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ORIGINAL PAPER

Patient and Provider Perspectives on HIV Stigma in Healthcare Settings in Underserved Areas of the US South: A Mixed Methods Study

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Abstract

Stigma experienced in healthcare settings is a barrier to ending the HIV epidemic. Using a convergent parallel mixed methods approach, we collected qualitative data from 14 focus groups with People with HIV (PWH) and Healthcare workers (HCW) and quantitative survey data (N = 762 PWH and N = 192 HCW) from seven HIV healthcare clinics outside of major urban areas in the southeastern US. Four key themes emerged: (1) HIV-related stigma and discrimination in healthcare settings; (2) experiences of intersectional stigma; (3) disclosure concerns in healthcare settings; and (4) impact of stigma on HIV-related health behavior. Implications for future stigma interventions in healthcare settings include the importance of engaging PWH in the development of interventions, the need for interventions in settings that do not specialize in HIV care, and the importance of engaging all staff when addressing HIV-related stigma.

Keywords Stigma · Healthcare discrimination · HIV · South · Mixed methods

Resumen

El estigma experimentado en los entornos de atención médica es una barrera para poner fin a la epidemia del VIH. Utilizando un enfoque convergente de métodos mixtosparalelos, recopilamos datos cualitativos de 14 grupos focales con personas con VIH y trabajadores de la salud y datos de encuestas cuantitativas (N = 762 personas con VIH y N = 192 trabajadores de la

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salud) de siete clínicas de atención médica de VIH fuera de las principales áreas urbanas en el sureste de los Estados Unidos. Surgieron cuatro temas clave: (1) el estigma y la discriminación relacionados con el VIH en los entornos de atención médica; (2) experiencias de estigma interseccional; (3) preocupaciones de divulgación en entornos de atención médica; y (4) el impacto del estigma en el comportamiento de salud relacionado con el VIH. Las implicaciones para futuras intervenciones de estigma en entornos de atención médica incluyen la importancia de involucrar a las personas con VIH en el desarrollo de intervenciones, la necesidad de intervenciones en entornos que no se especializan en la atención del VIH y la importancia de involucrar a todo el personal al abordar el estigma relacionado con el VIH.

Introduction

HIV and intersectional stigma experienced in healthcare settings undermines efforts to deliver effective healthcare, reduce HIV transmission, and decrease morbidity and mortality in people with HIV (PWH) [1–4]. Enacted stigma in healthcare settings may manifest as discrimination: negative talk about PWH, unwanted disclosure of HIV status, wearing personal protective equipment in excess, and unwillingness to provide care [5]. These experiences are particularly harmful as they violate patients' rights to confidentiality and personal privacy, care in a safe setting, and to be free from abuse and harassment [6–8].

In spite of major public health and biomedical breakthroughs such as treatment as prevention (TasP) [9, 10] and undetectable equals untransmittable (U = U) messaging [11], stigma remains a major barrier to ending the HIV epidemic, particularly in the southeastern US [1]. The social and systemic barriers—including cultural conservatism, low socioeconomic status, and HIV criminalization legislation—that are associated with many southeastern areas influence stigmatizing perceptions of PWH, generate misinformation, and contribute to fears of HIV status disclosure [12]. Altogether, HIV stigma in the southeastern US is a significant public health concern. Stigma contributes to lower healthcare utilization and suboptimal medication adherence that perpetuate higher prevalence of AIDS diagnoses and HIV-related mortality in this region [13–15].

In the southeastern US much of the HIV epidemic is occurring in rural and suburban contexts, more so than any other region. The Centers for Disease Control and Prevention (CDC) estimate 24% of new HIV diagnoses in the southeastern US occur in rural and suburban areas [15]. Community HIV healthcare clinics play a major role in delivering prevention and treatment services to people at risk for acquiring HIV and PWH in these often underserved and high incidence areas [16, 17]. Community HIV healthcare clinics have been responsive in providing culturally relevant HIV services to marginalized populations through the evolving prevention and intervention landscape [16]. However, the co-occurring epidemic of HIV and its intersecting stigmas (i.e., homophobia, racism, substance use stigma, economic situation stigma) prevents HIV healthcare services from reaching and retaining many individuals who may need their services the most [18–20]. Research is needed that addresses HIV and intersectional stigma and discrimination from perspectives of both PWH and HCW in these underserved communities in the southeastern US to design effective stigma reduction interventions. Such interventions may bring together PWH and HCW to problem-solve and address HIV stigma and discrimination in their HIV healthcare clinic and community [21].

The aim of the present study is to address the gap in the literature on how stigma manifests in HIV healthcare clinics and other healthcare settings in the southeastern US using a mixed methods analysis of data from both PWH and HCW recruited from clinics outside of major urban areas. Data were collected as part of a preliminary study refining a stigma-reduction intervention—the Finding Respect and Ending Stigma around HIV (FRESH) intervention [21]—using focus groups and surveys with validated measures of stigma and discrimination related to HIV and other stigmatized characteristics. These data were used to understand how stigma and discrimination impact care engagement and treatment outcomes for PWH.

Methods

Participants and Procedures

The present study uses a convergent parallel mixed methods design. All data were collected between June 2018 and May 2019. PWH and HCW were recruited from seven healthcare clinics in Alabama and Tennessee that provide clinical HIV services for PWH; none were located in a major urban area. Inclusion criteria for PWH participants were (1) over 18 years of age, (2) living with HIV, (3) established HIV primary care at one of the seven clinic sites, (4) English-speaking, and (5) able and willing to provide informed consent. PWH were excluded if they had a significant cognitive or developmental impairment that would prevent them from providing informed consent. Inclusion criteria for HCW participants included being (1) over 18 years of age, (2) currently employed at one of the seven participating clinics in a role that included any kind of client contact, (3) English-speaking, and (4) able and willing to provide informed consent.

Both PWH and HCW were recruited using convenience sampling. Each participating clinic had a member of the staff (a "clinic champion") who recruited via word-of-mouth and posted recruitment flyers in their respective clinics. PWH who attended the participating clinics were asked to complete a paper, tablet, or computer-based survey lasting approximately 30 min at the time of their clinic visit and received a $10 reimbursement for their participation. Clinics that did not have computers available for patient use or did not have capacity to store tablets opted to provide paper-based surveys. All HCW were encouraged to complete a separate paper, tablet, or computer-based survey designed to assess HCW perspectives. As a thank-you for participation, the clinic with the highest proportion of workers who completed surveys received a lunch from the study team.

Following the survey period, PWH and HCW were invited to participate in focus groups to elaborate on topics covered in the surveys and to provide feedback for refinement of the FRESH intervention. Two focus groups were conducted at each site, one for PWH and one for HCW. A total of 14 focus groups were completed. All focus groups were moderated by one member of the study team experienced in qualitative research methods. Focus group guides developed by the research team were used to facilitate discussion around experiences of HIV-related stigma in HIV healthcare settings as well as feedback on potential stigma-reduction intervention approaches. Due to the complexity of stigma mechanism language (e.g., enacted stigma, disclosure concerns, discrimination, intersectional stigma), those concepts were not explicitly addressed in focus group guides. Participants were asked to discuss HIV-related stigma in healthcare settings in general.

The study was approved by the University of Alabama at Birmingham Institutional Review Board and all participants provided informed consent prior to engaging in any study procedures.

Quantitative Survey Measures

Demographic Information

All participants reported their age, race and ethnicity, gender, and education level. Healthcare workers also specified how many years they had been working in their current occupation at their clinic and categorized their occupation as medical or medical support staff (physician, physician assistant, nurse practitioner, nurse, nursing assistant, laboratory technician, pharmacist, pharmacy technician); allied health, social support, or prevention staff (social worker, dietician, medical technologist, occupational therapist, physical therapist, disease intervention specialist, outreach worker, health educator); administrative and clinic support staff (administrator, receptionist, financial services, record keeper, secretary, accountant, driver, security, housekeeping, other).

Enacted HIV Stigma in Healthcare Settings

PWH and HCW completed an 8-item measure of enacted stigma in healthcare settings in the past 12 months [5]. PWH reported their experiences of enacted HIV stigma in any healthcare setting. For example, PWH responded to, "In the past 12 months, how often have you experienced the following at a health facility? Healthcare workers were unwilling to care for you because you are living with HIV." HCW reported their observations of enacted HIV stigma in the clinic where they were employed. HCW responded to a parallel item, "In the past 12 months, how often have you observed the following in your health facility? Healthcare workers unwilling to care for a patient living with HIV." All participants responded on a scale from 1 = Never, to 4 = Most of the time. The scale has been validated in international and domestic healthcare settings [5, 22, 23]. Two items in the original scale were designed to be reverse-scored. Those items reduced the reliability of the measure and were omitted for this analysis. Internal consistency for the revised 6-item scale was very good (PWH Cronbach's alpha = 0.86; HCW Cronbach's alpha = 0.76).

Everyday Discrimination Scale

As a measure of intersectional stigma, PWH participants reported the frequency of experiencing discrimination in their day-to-day life related to their HIV status, sexual orientation, race, gender, economic situation, and substance use across nine items for each type of discrimination [24]. For example, participants responded to "You are treated with less respect because of your [sexual orientation]" on a scale from 1 = Never, to 6 = Nearly every day. Internal consistency was very good for each type of discrimination (Cronbach's alpha: HIV Status = 0.94; Sexual Orientation = 0.95; Race = 0.95; Gender = 0.94; Economic Situation = 0.95; Substance Use = 0.95). For descriptive purposes, composite mean scores were calculated for each type of discrimination and then dichotomized as 0 = Never experienced, and 1 = Experienced.

HIV Disclosure Concerns

PWH participants completed the revised HIV Stigma Scale [25, 26] that includes a subscale for HIV disclosure concerns [8 items]. Response options ranged from 1 = Strongly disagree, to 4 = Strongly agree. Internal consistency for the subscale was very good (Cronbach's alpha = 0.83).

ART Adherence

ART adherence was assessed by asking PWH participants, "In the last 30 days, on how many days did you miss at least one dose of your HIV medications?" [27]. Because measures of ART adherence (missed dose counts) tend to have a positive skew, responses were dichotomized as 0 = ≥ 95% adherence (less than or equal to 2 missed doses in the past month), and 1≤95% adherence (more than 2 missed doses in the past month) [28, 29].

Data Management and Analysis

Qualitative Data

Focus groups were audio recorded and transcribed by professional transcriptionists experienced with qualitative research. Members of the study team developed a coding framework and two coders applied codes using thematic analysis using NVivo software [30]. Three focus group transcripts were initially double-coded by the coders and team discussions were used to resolve discrepancies and come to joint understanding. After consensus had been reached, the remainder of the transcripts were individually coded by one of the two main coders. Thematic analysis [31] was used to identify key themes and sub-themes.

Quantitative Data

Data were managed using SPSS version 25 [32]. Descriptive analyses were conducted separately for PWH and for HCW to characterize the samples. For each stigma scale, the items were described in addition to the overall scale means and standard deviations. The dichotomized Everyday Discrimination Scale scores were summed to describe the number of different types of discrimination PWH experienced, and contingency tables were used to characterize how frequently each type of discrimination co-occurred with HIV-related discrimination.

Logistic regression was used to assess the associations between enacted HIV stigma in healthcare settings and HIV disclosure concerns on dichotomous ART adherence among PWH. Covariates included age, binary gender (0 = male, 1 = female and transgender), binary race (0 = white; 1 = Black, Hispanic/Latinx, Asian, multi-race, other), and binary education (0 = less than high school degree, 1 = high school degree or more).

Joint displays were used as a tool to visually display and integrate qualitative and quantitative research findings [33].

Results

Participant Characteristics

Demographic characteristics of the PWH (N = 762) and HCW (N = 192) are presented in Table 1. A total of 44 PWH and 56 HCW participated in focus groups. The distribution of participants among clinic sites and description of clinical services are presented in Table 2.

Themes

Four major themes emerged from the data as salient in both the qualitative and the quantitative data, namely: (1) HIV-related stigma and discrimination in healthcare settings, (2) experiences of intersectional stigma, (3) disclosure concerns in healthcare settings, and (4) impact of stigma on HIV-related health behavior. Below we present qualitative and quantitative data on each theme, followed by a joint display that integrates the key qualitative and quantitative findings.

Theme 1: HIV-Related Stigma and Discrimination in Healthcare Settings

Qualitative

While HIV healthcare settings were generally described as nonjudgmental spaces by both PWH and HCW, some participants observed negative treatment directed towards PWH due to HCW perceptions of their risk behaviors. One PWH described what they heard HCW talking about while at the clinic:

> The nurses, they'll all sit around. They'll talk about them. I'm talking to my nurse about this patient, and then they'll make snide comments about if they did see this on their chart. We're all sitting there, and they're gossiping, talking about, "I don't want to go in that room." I think somebody has said that before. "I don't want to go in there. I don't want to. Oh, let me glove up. Let me wear a mask or something." Because this particular patient wasn't getting treatment. He was doing drugs and everything else under the sun. (Site D, PWH)

HCW participating in focus groups did not describe any specific observations of HIV-related discrimination directed towards PWH in their healthcare setting. However, one HCW noted that stigma may be important to address at all levels of staff in a clinic:

Table 1 Descriptive information for people with HIV (N = 762) and healthcare workers (N = 192) from HIV healthcare settings in the southeastern US who completed surveys

	People with HIV n (%)	Healthcare workers n (%)
Age		
18–24	60 (8%)	5 (3%)
25–34	175 (23%)	62 (32%)
35–44	180 (24%)	59 (31%)
45–54	177 (23%)	33 (17%)
55–64	123 (16%)	28 (15%)
65+	22 (3%)	5 (3%)
Clinic		
A	146 (19%)	30 (16%)
B	72 (9%)	14 (7%)
C	63 (8%)	54 (28%)
D	111 (15%)	37 (19%)
E	180 (24%)	17 (9%)
F	100 (13%)	21 (11%)
G	90 (12%)	19 (10%)
Gender		
Male	462 (61%)	26 (14%)
Female	269 (35%)	166 (87%)
Transgender or other identity	10 (1%)	0
Education		
Less than high school diploma	98 (13%)	0
High school diploma/GED	275 (36%)	9 (5%)
Some college	212 (28%)	38 (20%)
College graduate	120 (16%)	126 (66%)
Other	23 (3%)	19 (10%)
Race/ethnicity		
Black	474 (62%)	91 (47%)
White	205 (27%)	86 (45%)
Hispanic/Latinx	17 (2%)	10 (5%)
Asian	1 (< 1%)	4 (2%)
Multi-racial	20 (3%)	1 (1%)
Other	17 (2%)	0
Health-related occupation		
Administrative and clinic support staff	–	80 (42%)
Allied health, social support and prevention staff	–	59 (31%)
Medical and medical support staff	–	53 (28%)

> When we're talking about HIV knowledge update, a lot of times in organizations, when we hear healthcare, we think of the medical field, but healthcare starts with front desk all the way back. A lot of times, we have all these interventions that deals with—directly with the medical part of the healthcare rather than the front desk person who is the first person they see when they come into the office. We need training set up for them and programs that update them on information. (Site E, HCW)

More frequently, PWH described experiences of discrimination they had outside of HIV healthcare settings. One PWH described an experience when they were seriously ill: "I ended up in the ICU, but the doctor that treated me first all he wanted to know was my story. Literally, I was laying there. I was septic, and he wanted to know how I got HIV. He wanted to know all about it." (Site A, PWH).

Table 2 Number of people with HIV (PWH) and healthcare workers (HCW) that completed focus groups and surveys, description of clinical services, and population estimate of county by HIV healthcare setting

Clinic	A		B		C		D		E		F		G	
	PWH	HCW	PWH	HCW	PWH	HCW	PWH	HCW	PWH	HCW	PWH	HCW	PWH	HCW
Focus groups	4	8	8	8	8	8	7	7	5	8	8	6	4	11
Surveys	146	30	72	14	63	54	111	37	180	17	100	21	90	19
Health services provided	HIV, Hepatitis C, STI testing, prevention and care		HIV, Hepatitis C, STI testing prevention and care		HIV, Hepatitis C, STI, TB testing, prevention and care; telehealth		HIV, Hepatitis C, STI, TB testing, prevention and care; substance use care		HIV, Hepatitis C, and STI testing, prevention, and care; telehealth		HIV, Hepatitis C, STI, TB testing, prevention and care		HIV, Hepatitis C, STI, TB testing, prevention and care	
Additional support services provided	Case management; financial assistance; housing, food and transportation services; support groups; ADAP		PrEP navigation; case management; housing services; ADAP		Support groups; PrEP navigation; case management; housing and food services; financial assistance; ADAP		PrEP navigation; case management; support groups; nutrition and mental health counseling; transgender specialty care; ADAP		Case management; support groups; housing services		Case management; nutrition and mental health counseling; ADAP		Case management; nutrition and mental health counseling; transportation services; ADAP	

ADAP AIDS drug assistance program; *PrEP* pre-exposure prophylaxis

Another PWH described their experience in a dental office in the community before accessing co-located dental care at their community HIV healthcare setting:

> Before they brought the dental clinic here, I went to the dentist, and you have to let the doctor know. My doctor should have let the doctor know [my HIV status]. Evidently, the workers didn't know. I guess when they got to one of the workers, they knew that I had HIV, and she was distant. I could feel it. I could feel the difference when she first came in the room and after she got the information. It's like they just was distant and didn't want to touch me. She looked like she put on an extra set of gloves or something. It's hurtful. It's very hurtful. Being here, after I've gotten the treatment here, it's totally different because I'm not being judged by my virus. (Site B, PWH).

Another PWH described a distressing situation at a dental clinic illustrating multiple manifestations of HIV-related stigma in a healthcare setting:

> [The front desk worker] said, "Well, how did you get [HIV]?" I said, "What does it matter?" 'Cause she said, "Did you have a—" first, she asked me did I have a blood transfusion. I said, "No." She said, "Well, how did you get it then?" I said, "Does it matter how I got it?" She said, "Wait again." Then she said, "Well, we can't wait on you." I said, "Why not?" She said, "Cause he'll take too long to clean up behind you, and you need to come back at the end of the day. You should have told us that on the phone." Just saying it right in the reception, right in the front door. Therefore, people was surrounding me, so everybody picked up on it, and everybody just started looking at me. I just recently found out that year, so I couldn't—I was trying to learn how to deal with this myself. I just asked them, "Could y'all give my little money back that I paid?" "No, 'cause you did get your X-ray." I got in the car. I had a little pride about myself 'cause I got in the car. It hurt my feelings so bad, so I started crying. I was like, Lord, I don't never want nobody else to feel the way I feel." (Site B, PWH)

A HCW added that they see patients at their HIV healthcare clinic that come in reporting difficult experiences with outside providers:

> "It's just is frustrating 'cause even though doctors and everything are supposed to be professional and know about HIV, they don't. They have predisposed ideas about it and just—'cause I've had patients come in and just be upset about their experience they maybe had with a dental care provider or just a primary care physician." (Site C, HCW)

Quantitative

Descriptions of observations of enacted HIV stigma in any healthcare setting (PWH) and in their specific HIV healthcare setting (HCW) are described in Table 3. On average, PWH reported relatively rare experiences of enacted HIV stigma in healthcare settings (M = 1.3, SD = 0.6) in the past 12 months. HCW observations of enacted stigma in their own facility in the past 12 months were also rare on average (M = 1.2, SD = 0.3).

Among HCW, observations of enacted HIV stigma occurring in their clinic were similar based on occupation type within the clinic comparing medical and medical support staff; allied health, social support, prevention staff; administrative and clinic support staff (F (2,189) = 1.0, p = 0.37). Controlling for number of years HCW worked in their current occupation did not significantly impact results.

Theme 2: Experiences of Intersectional Stigma

Qualitative

Both PWH and HCW agreed that stigma experienced in HIV healthcare and other healthcare settings goes beyond the identity of living with HIV to include other identities like sexual orientation, gender, and economic situation. One PWH described:

> I have come to [this clinic] for about nine years now, and I just watch people that—around this area when I come in, they get tested, everything, they're looking at me like, why are you going in there? I'm a white lady, a straight white lady going in this clinic, and they're like, why are you going in there? They don't say it, but you could tell. (Site D, PWH)

One couple described their previous experiences of homophobia in an HIV care setting:

> Respondent 1: "[My partner and I] used to go to an HIV doctor in Florida […] He was obviously homophobic on top of—and he was an HIV doctor. He [partner] went to the same doctor. He knows. We're a couple. We've been together 35 years. This doctor was very homophobic, made rude comments to us all the time and wouldn't help us get our medicine when we needed it and all kinds of stuff."
> Respondent 2: "Would not return your phone calls, ignored you when you called to get a prescription refill."
> Respondent 1: "It goes beyond HIV. It goes into homophobia, people who are transgendered, people who are gay with HIV, your race. There's a lot of phobias out there—"
> Respondent 2: "A lot of stigmas."
> Respondent 1: "That are connected in with HIV environment too. Not every doctor is friendly of people who are homosexuals or different." (Site B, PWH)

A HCW pointed out the intersectional nature of HIV stigma, particularly as tied to sexual orientation:

> I think with our clients, this population, there's a lot more tied in with just stigma and HIV. There's racial issues, trust issues, poverty, mental illness. There's a lot of things that have to come into play on our side as far as in assessments to see where those barriers are that we might can have them overcome they might not even know that they have. With this disease, sexual orientation, what their identity is, is also part of that stigma with this disease. (Site C, HCW)

Quantitative

Overall, 51% of PWH reported experiencing HIV-related discrimination and 60% of PWH reported experiencing more than one type of everyday discrimination (Fig. 1A). Among the 387 PWH who experienced any HIV-related discrimination, 277 (72%) also experienced race discrimination, 231 (60%) also experienced gender discrimination, 266 (69%) also experienced discrimination based on their sexual orientation, 186 (48%) also experienced discrimination due to their economic situation, and 163 (42%) also experienced discrimination based on substance use (Fig. 1B).

Theme 3: Disclosure Concerns in Healthcare Settings

Qualitative

In focus group discussions, PWH described experiencing and HCW described observing pervasive concerns of PWH about being seen at the HIV healthcare clinic in their community, and fears of unwanted disclosure by healthcare staff or their medical record. One PWH described the tension between having a relationship with HIV healthcare staff at the risk of serostatus disclosure:

> If you're local and you're seeking care, it can be extremely difficult to access care when confidentiality is such a concern. I think [this clinic] attempts to be very personal in its outreach in terms of reaching out to people, and it's a very tough situation because in attempting to reach out to people and be very personal, they also run the risk of exposing people's

Table 3 Endorsement of enacted HIV stigma in healthcare settings among PWH and HCW

	PWH	HCW
	Question stem In the past 12 months, how often have you experienced the following at a health facility (clinic, doctor's office, etc.)?	*Question stem* In the past 12 months, how often have you observed the following in your health facility?
Healthcare discrimination Range 1 = Never – 4 = Most of the time	M (SD)	M(SD)
1. Healthcare workers unwilling to care for a patient living with HIV	1.3 (0.8)	1.1 (0.4)
2. Healthcare workers providing poorer quality of care to a patient living with HIV than to other patients	1.3 (0.7)	1.1 (0.4)
3. Healthcare workers talking badly about people living with or thought to be living with HIV	1.3 (0.7)	1.3 (0.6)
4. Healthcare workers confronting or educating someone who was mistreating or speaking badly about people living with HIV*	1.5 (0.9)	1.7 (1.0)
5. Healthcare workers disclosing a patient's HIV status without the patient's permission	1.2 (0.6)	1.1 (0.4)
6. Healthcare workers using extra infection control precautions (like wearing extra gloves) when caring for a patient living with HIV	1.7 (1.0)	1.3 (0.8)
7. Healthcare workers providing extra support or care for patients living with or thought to be living with HIV*	2.1 (1.2)	2.9 (1.2)
8. Healthcare workers sending or referring patients living with HIV or other health facilities because the workers do not want to treat them here	1.2 (0.6)	1.1 (0.4)
Total scale mean	**1.3 (0.6)**	**1.2 (0.3)**

PWH people with HIV; *HCW* healthcare workers

*Reverse scored items, not included in total scale mean

> names and drawing into this culture of gossip, of people talking about people's HIV status and who has what. It's a difficult road to walk. (Site D, PWH)

Although HIV healthcare settings provide services beyond HIV care and can serve many needs of the community, PWH may still express HIV disclosure concerns during their visit:

> We have people in our clinic that come in and they're like, "do people know why I'm here?" I get that question all the time. Because they see somebody in the waiting room they know and they're like do they know why I'm here, or is there somethin' sayin' why I'm here? I'm like they don't know why you're here. We have five different clinics goin' on. I mean, we don't advertise that you're here. I guess it was different when they were at their other place 'cause they have one certain day that everybody was there for HIV clinic. (Site F, HCW)

HIV disclosure concerns were at the HIV healthcare setting, as well as other healthcare settings, like hospitals:

> We have to stop it because people are dying because of stigma because they don't want to deal with it at all. I've seen patients discharge themselves from the hospital because of stigma. They've left because they saw someone that they knew in the lobby, so they said, "I'm not going to this hospital. I'll just go home, and I'll do something else." It's definitely an impactful situation to be the person that's on both sides. (Site D, PWH)

Disclosure concerns were not only relevant for HIV serostatus, but for intersecting identities like sexual orientation as one HCW pointed out: "I think, for some of our clients, too, it's not just that they're HIV positive, it's that

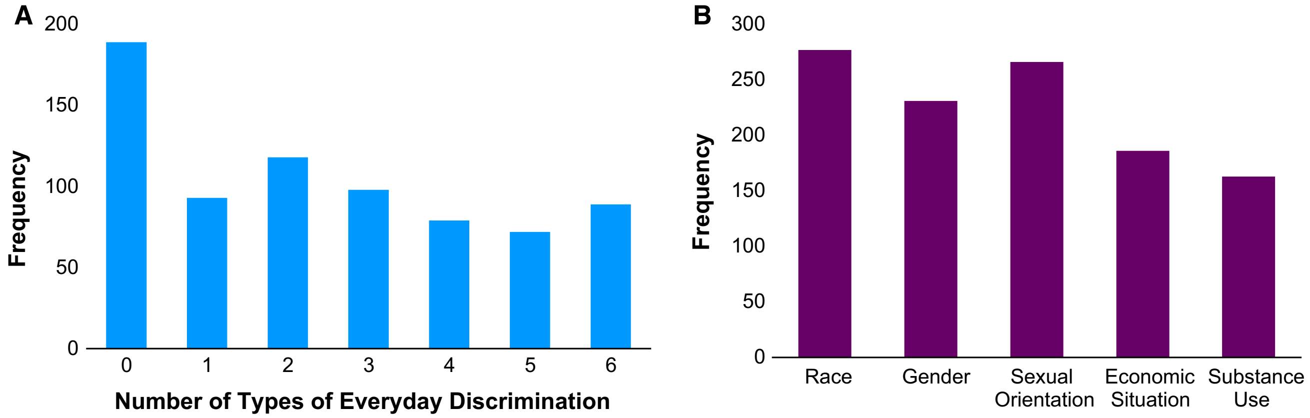

Fig. 1 **A** Number of types of everyday discrimination people with HIV (N = 762) experienced including HIV, race, gender, sexual orientation, economic situation, and substance use discrimination; **B** Other types of everyday discrimination among people with HIV who experienced HIV-related discrimination (n = 387)

they're also gay, and some of their families don't know, and so to reveal one would be to reveal the other." (Site E, HCW)

Quantitative

On the Enacted HIV Stigma in Healthcare Settings Scale (Table 3), 17% of PWH indicated they had experienced unwanted serostatus disclosure in a healthcare setting in the past 12 months. Nine percent of HCW reported they had observed an unwanted serostatus disclosure at their HIV healthcare clinic in the past 12 months. On the Disclosure Concerns subscale of the HIV Stigma Scale, PWH agreed they had concerns about HIV serostatus disclosure on average (M = 3.0, SD = 0.7, Range = 1–4).

Theme 4: Impact of Stigma in Healthcare Settings on HIV-Related Health Behavior

Qualitative

PWH and HCW observed that stigma-related fears cause some clients to avoid needed health care utilization:

> I feel that even some don't wanna be seen coming here. They'll choose to park elsewhere because of stigma. I recently had somebody didn't even wanna be tested here because they knew somebody would see them comin' in here that is related to them in another office, and that's the stigma that is holdin' them back from healthcare that they need. (Site E, HCW)

A few PWH noted that experiencing stigma in healthcare settings could lead to negative psychological consequences and impact access to medical care and ART:

> Well, I had a thought when you were talking about self-esteem and not wanting to go back to the doctor. I thought of noncompliance. I mean I wonder how many people are not going to get the medical care they need, and not getting the meds they need or tested because they don't want to deal with that because they feel like we've all felt, and that's scary to me. That's sad and scary. (Site A, PWH)

Quantitative

Enacted stigma in healthcare settings was significantly related to sub-optimal ART adherence among PWH, aOR = 1.38, 95% CI: [1.03, 1.84], $p = 0.028$. Disclosure concerns were also related to suboptimal ART adherence among PWH aOR = 1.29, 95% CI: [1.00, 1.65], $p = 0.046$. Among the covariates included, only race was associated with ART adherence such that non-white PWH were more likely to report suboptimal adherence compared to white PWH, aOR = 2.16, 95% CI [1.46, 3.20], $p < 0.001$.

Integration of Qualitative and Quantitative Findings

A joint display of the key qualitative and quantitative findings is shown in Table 4. Theme 1, HIV-related stigma and discrimination in healthcare settings, highlighted impactful experiences of HIV stigma in HIV healthcare settings and in other healthcare settings (e.g., dental care, hospitals). However, such events were not reported frequently in the quantitative measures of enacted HIV stigma in healthcare settings in the past 12 months. Theme 2, experiences of intersectional stigma, indicated the pervasiveness of other forms of stigma that PWH face in their communities such as homophobia, racism, sexism, and substance use stigma; and this was supported by the reports of everyday discrimination based on different personal attributes in the quantitative data from PWH. Theme 3, disclosure concerns in healthcare settings, underscored disclosure concerns and related anticipated stigma that PWH face when accessing HIV care and that these concerns may lead to avoidance of care. Observations of unwanted disclosure of HIV status were rarely reported by both PWH and HCW, but do occur. Theme 4, impact of stigma on HIV-related health behavior, explored the relationships between enacted HIV stigma in healthcare settings and HIV disclosure concerns with ART adherence among PWH.

Discussion

PWH and HCW agreed that enacted stigma—both HIV-related and other intersectional stigma—in healthcare settings continues to occur in both HIV and other healthcare settings. Qualitative descriptions of these experiences highlight the negative impact enacted stigma in healthcare settings has on PWH. The experiences described often occurred while receiving healthcare outside of HIV specialty settings, such as inpatient hospitalization or dental visits. Experiences of stigma ranged from HCW interrogating PWH about how they acquired HIV even when HIV is not the reason for the healthcare visit, gossiping or talking negatively about other PWH, distancing from PWH or wearing excessive personal protective equipment, and denying services. Qualitatively, HCW acknowledged the stigma that PWH face, and noted that reception staff and other workers, "from the front desk all the way back," would benefit from HIV education on stigma prevention training, consistent with prior research [34, 35].

Quantitative frequency measures of enacted stigma in healthcare settings in the past 12 months from both HCW and PWH suggested these experiences may not occur often. However, the qualitative findings describe that even a rare occurrence of stigma in this type of setting—where a client has come to receive help and support—can be highly memorable and damaging. Previous research has elucidated the significant negative impact of healthcare setting stigma on self-perceptions (e.g., internalized stigma) and health behaviors [6, 14, 23]. Furthermore, addressing HIV stigma alone will be insufficient based on measures of everyday discrimination. Other forms of discrimination that PWH face such as homophobia, racism, sexism, economic situation, and substance use stigma must necessarily be addressed to create safer spaces for PWH to receive care.

PWH described facing significant disclosure concerns when accessing care for HIV in their local communities. This may be even more important in smaller and more close-knit rural and peri-urban communities. Both PWH and HCW experienced and observed unwanted HIV serostatus disclosure in HIV healthcare and other healthcare settings, a serious breach of patient confidentiality. HIV healthcare settings must consider protection of patients' privacy and confidentiality while building supportive relationships to engage community members in care. Many HIV healthcare settings provide a range of services to the community that are not limited to HIV services. Importantly, both enacted HIV stigma in healthcare settings and HIV disclosure concerns have potential implications for healthcare utilization. Both HCW and PWH expressed concerns that stigma is a barrier to accessing medical care and could also prevent people from accessing the medications they need to prevent HIV progression and transmission. Together with the quantitative findings, these data suggest that even rare experiences of stigma can adversely impact HIV-related health and well-being. Whole-person approaches to care are needed and will require resources like funding and culturally responsive healthcare workers to successfully engage communities that need their services most [16].

Findings from this study have implications for future research and the development of stigma interventions in healthcare settings. First, measures of stigma that assess frequency of events without assessing impact may not capture the true experience of stigma (even when rare) among PWH. Mixed methods designs and measures of the psychological effects of stigma may better capture the impact of experienced stigma and discrimination on health outcomes. Second, stigma education and interventions should not stop at medical staff, but should also be developed for healthcare professionals such as receptionists, administrative staff, and other clinic support staff. This recommendation is consistent with a prior review of stigma interventions in healthcare settings [35]. Interventions are also urgently needed for healthcare workers outside of HIV healthcare settings such as dentists, internists, and other specialty care providers. A recent review of stigma interventions for PWH found very few interventions exist for HCW outside of HIV specialty care [36], an important gap to address in future implementation of stigma interventions.

Intersectional stigma and disclosure concerns are significant barriers for PWH to engage in healthcare, especially in smaller more close-knit rural communities in the southeastern US. Both PWH and HCW described the efforts made to avoid serostatus disclosure among PWH, including avoiding healthcare. Disclosure concerns are also pertinent to other

Table 4 Joint display of qualitative and quantitative findings

Theme	Illustrative quotations	Main quantitative findings	Interpretations
1. HIV-related stigma and discrimination in healthcare settings	"We're all sitting there, and they're gossiping, talking about, 'I don't want to go in that room.' I think somebody has said that before. 'I don't want to go in there. I don't want to. Oh, let me glove up. Let me wear a mask or something.' Because this particular patient wasn't getting treatment. He was doing drugs and everything else under the sun." (Site D, PWH) "A lot of times, we have all these interventions that deals with—directly with the medical part of the healthcare rather than the front desk person who is the first person they see when they come into the office. We need training set up for them and programs that update them on information." (Site E, HCW)	On average, PWH reported rare experiences of enacted HIV stigma in healthcare settings ($M=1.3$, $SD=0.6$) HCW observations of enacted stigma in their own clinic were also rare on average ($M=1.2$, $SD=0.3$) Among HCW, perceptions of enacted stigma occurring in their clinic did not significantly differ based on type occupation within the clinic	HIV-related stigma and discrimination occur in healthcare settings in underserved areas of the southeast US and may be particularly salient in healthcare facilities that do not specialize in HIV care Experiences of HIV stigma and discrimination appear infrequent based on quantitative measures, but impactful based on qualitative descriptions
2. Experiences of intersectional stigma	"I think with our clients, this population, there's a lot more tied in with just stigma and HIV. There's racial issues, trust issues, poverty, mental illness." (Site C, HCW) "This [HIV] doctor was very homophobic, made rude comments to us all the time and wouldn't help us get our medicine when we needed it and all kinds of stuff." (Site B, PWH)	60% of PWH reported experiencing more than one type of everyday discrimination The majority of PWH who experienced HIV-related everyday discrimination also experienced everyday discrimination related to another identity or identities	HIV is tied with other marginalized identities that are stigmatized. Experiences of intersectional stigma – particularly around race, sexual orientation and substance use – occur in healthcare settings in the southeastern US
3. Disclosure concerns in healthcare settings	"If you're local and you're seeking care, it can be extremely difficult to access care when confidentiality is such a concern." (Site D, PWH) "We have people in our clinic that come in and they're like do people know why I'm here? I get that question all the time." (Site F, HCW)	17% of PWH indicated they had experienced unwanted serostatus disclosure occur in a healthcare setting 9% of HCW reported they observed an unwanted serostatus disclosure at their clinic PWH agreed they had concerns related to serostatus disclosure (HIV stigma scale disclosure concerns subscale: $M=3.0$, $SD=0.7$, Range = 1–4)	PWH in the southeastern US have heightened concerns around unwanted disclosure when attending HIV healthcare clinics. Unwanted disclosure does occur in HIV healthcare and other healthcare settings
4. Impact of stigma on HIV-related health behavior	"That's the stigma that is holdin' them back from healthcare that they need." (Site E, HCW) "[When I was pushed away from healthcare], I felt bad, like my self-esteem go down." (Site A, PWH)	Both enacted stigma in healthcare settings and disclosure concerns were related to suboptimal ART adherence ($aOR=1.38$, 95% CI: [1.03, 1.84], $p=0.028$, and $aOR=1.29$, 95% CI: [1.00, 1.65], $p=0.046$ respectively)	Enacted stigma in healthcare settings and HIV disclosure concerns may be associated with lower healthcare utilization and ART adherence

PWH people with HIV; *HCW* healthcare workers; *ART* antiretroviral therapy characteristics like one's sexuality or substance use that may be assumed when accessing HIV healthcare services. Although HIV healthcare settings often provide many services, disclosure concerns still arise among PWH. Importantly, PWH should be involved in the development of future HIV stigma interventions to address disclosure concerns and intersectionality to find multi-level approaches that will work for their communities [21, 36].

Results of this study should be interpreted in light of some limitations. First, quantitative data are cross-sectional. Results from the logistic regression models should thus be interpreted as exploratory and do not imply causality. Future studies using longitudinal models should explore these relationships and their potential mechanisms. Second, participants in the study were recruited using convenience sampling at participating clinics and may not represent all PWH and HCW in underserved areas of the southeastern US. PWH were included if they were established with HIV care and may not represent experiences of PWH who were lapsed or out of care. Third, being a PWH and a HCW are not mutually exclusive. In situations where a HCW was also living with HIV, the individual decided which group they identified with for the study. Measures of intersectional stigma are described here categorically that may oversimplify and limit the interpretation of the complexity of intersectional identities [37, 38]. Finally, social desirability may have affected responses especially among HCW regarding observations of stigma and discrimination in their clinic setting.

The present mixed methods study contributes data on HIV-related stigma in healthcare settings in underserved areas of the southeastern US. Stigma intervention efforts developed for these areas need to focus on healthcare settings other than HIV care, train non-clinical healthcare staff that may not necessarily have direct patient contact, address intersectional stigma, and enact stronger locally appropriate protocols to protect patient privacy. PWH should be involved in the development, delivery, and evaluation of these stigma interventions. Finally, evaluations of stigma interventions need to include measures of health outcomes like internalized stigma, ART adherence, and clinic visit attendance to determine effectiveness in making progress towards ending the HIV epidemic.

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Data Availability Data are available upon request.

Declarations

Conflict of interest The authors have no conflicts of interest to disclose.

Ethical Approval All procedures were performed in accordance with the ethical standards of the Institutional Review Board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent All participants engaged in the present study were provided with information on the study's purpose, risks and benefits of participation, measures for protecting their confidentiality, and that data would be published for scientific purposes. Participants provided written informed consent after agreeing to study procedures.

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