma

Participants commonly shared the perception that, in their communities, women of color (and particularly Black women) are viewed negatively compared to women of other racial and ethnic groups, as Danielle (Black Participant, Age 36–45, Atlanta, GA) elaborated:

[People] just kind of look at Black women as being stupid and reckless and poor, just sleep around ... It's just ... all these negative things ... it affects me personally

... Because I'm a woman that's living with HIV, and I'm a Black woman, too. These are things that's been stigmatized the worst.

The perception that Black women are viewed as being more promiscuous than other women was shared by white participants, as reflected in the following quotation:

[Black people] have the stigma of being very physical and promiscuous ... more than white people. (Melissa, White Participant, Age 36–45, Jackson, MS).

Another participant shared the perspective that HIV-positive status is one of many negative characteristics that are “expected” of Black women. Many women talked about the negative connotations of being Black, female, and HIV-positive, and how the stigma of each reinforced the other.

Interpersonal Stigma

Women from the Jackson, MS in particular shared experiences with, and observations of, racism by members of their close social circles, primarily circumstances in which white acquaintances expressed disfavor for Black individuals. Linda (White Participant, Age 56–65, Jackson, MS) shared about her experience with her ex-husband:

When I was married, my husband he's very racist. He didn't like nobody I worked with, not a soul. It didn't matter if they were line staff or they were in management, he didn't like any of them, because their skin was Black.

Nancy (Black Participant, Age 56–65, Jackson, MS) shared her observations of racism by a coworker in the medical care setting:

You know, I see it on my job, people do discrimination.... Well, for instance, we've got a nurse, she's white and she's very racist. She just don't care for African Americans and she lets you know she don't care her racism shows a lot.

Other study participants, particularly Latina and multi-racial participants from the California site, shared perceptions of ethnic discrimination, as manifested in social rejection and intimidation. Jennifer (Hispanic/Latina Participant, Age 36–45, San Francisco, CA) described an experience at the intersection of racism and poverty stigma:

I asked [a male shop employee] how much will it cost me to fix this [car stereo] system. The guy looked at me and he goes, “Well, sweetheart, just take your car back and don't come back.” I said, “Well, why?” “Oh, you wouldn't be able to pay it. You guys don't really earn enough money to pay me.” When asked, “What did he mean by you guys?”, the participant clarified: “Like you guys like Spanish people, like Hispanic people”.

Amber (Multiracial Participant, Age 36–45, San Francisco, CA) shared a childhood experience:

I feel like my mom was discriminated a lot because she still has an accent. I guess people would assume she is uneducated. They just talked to her any kind of way. I do remember at age seven, my mom driving to a gas station and these two big white guys came out. They told my mom to go back to her country.

Incarceration Stigma

Structural Discrimination

Several study participants shared prior incarceration experiences, or that of others within their lives. On repeated occasions, in these discussions, the women in our study described instances in which their criminal history was voluntarily and involuntarily disclosed within institutional settings. Many participants reported being segregated from other women within jail or prison after such disclosure. Denise (Black Participant, Age 46–55, Birmingham, AL) stated:

...when I was locked up... somehow [participant's HIV status] leaked out... when a lot of the inmates found out I'm HIV positive... They put me in the cell by myself. The only time they would let me out is to take a shower and back in or to come and get my tray and back in the cell.

Participants also perceived that access to information about HIV and the medical care needs of those who are HIV-positive was withheld from them while incarcerated. Kathleen (White Participant, Age 46–55, San Francisco, CA) shared an experience in which she attributed prolonged lack access to her HIV medication to the police:

When they sent me to jail, ... they didn't let me get my meds [from the] car I was in. They didn't take my belongings knowing that I'm HIV positive. That's right there with my name. I said it from the beginning. They could have gone into the car and gotten the meds out ... It's my belonging, but instead. ... you stopped my meds, ... and made it impossible for me to get back to my meds for 30 days.

Community Stigma

Interviewees (particularly those who had spent time in jail or prison) shared the perception that incarceration stigma was salient within their communities. Megan (White Participant, Age 36–45, Birmingham, AL) explained the perception that people with no incarceration history have of those who have a history of incarceration:

People look at you crazy. People [think that] if you have been to jail, you are a bad person. You must be some kind of criminal, done something wrong. You know just god awful. I guess I have more of a stigma going to prison than I do in the county jail. Prison is just for awful people. So I had to deal with that a little bit.

Interpersonal Stigma

Participants most commonly discussed experiences of incarceration stigma enacted by family members. Several participants shared the perception that their family were ashamed of their criminal history, as Diane (White Participant, Age 46–55, Jackson, MS) shared:

When I was actually back in my small home town and I went to jail My mom had to come to the jail to get me and she was not happy about that Families have their rules, and that's been our rule, "What will people think?"

Melissa (White Participant, Age 36–45, Jackson, MS) discussed the sharing of her criminal history with others by her mother, despite her personal choice not to disclose that information to others:

I mean, I've been in jail before and my mom had to check me out. But the only thing about it is I don't tell—my friends or stuff like that. My family already knows it because my mom's going to tell everybody in the country. So she makes sure that she has to put me down, make me feel stupid.

Weight Stigma

Structural Discrimination

Multiple women in our study perceived that they have been unfairly evaluated based upon their weight in work settings. As Samantha stated (White Participant, Age 36–45, Atlanta, GA):

I'm a big girl. I think and I don't want to say it's discrimination, but I know people look at me and felt some of the she doesn't take care of herself that sort of thing. Because of my obesity, absolutely. I felt that in job interviews and people looking at me that sort of thing. You can see it and feel it sometimes.

Sara (Black Participant Age 36–45, Jackson, MS) described an instance of perceived employment discrimination in further detail in response to the question, “in what areas of life, healthcare, work or family, have you directly experienced stigma or discrimination?”: I came in [to interview] for being a cashier and [the manager] was like, “do you know that you have to stand? It is a lot of work.” I said, “yes, I do ... I use to be an assistant manager and a cook so I know what standing up on my feet is.” She was like, “it is going to be long hours” ... she didn't give me the job neither.... [because of] the size.

Community Stigma

Several women shared the perceptions that others make assumptions about people who are obese/overweight. Erin states (Black Participant, Age 36–45, Jackson, MS) in response to the question, “So, we have talked about HIV, we talked about race, any other thoughts about why people treat other people differently?”:

You know a lot of people ... feel that [because] you are bigger, that you must lazy, you must be sitting down and aren't doing anything. They have so many you know just wrong ideas... just because you are big doesn't mean you are not healthy because there are some skinny people out there that are very unhealthy.

Participants shared the sentiment that obese or overweight women are judged for circumstances that are not entirely in their control. As Kathryn (White Participant, Age 36–45, San Francisco, CA) shared, “I just feel like the world is very critical toward obese people.... If I could control being fat, then I wouldn't be fat”.

Interpersonal Stigma

In response to the question, “Can you describe a time when you felt stigmatized or discriminated against?”, several participants responded that they have been viewed as lesser

than other people due to being overweight or obese. In a statement that highlights the intersection of weight stigma and sexism, Vanessa (Black Participant, Age 36–45, Birmingham, AL) stated:

I'm overweight. People look at me funny because I'm overweight.... There have been guys that my friends will try to set me up with because I don't date. They'll be like she has a cute face. Oh, she dresses nice. Oh, she has a good attitude. Oh, she has a friendly personality. But I wouldn't date her because she's too fat.... They say that.

Amy (White Participant, Age 36–45, Jackson, MS) reflected upon childhood experiences in which she was repeatedly bullied for her weight, “I was picked on for 11 years because I was different at school because I was the big kid.... Called me names, pulled my hair, tried to make me chase them when they knew I couldn't catch them. Just being mean.... It screwed me up for a long time”.

Complexity of Intersectional Stigma

When prompted to reflect upon the coexistence of multiple marginalized social identities or statuses, many participants indicated a sense of familiarity with this concept. As Cheryl (Black Participant, Age 46–55, Birmingham, AL) quipped in response to the question, “Are there parts of who you are or aspects of your identity that some people may judge you or treat you differently for?”: “Oh my goodness, I got like six people inside of me [laughs]. Now what do you want to know about them six people?”.

Relatedly, study participants shared that the specific marginalized status upon which one is stigmatized or discriminated against is difficult to disentangle. Amber illustrated these sentiments (Multiracial participant, Age 36–45, San Francisco, CA):

All my life I've always wondered what people discriminated against me for. Is it because I was Black? Is it because I was biracial? I never knew if people were discriminating against me because I was HIV-positive, because I was a woman. Honestly, I don't know what. I can't like really pinpoint. I just know that something. I guess it is like a gut feeling. Something just didn't feel right. Like somebody insulted me and like later I'm like what was that for?

Participants shared the perception that various forms of stigma and discrimination are rooted in similar lack of knowledge, understanding and acceptance of differences. In that vein, Amy (White Participant, Age 36–45, Jackson, MS) shared:

When people don't know, they get scared - whether it's with HIV and AIDS or whether it's someone walking down the street they haven't seen [before] Regardless of what type of discrimination, it's still discrimination ... it's all wrong. [People will] look you up and down, look at how your hair is, how your skin is, how you dressed and how you carry yourself. That's when they go to talking because their ways are a little bit different from yours. It all boils down to difference...

Resilience and Resistance to Stigma

In the face of perceptions of intersectional stigma and discrimination within our sample, most participants shared an optimistic outlook for the future. The women in our study viewed the future as one that could be more accepting of women living with HIV if current knowledge and attitudes about societal differences change. Interviewees expressed a desire for greater tolerance. In the words of Sara (Black Participant, Age 26–35, Jackson, MS) in response to the question, “How would you like to see society change to become more accepting of women with HIV?”; “I like to see [greater acceptance] and that is for just not even dealing with HIV. I like to see people get along regardless of who they are, what background, what race, you know, what religion, whatever”.

Participants described several sources of their own resilience and resistance to stigma, to include self-assurance, religious and spiritual activity, mental health care, and social support, including solidarity with similar lived experiences. Several participants identified their previous “struggles” as sources of present resilience. As Lori (White Participant, Age 46 – 55, Birmingham, AL) stated in response to the interviewer prompt, “where do you think that determination came from?”:

I think I have always had that [determination]. Survivor. Both my parents worked two jobs. We were indigent. It just has always been – life has always been a challenge. Everyone has challenges Today I am not playing a victim anymore. I am a recovering addict. I am not ashamed of that. I am HIV positive. I am not ashamed of that, but I am dealing with it and facing it today.

Several participants also viewed prior stigma experiences as sources of strength. As Cynthia (White Participant, Age 56 – 65, San Francisco, CA) shared when asked about how facing multiple forms of stigma and discrimination affects her: “[Stigma and discrimination] made me stronger. They made me want to live more. Maybe initially it hurts my feelings, but I’m a survivor. I’m going to stick it in your face ... I’m healthier than most of the people who are giving me the stigma”.

Discussion

Findings from this qualitative analysis suggest that women living with HIV across geographic areas in the U.S. perceive many forms of stigma in addition to HIV-related stigma. The current study highlights racism, sexism and sexual stigma perceived and experienced by women living with HIV, as documented in other settings (C.H. Logie et al., 2011), in addition to forms of stigma less commonly studied in this population, including incarceration (Brinkley-Rubinstein, 2015), poverty, and weight stigma. Our exploration also highlights that U.S. women living with HIV perceive these interrelated forms of marginalization at multiple levels of influence - by their communities, in interpersonal interactions, and within systems. These complex social environments within which HIV-positive women navigate profoundly shape their lived realities, life opportunities and well-being (Watkins-Hayes, 2014).

to think about intersectionality additively, or to consider their social identities separately, rather than synergistically. This is a common pitfall in qualitative intersectionality research (Bowleg, 2008).

Additionally, the intersectional stigmas explored are not exclusive to women living with HIV, though only this population was included in this study. While many of the same intersecting stigmas are relevant to risk of HIV acquisition among HIV-negative women (P. Y. Collins et al., 2008) and men (Fields et al., 2016), the social position of HIV-positive women is distinct from that of other groups and as such may have unique clinical implications (Turan et al., 2017). Finally, as WIHS participants attend regular research visits with follow-up by research staff, the women engaged in this study may differ from the general population of women living with HIV in characteristics relevant to the study results (e.g., amount of social support, strategies for stigma management, etc.). Further, participant characteristics such as time since diagnosis may differ among WIHS sites, which may be reflected within interviewee experiences.

Despite these limitations, the study has important strengths. The inclusion of study participants living in multiple cities and geographic regions of the U.S., including environments with both urban and rural representation, allows for a rich and multi-dimensional understanding of patterns of stigma among U.S. women living with HIV. Finally, our study expands the lens of intersectional stigma to include less examined stigmas associated with poverty, prior incarceration, weight, and mental health that are experienced by women living with HIV across community, interpersonal and structural domains.

Conclusion

Intersectional approaches have the potential to uncover the complexity of social processes of marginalization, barriers to accessing health and social services, and strategies employed to navigate stigma. The nascent HIV literature on intersectional stigma highlights how HIV serostatus, race, gender, economic status, and sexuality are interdependent and profoundly shape life experiences, opportunities, and healthcare access and uptake among women living with HIV (C.H. Logie et al., 2011; C.H. Logie et al., 2016; Sandelowski et al., 2009; Sangaramoorthy et al., 2017; Watkins-Hayes, 2008). By examining the heterogeneity of stigma experiences among a large sample of women living with HIV across multiple U.S. cities, we uncovered the importance of also considering stigma experiences at the intersection of obesity, poverty, and incarceration. As Bowleg argued (2008), it is not possible for an interviewer to query a participant about every identity, rather the researcher can provide the opportunity for participants to consider multi-dimensionality relevant to understanding their lives. The rich complexity of women's lives in this study highlight the need for public health strategies to consider community, interpersonal and structural dimensions across intersecting, interdependent identities to promote the wellbeing, and reduce social and health disparities, among women living with HIV.

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Research Highlights

- Focus on the clinical implications of HIV-positive women's unique social position.
- Imparts rich, multi-dimensional understanding of stigmas among U.S. women with HIV.
- Expands lens of intersectional stigma to types less examined in this population.

Table 1

Characteristics of the Study Participants

Characteristics	n	%
Race		
Black	46	61
White	20	26
More than one race	6	8
Native American	1	1
Unknown/Not Reported	3	4
Ethnicity		
Hispanic or Latina	5	7
Not Hispanic or Latina	71	93
Age Group *		
26 – 35	8	10
36 – 45	18	24
46 – 55	35	46
56 – 65	15	20
Highest Level of Education Completed		
<High School/GED	11	14
High School/GED	19	25
Some College/Associate	34	45
College and above	12	16
Monthly Income Range		
\$1000 or less	43	57
\$1001 – 2000	22	29
\$2000 – 3000	5	7
More than \$3001	6	8
WIHS Location [±]		
Atlanta, GA	25	33
Birmingham, AL	13	17
Jackson, MS	13	17
San Francisco, CA	25	33
Highly active antiretroviral therapy (HAART) Status		
On HAART	70	92
Naïve/ Not Using	6	8

Characteristics	n	%
Sexual Orientation		
Heterosexual	63	83
Bisexual	6	8
Lesbian	7	9
No. of Children		
None	24	32
1 or more	52	68

* Note: Participant age ranged from 26 to 62 years (mean=48)

[±] City and state names omitted for blinded review.

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