

# “She Told Them, Oh That Bitch Got AIDS”: Experiences of Multilevel HIV/AIDS-Related Stigma Among African American Women Living with HIV/AIDS in the South

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## Abstract

African American women bear a disproportionate burden of HIV/AIDS in the United States. Although they constitute only 13% of the US population, African Americans account for nearly 65% of all new HIV infections among American women. In addition, this population suffers comparatively greater adverse health outcomes related to HIV status. African American women living with HIV in the South may be further burdened by HIV/AIDS stigma, which is comparatively more pronounced in this region. To further explore this burden, we used narrative data and the Social Ecological Model to explore how African American women living with HIV in the US South recount, conceptualize, and cope with HIV/AIDS stigma at interpersonal, community, and institutional levels. Our narrative analysis suggests that HIV-positive African American women living in the South are vulnerable to experiences of multilevel HIV stigma in various settings and contexts across multiple domains of life. Stigma subsequently complicated disclosure decisions and made it difficult for women to feel supported in particular social, professional and medical settings that are generally regarded as safe spaces for noninfected individuals. Findings suggest that the debilitating and compounded effect of multilevel HIV/AIDS stigma on HIV-positive African American women in the South warrants closer examination to tailor approaches that effectively address the unique needs of this population.

## Introduction

THE HIV/AIDS EPIDEMIC has been characterized as disproportionately affecting particular populations, with striking differences evidenced by race/ethnicity, gender, sexual orientation, economic status, and geographic location. In particular, African American women of childbearing age residing in the Southern United States bear a disproportionate HIV/AIDS burden. African American women constitute only 13% of the US population, yet at the national level they account for nearly 65% of all HIV infections newly identified among women<sup>1</sup>; HIV infection rates among African American

women are nearly 20 times the rate among white women and almost 5 times the rate among Latinas. According to the most recent data reported by the Centers for Disease Control and Prevention, at the end of 2011, it was estimated that 491,100 black/African American women were living with HIV in the United States and Puerto Rico.<sup>1,2</sup>

Despite advances in highly active antiretroviral therapy, which substantially improved the overall quality and quantity of life for persons living with HIV/AIDS (PLWHA), African American women with HIV remain vulnerable to adverse health outcomes associated with HIV disease.<sup>3,4</sup> Even when linked to appropriate care and treatment services, African

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American women living with HIV are relatively more likely to experience morbidity and to face health issues related to depression, post-traumatic stress disorder, and substance abuse.<sup>3-5</sup> In addition, African American women with HIV contend with demands stemming from institutional and interpersonal racism and discrimination, sexism, and economic hardships. These factors intensify the psychological distress associated with living with HIV,<sup>6,7</sup> thus highlighting the need to explore multilevel, additive stigma as experienced by African American women living with HIV/AIDS in the US South.

Multiple forms of social and structural marginalization, including neighborhood segregation, racial discrimination, homophobia, powerlessness, and social isolation,<sup>8,9</sup> increase HIV vulnerability and contribute to lower quality of life for PLWHA.<sup>10-13</sup> Among these inequities, HIV-related stigma is increasingly recognized as a factor that pervades multiple dimensions of the PLWHA experience. Importantly, HIV/AIDS stigma is a major impediment to both HIV/AIDS treatment and prevention and has been associated with reduced likelihood for testing,<sup>10-13</sup> poorer treatment engagement and retention,<sup>10,11,14</sup> lower quality of medical care,<sup>15</sup> poorer preventive behavior,<sup>12</sup> reduced uptake of pre-exposure prophylaxis,<sup>16</sup> and reduced disclosure of HIV status.<sup>17</sup> Stigma also impacts mental health and quality of life for PLWHA.<sup>18,19</sup> For these reasons, examination of the linkage between stigma and quality of life warrants attention.

Despite documented consequences of HIV/AIDS stigma, this psychosocial construct has been criticized for being narrowly defined and individually focused,<sup>20</sup> thus lacking necessary consideration to unique interpersonal and structural factors that give rise to HIV stigma within a particular sociocultural context. Given this, investigating the pervasive and complex nature of HIV-related stigma through the application of multilevel frameworks is a public health priority. HIV-related stigma contributes to the additive burdens already regularly encountered by this population related to gender, race, and class discrimination. Surprisingly, few studies have examined experiences of layered, additive stigma in this population. To address this knowledge gap, we used narrative data and the Social Ecological Model (SEM)<sup>21</sup> to explore how African American women living with HIV in the US South recount, conceptualize, and cope with HIV/AIDS stigma at interpersonal, community, and institutional levels. The SEM has been similarly applied to examine the influence of individual-level experiences, environmental interactions, cultural belief systems, and available informal and formal support networks on the overall health and well-being of HIV-positive African American women.<sup>22</sup> Due to the penetration of HIV-related stigma across multiple domains of life, an enhanced understanding of stigma experienced by HIV-positive African American women is needed to tailor approaches that would effectively address the unique needs of this population.

## Methods

### Recruitment

The parent study in which this work is embedded focused on pregnancy intentions of HIV-positive African American women of childbearing capacity.<sup>23</sup> The study used a qualitative, phenomenological research design with 42 ( $n=42$ ) HIV-positive African American women of childbearing capacity. Utilizing both direct and passive approaches, women

were recruited from five South Carolina clinics or AIDS Service Organizations (ASOs) to complete in-depth face-to-face interviews. Interviews were conducted at a mutually agreed-upon site that provided both the interviewer and respective participant with privacy, comfort, and convenience. Selection criteria for research study participants included the following: self-identified African American, female, self-reported HIV/AIDS seropositive status, between the ages of 18-49, English speaking, and residing in South Carolina. With consideration to the focus of the broader study, participants were excluded if they reported being unable to become pregnant because of natural causes, use of an implanted contraceptive device, or prior sterilization procedures.

To qualitatively explore perspectives about reproduction and motherhood and how they were impacted by healthcare provider advice, women in the parent study were asked questions, such as *In what ways, if any, has being HIV positive changed your relationship with your children? Please tell me about any advice or opinions that healthcare providers have given to you about becoming pregnant; Who have you shared your HIV diagnosis with?* (Table 1). Many women experienced stigma and discrimination related to pregnancy, motherhood, and HIV status disclosure decisions; women also encountered stigma in other social, professional, and medical environments. Thus, we revisited those data to examine how participant narratives might usefully inform our conceptual understanding of HIV/AIDS-associated stigma in this population.

TABLE 1. INTERVIEW GUIDE QUESTIONS

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- Please walk me through your normal day. [Probe: From the moment you wake up until you go to sleep at night]
  - How did you find out that you were HIV positive?
  - In what ways, if any, has your HIV/AIDS diagnosis changed your life?
  - In what ways, if any, has being HIV positive changed your relationship with your children?
  - How often do you think about your status? [Probe: Never, once a week, once a month, every day, constantly]
  - When do you think about your positive status the most?
  - Who have you shared your HIV/AIDS status with?
    - What influenced your decision to share with that person or persons?
  - Do you have any family members living with HIV?
    - What about close friends, are any of them living with HIV?
    - How, if at all, has it affected your life? [Probe: Caring for them, resource, social support]
  - Please tell me about any advice or opinions that healthcare providers have given to you about becoming pregnant.
  - Who can you count on for emotional and/or social support?
  - Please describe the things that you do to cope with being HIV positive. [Probe: Religion, meditation, support groups, family and friend support]
  - What has been your experience with the healthcare system?
  - Have you ever been prescribed antiretroviral drugs by a healthcare provider?
    - Are you currently taking antiretroviral drugs? Why or why not?
-

### *Data collection and instrumentation*

After obtaining informed consent, semistructured interviews lasting up to 90 min in duration were conducted by the first author who is formally trained in in-depth face-to-face interviewing techniques. In addition, a sociodemographic survey was administered to study participants. All participants were compensated \$25.00 for their time and interview participation. Those participants who referred other individuals who were then subsequently enrolled in the study received an additional \$5.00 per enrollee. Data were collected from June 2009 through July 2010. All protocols and procedures were reviewed and approved by the University of South Carolina's Institutional Review Board for Human Use.

### *Data analysis*

Two coders independently analyzed interview transcripts utilizing NVivo 10 software. NVivo allows for hierarchical or tree-like coding and analysis of large amounts of text across multiple themes based on participant responses. Data were analyzed systematically using qualitative content analysis, using both inductive and deductive approaches. The principal investigator developed a draft codebook based on the theoretical SEM, before conducting interviews. The two coders later searched for data-derived codes from the transcribed interviews with the aim of capturing a broader, more topical perspective.<sup>24</sup> Data-derived codes were discussed by two coders after 20% of the recorded interviews were transcribed, read, and analyzed.<sup>24</sup> Codes were then compared to the previously developed codes and finalized through coder consensus. The final codebook was used to comprehensively analyze data from interviews by coding emerging themes, patterns, and perceptions from the extracted open-ended responses. After researchers independently analyzed the data, they then convened to discuss, critically describe, analyze, and justify identified themes. A subsequent consensus meeting was held to resolve coding discrepancies. Demographic survey data were analyzed using SPSS 16.0 for Windows.

## **Results**

### *Sociodemographic characteristics of study sample*

Forty-two ( $n=42$ ) HIV-positive, African American women participated in face-to-face interviews. The mean age in the sample was 37.7 years ( $SD=9.2$ ), with 52.4% of women between the ages of 40–49 (range 19–49). Women in the sample were predominantly single (70.4%), self-identified as Baptist (66.7%), and unemployed (66.7%) with an annual income under \$10,000 (73.8%). Approximately 19% of the respondents had less than a high school education; 33.3% completed high school or received a general equivalency diploma; 38.1% attended college; and 7.1% of respondents received a college degree. Half (50.0%) of participants lived with a family member; ~24% of women lived alone; 14.3% lived with a partner or husband; and 9.5% respondents lived in some type of transitional housing. Almost one-half (47.6%) of women received Medicare and/or Medicaid; 42.9% were uninsured; and 9.5% reported coverage from another form of health insurance. Most participants (97.6%) were obtaining healthcare from a clinic or ASO located in an urban area (52.4%) or rural area (45.2%). A majority reported acquiring HIV through unprotected heterosexual intercourse (85.7%).

The mean number of years living with HIV was 10 ( $SD=7.8$ ), with a range of less than 1–29 years.

### *Qualitative results*

To guide the qualitative analysis and to categorize participant responses, we utilized the SEM, which for our purposes valuably gives consideration to the dynamic interaction of lived experiences on multiple social levels. This model contextualizes individuals' behaviors using dimensions that are characterized as intrapersonal (e.g., knowledge, attitudes, behavior), interpersonal (e.g., social networks, social support), community (e.g., relationships among organizations/institutions and informal networks), and institutional (e.g., social institutions with organizational characteristics and formal rules and regulations) to inform a framework for understanding and describing the interactions between these levels.<sup>21</sup> Recognizing that individuals' realities are constructed through the interrelationship and intersection between personal, behavioral, and environmental factors,<sup>25</sup> the SEM was thus an appropriate framework to inform research related to HIV stigma among African American women living in the US South.

Within the 42 qualitative interviews, women relayed experiences of stigma at the interpersonal, community, and institutional levels. Stigma described at the intrapersonal and public policy levels were not thematic and therefore were not included in the conceptual model. What follows is a summary of women's responses related to multilevel HIV/AIDS stigma. Although responses are categorized to reflect specific levels of the SEM, in most cases, participants' experiences were not limited to a single level. Many participants described stigma at various levels, with those experiences overlapping in multiple levels of the SEM.

**Interpersonal-level stigma.** Interpersonal-level stigma refers to those experiences of stigma within one's immediate social environment impacting direct interpersonal interactions.<sup>26</sup> In our sample, women recounted feeling stigmatized primarily by family members and friends. Upon disclosing their HIV status to persons in their immediate social environment, women reported frequent experiences of both perceived (identified by target) and enacted (experienced acts of discrimination) stigma. Collectively, women reported painful negative experiences, including family members deeming them unfit to care for their own children because of their infection; family members avoiding close physical contact with them; and, as a consequence of overwhelming fear of transmission, family members imposing the use of disposable plastic plates and forks. Consistent with previous study findings, the prospect of disclosure to others in their immediate social environment presented a quandary for women. Women desired to disclose their status to their family to obtain social support, yet such disclosure consequently and paradoxically would make them vulnerable to stigma and discrimination.<sup>27</sup> Despite the described demoralizing interactions, in the absence of other alternative social support networks, many women elected to maintain familial and friendship ties.

Positive or negative post-disclosure social interactions can profoundly influence how PLWHA conceptualize or cope with their illness. In fact, Watkins-Hayes et al. contend that such interactions ultimately "shape women's movement from beliefs and behaviors that suggest that they are 'dying from' the

disease to attitudes and actions consistent with the notion that they can 'live with' HIV."<sup>28</sup> Several women in our sample described instances where, without their explicit consent, a family member disclosed their status as a result of a disagreement that occurred unrelated to their HIV status. For example, one participant described feeling betrayed by her cousin who as a result of a disagreement, subsequently intentionally disclosed the participant's status to other individuals:

"I got a cousin, she, she's mad at me, she's been mad at me for six months or whatever, she kind of like put it out there—oh, that bitch's got AIDS." [Age 46; Diagnosed in 2010]

Similarly, one woman described hurtful HIV status stigma experiences provoked by her younger sister:

"My baby sister she'll throw it [my status] in my face. That kind of hurt my feelings and stuff like that. She was the main one who put it out [my status] back in the day. She used to call me all kinds of names and say you have AIDS. I'll be like girl I do not have AIDS. She would say well, you got HIV, what's the difference?" [Age 39; Diagnosed in 1989]

Another participant recounted a similar experience of stigma. For this participant, the enacted stigma not only demoralized her but also affected her ability to mother her own children. For many minority women with HIV, motherhood is one of the few socially valued roles available to them.<sup>29</sup> Problematically then, experiences of stigma can compromise the fulfillment of this role.

"My mom found out I was HIV, you know, she didn't want me to be around my kids, she didn't want my kids to sleep with me. It hurt because it, I mean, my kids can't catch it, you know what I'm saying, by touching and kissing on them." [Age 19; Diagnosed in 2007]

In some instances, participants described greater acceptance over time of their HIV status by family members. As one participated stated:

"My other family members, for a long time used plastic forks and stuff because they didn't understand it. But, I guess now they do [understand] because they come to my house now and they don't eat off of plastic." [Age 35; Diagnosed in 1996]

**Community-level stigma.** At the community level, HIV stigma experiences can intersect an individual's immediate social circles as well as within their broader community.<sup>26</sup> In our sample, experiences of community-level stigma were described as occurring primarily in the context of interactions within church and public housing settings. Although some of these experiences did not involve direct interaction with the individual, the implications of such encounters adversely impacted the individual's overall health and well-being. Experiences of community-level stigma also extended to participants' families and similarly led to family members' social isolation and rejection. The intersection of Southern location, low socioeconomic status, and historical racism likely contributed to the heightened experiences of HIV stigma in the described community settings.<sup>12,30</sup>

Parental disclosure of HIV status to children represents a complex decision. Parents are typically concerned that status disclosure will result in adverse outcomes, including "the psychological burden of shock, fear, and stigma."<sup>31</sup> Because of the effects of stigma, some children, unfortunately learn of

their parent's status accidentally through others, ultimately robbing parents of their disclosure autonomy and opportunity to comfort their children. For vulnerable populations, Val-lerand et al. contend that mothers may face additional stressors associated with disclosure.<sup>32</sup> One of our respondents described how someone in her extended social circle disclosed her status to her son, which not only affected her adversely but also had an injurious effect on her son:

"I had him [my son] two years before my diagnosis. I didn't tell him until later on down the line, well actually I didn't tell him; somebody else told him. His father's other child's mother, you know, told him doesn't your mother have HIV and, you know, they, they were taunting him and, and he was like no, my mother, don't have AIDS." [Age 33; Diagnosed in 1995]

In addition to stigma experienced within her social circle, this woman's status was similarly disclosed within the church setting, compromising her relationship with other church members and testing her faith. Although she experienced stigma at the community level, it also resulted in intrapersonal or internalized stigma. Churches, which are traditionally viewed as crucial coping mechanisms, sources of social support, and safe spaces for individuals, especially for African Americans, can in contrast serve to further stigmatize, marginalize, and isolate HIV-positive individuals.<sup>33</sup>

"My mother went to the church and behind my back was telling everybody I was HIV-positive. And before long the whole church knew. It was embarrassing and people were looking at me and were treating me bad because of my diagnosis. They, themselves had handed me a death sentence. I left the church." [Age 33; Diagnosed in 1995]

There is an established relationship between unstable housing and suboptimal health outcomes among PLWHA.<sup>34</sup> As a result, programs such as Housing Opportunities for Persons with AIDS (HOPWA) administered through the Department of Housing and Urban Development (HUD) provide short- and long-term supportive housing facilities to address the needs of people who are living with HIV/AIDS. These facilities, however, are often known to members of the community as HIV/AIDS housing, undermining the constructive intent of such housing programs. For one study participant, residing in a public housing community that offers subsidized housing to low-income PLWHA led to experiences of stigmatization. Due to her geographic location in a particular residential development, the woman believed her status was involuntarily disclosed, leading to feelings of depression and isolation.

"I'm more depressed than anything. I don't look towards tomorrow. I stay to myself. A few people come around and it's like a clique and where I live in housing most of the people have it [HIV]. And people in the area they know about that housing situation so they automatically start talking. My family has pretty much disowned me." [Age 47; Diagnosed in 2009]

**Institutional-level stigma.** The institutional level refers to larger societal structures and institutions with formal rules and regulations for operations.<sup>26</sup> In our sample, institutional-level stigma was manifested primarily as experiences of exclusion, stigmatization, and discrimination within the healthcare system, pharmacy, employment, and prison settings. These experiences differ conceptually from the

community-level descriptions as they involve the violation of privacy and confidentiality policies that ought to be implemented within institutional settings to protect the legal and human rights of PLWHA. Despite the enactment of the Health Insurance Portability and Accountability Act (HIPAA), which provides federal privacy protections for individually identifiable health information, PLWHA reported violations of privacy by healthcare workers and pharmacy staff. Given women's cognizance of measures in place to protect patient health information, they were especially alarmed by the improper and unauthorized use of such information in these institutional settings. One participant recalled the social, emotional, and psychological disturbances associated with unintentional but still damaging disclosure of her HIV status in the presence of other clinic patients, stating:

"I was in the waiting room and of course there were other people in there and every time they would come out and call somebody back, they would have the regular manila charts like these, you know, they'd call your name - until they got to mine and called me and it had a big old red sticker on the back of mine saying medical alert. And when the nurse came out and called me... I could see it and everybody else could see it, too, and people were like looking at her and I was like, no, they did not do this." [Age 38; Diagnosed in 2005]

Another participant described a disrupted clinical intake interview after informing a nurse that she was HIV positive.

"They said, do you have anything else in your prior history that we need to talk about? I said, I'm HIV-positive and they said, hold one moment ma'am and they came back with a mask to finish my interview." [Age 43; Diagnosed in 1986]

Many clinics that exclusively provide healthcare services to HIV-positive individuals have the capacity to offer patients a range of comprehensive services or "one-stop-shop care" in a single location. In contrast to clinics that offer services to all patients, including those infected with HIV, evidence suggests that patients are vulnerable to stigma, discrimination, and disclosure when attending clinics that serve only HIV-positive patients and may deter them from engaging in continual care.<sup>14</sup> One participant described how her fear of anticipated stigma related to seeking care at an HIV-only clinic prevented her from attending HIV appointments. Due to her low socioeconomic status, this woman's only option for HIV care was utilizing a community clinic that offered HIV-related services only, as opposed to a private provider where HIV services can be masked. Thus, she felt she would be readily identified by others and susceptible to stigma.

"I don't want to go [to the doctor] because then I would, I just, I, like I said I'm in denial. Everybody will know your business or something or it just, it might be worse than what it is and I just, I don't want to deal with it like that." [Age 39; Diagnosed in 2009]

In addition to stigma and discrimination both perceived and exhibited in the clinic setting, PLWHA, especially those residing in nonurban communities, report avoiding local pharmacies for HIV medication refills so as to minimize HIV disclosure risks. To circumvent disclosure risks, one participant described how she began filling her HIV prescriptions in an adjacent town because she suspected that her health information would not be kept private by hometown pharmacy staff with potential overlapping social networks.

"I would take my prescriptions to the pharmacy two towns over because I didn't want to run into anybody or have anybody in the pharmacy filling AZT for me in my hometown. It's a small town [Age 33; Diagnosed in 1998]."

Experiences of institutional stigma in the workplace generally stemmed from instances when members of their interpersonal or community-level social networks disclosed a participant's status to their employer. Although many women recognized institutional-level stigma as a human rights violation, the majority of affected participants elected not to pursue legal action. Those decisions appeared to be rooted in disempowerment resulting not only from the associated HIV/AIDS-related stigma but also from marginalization further posed by race, gender, and class. Experiences of losing employment led to financial instability, which further compounded the stressors associated with HIV/AIDS. One participant suspected that she was fired from her job once her supervisor learned of her HIV-positive status through an overlapping social network. Unlike many other participants who believed that voicing their complaints would result in inaction, this particular participant sought legal action.

"I got fired because my job had a suspicion that I had the virus, but they didn't know. My boss knew because she also went to my grandparent's church, and so she kind of knew what was going on. I got a lawyer." [Age 24; Diagnosed in 2006]

One woman anticipated institutional-level stigma resulting from multiple social marginalized identities. She worried about her ability to find work because of the stigma she had experienced as a result of being HIV positive and previously incarcerated. Until 2013, HIV-positive inmates in South Carolina, regardless of their offense, were housed in maximum-security prisons, segregated from other prisoners, and forced to wear badges or markings that confirmed their status.<sup>35</sup> After being released from prison, this woman worried about encounters with other released inmates because her status had been disclosed to them while incarcerated.

"I don't suffer from a lot of pain but I still have to live with stigmas when I go out and look for jobs because there's certain areas that I work in that once I was incarcerated that someone I may know may come and tell my status." [Age 43; 2 children; Diagnosed in 1986]

## Discussion

Our narrative analysis suggests that African American, HIV-positive women living in the South are vulnerable to experiences of multilevel HIV stigma. Consistent with the SEM, participants experienced stigma as a result of dynamic interactions between personal and environmental factors at the interpersonal, community, and institutional level. Within each level, women were forced to decide if they wanted to disclose their HIV status. Black and Miles<sup>36</sup> describe the "calculus of disclosure" that HIV-positive African American women experience when deciding to whom they will disclose their status. For many women, disclosure presents a paradoxical double-edged sword; disclosure can provide support, but equally it can also make an HIV-positive woman susceptible to stigmatization and discrimination.<sup>27,36</sup> Because of the effects of stigma, some women in this sample had their status disclosed involuntarily by others. The

magnitude of distress varied depending on who initiated status disclosure and who received the information. Women expressed great emotional and psychological distress when their children were the recipients of this untimely information. For HIV-positive women, deciding if, when, or how to disclose their status to their children represents a particularly complex decision, one that is made more difficult by the impact of HIV/AIDS stigma.

For many women in our sample, experiences of HIV stigma at multiple levels rendered them unable to feel comfortable in places that are generally considered to be safe spaces for noninfected individuals. Due to the overlapping nature of these levels, women felt stigmatized in many, if not all spheres, of their social interactions, including churches. In African American communities, churches commonly are prominent institutions that offer vital support, education, and resources.<sup>37</sup> More recently, churches have served as important centers for health promotion interventions.<sup>38,39</sup> Although faith-based interventions for HIV prevention and education have been shown to be feasible and effective in African American churches,<sup>33,40</sup> existing HIV/AIDS stigma has been reported as a barrier to HIV program implementation.<sup>41</sup> Coleman et al. argue that pastors and church leaders can play a crucial role in mediating the church environment in a way that promotes empathy and acceptance of HIV.<sup>41</sup>

Healthcare systems have both a legal and an ethical obligation to protect personal health information for all patients, including HIV-positive patients. Although experiences of HIV-related stigma from healthcare providers are well documented,<sup>42,43</sup> less is known about the impact of this stigma on the HIV-positive individual. However, some evidence suggests that provider stigma is associated with decreased access to care.<sup>44</sup> Conversely, the perception of less judgment from healthcare providers and positive relationships with providers are associated with improved retention in care.<sup>14,45</sup> Although an upstream focus to alleviate stigma is critical, programs focused on individual-level solutions, such as patient navigation, can reduce barriers that prohibit HIV-positive individuals from engaging in HIV care.<sup>46,47</sup> Furthermore, recently validated scales to measure healthcare provider HIV stigma may allow healthcare facilities to better identify the specific nature of stigma and develop improved trainings and interventions to change providers' behaviors and beliefs<sup>48,49</sup> toward PLWHA.

Due to their marginalized racial and socioeconomic status, we contend that in many instances, HIV-positive African American women in this sample felt powerless to counter such stigma. Their individual experiences reflect larger institutional and societal issues that marginalize African Americans and people living with HIV/AIDS. Historical and present-day discrimination, as well as the persistence of institutional inequities in the South, shapes the experience of stigma and racism for many African Americans and perpetuates socially marginalized identities. Furthermore, HIV-related stigma contributes to the additive burdens on women who already experience discrimination related to gender and race.<sup>50,51</sup> In this study, we draw from Paul Farmer's argument that highlights the way in which HIV/AIDS-related stigma is more pervasive in those societies marked by other forms of discrimination and inequity compared to societies where racism is diminished. Farmer contends that existing social inequities, such as racism, sexism, and poverty, interact and

contribute synergistically to the risk of both HIV infection and HIV-related stigma. In many cases, when comparatively considered with those social and economic inequalities that give rise to stigma, stigma is easier to intellectualize.<sup>52</sup>

This study has several limitations, including purposive sampling among a group of women predominately seeking HIV care at health clinics and ASOs in the Southern United States. As a result, findings may not be generalizable to all HIV-positive women, particularly, to those women who are not seeking HIV care. Due to varying access, women who are not receiving HIV care may have dissimilar perceptions related to HIV/AIDS stigma and discrimination. Furthermore, our data pertain only to HIV-related stigma, but we recognize that there are other forms of additive stigma such as sexism, racism, and classism that reflect larger social systems and influence how stigma affects vulnerable populations. Intersectionality theory, born out of black feminist thought, purports that various social identities (e.g., race, ethnicity, gender, sexual orientation, and socioeconomic status) interact in a synergistic manner, resulting in experiences of stigma that cannot be understood by simply focusing on only one level or on the additive sum of individual levels.<sup>53</sup> Earnshaw and Kalichman<sup>54</sup> recommend that to appropriately understand HIV stigma, one should take an intersectional approach that accounts for the unique structural and interpersonal factors contributing to HIV stigma, including other types of stigma, within a given sociocultural context.<sup>54</sup>

Results from our study narratives suggest that the debilitating and compounded effect of multilevel HIV/AIDS stigma on HIV-positive African American women in the South warrants closer examination. To identify and address the root causes of social and institutional inequities, the examination should especially be directed at the intersectional nature of stigma experienced by this vulnerable population. Furthermore, it is important to consider that the collective experiences and stories presented in this study represent the lives of real women who are forced to navigate through inescapable, unjust intersections in settings where they live, work, love, play, and pray.

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