

# Perceptions and Impact of HIV Stigma among High Risk Populations in the US Deep South

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## Abstract

This study examines community HIV-related stigma in the US Deep South, a region disproportionately affected by HIV. Study participants included individuals at higher risk for HIV, primarily African American men who have sex with men and women participating in substance use treatment. Findings from six focus groups identified a lack of knowledge and significant fear about HIV in participants' communities. A dearth of accurate information about HIV and HIV prevention, including pre-exposure prophylaxis (PrEP), was reported as widespread and contributed to myths about HIV and increased stigma. HIV-related stigma was reported as pervasive and resulted in lowered participation in HIV testing and treatment. Participant suggestions for addressing stigma included extensive media HIV education and counseling/support for individuals living with HIV. Addressing HIV-related stigma in the Deep South is critical to reducing HIV transmission and improving HIV-related outcomes.

**Keywords:** HIV; AIDS; Stigma; Qualitative; Prevention

## Introduction

Higher levels of HIV diagnoses, prevalence and mortality have been consistently reported in the US Deep South<sup>#</sup> in comparison to other US regions [1,2]. The Deep South states share other similarities including overall poorer health [3], high poverty rates [4,5], and cultural climates that may

contribute to the spread of HIV including stigma related to HIV, gender identity and sexual orientation. HIV-related stigma has been identified as prevalent in the US [6,7] and particularly high in the Deep South [8-13]. HIV-related stigma has consistently been identified as contributing to poorer HIV-related outcomes including less use of health and social services, anxiety, negative body-image, and poorer medication adherence among individuals living with HIV and with avoiding or delaying HIV testing among those at high risk for HIV [8,9,14-20]. Anticipated stigma regarding the potential negative consequences of testing positive for HIV has been found to affect individuals' willingness to be tested [15,17,21]. Lack of accurate information about HIV and HIV-related stigma among health care providers has also been identified as persisting in the South, further contributing to the stigma experienced and witnessed by individuals living with and at higher risk for HIV [22].

Although high levels of perceived HIV-related stigma have been identified among individuals living with HIV in the South [11,12,23,24], few studies have examined perceptions and pervasiveness of community-level stigma and evaluated whether this stigma affects health-related beliefs and behaviors among individuals at higher risk for HIV in the Deep South. This article describes a qualitative study that examined perceptions of stigma related to HIV and HIV prevention, including pre-exposure prophylaxis (PrEP), among individuals at higher risk for HIV living in the US Deep South. Participants were primarily African American men who have sex with men (MSM) and women with substance use histories. Ascertaining levels of HIV-related stigma and their influence on HIV prevention within the broader at-risk community is valuable to inform the development of stigma reduction interventions that can serve to ultimately reduce HIV acquisition among individuals most vulnerable to HIV in the Deep South.

## Methods

The population studied in this research included individuals at higher risk for HIV. Six focus groups were facilitated in four Deep South states (3 in MS and 1 each in AL, SC, NC). Focus

<sup>#</sup> Defined here as including Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Texas

group participants (n=54) were identified through partnerships with AIDS Service Organizations (ASOs) and other social service providers in the study communities (Table 1). One focus group was a mixed gender group with nearly all African American participants and two focus groups were comprised of African American and Caucasian women receiving substance use treatment. Two of these groups were located in a mid-size city (population between 150,000-250,000) and one in a small city. The remaining three focus groups consisted of nearly all African American MSM. One was in a large metropolitan area (population greater than 500,000) and the other two were located in a small city (population 50,000-100,000). The group in the large metropolitan area primarily included individuals enrolled in or interested in a PrEP program. Just over half of the focus group participants were women (54%) and close to two-thirds (63%) were African-American.

Individuals considering participation in the study were presented with the study information and signed written consent forms to participate in a focus group. The study procedures were approved by the institutional review board at the authors' institution. Focus groups were facilitated between May 2016 and February 2017. The focus groups followed a standardized structure that included questions about HIV stigma perceptions and experiences, availability of information about HIV in the community, common HIV-related myths and inaccuracies, HIV prevention including PrEP, the faith community and HIV, and ideas to address HIV-related stigma. The focus groups were recorded and transcribed. The audio for one of women's groups was of poor quality so the facilitators' notes were used to supplement the transcription. The transcripts were analyzed using an inductive thematic approach [25]. "Inductive analysis is a process of coding the data without trying to fit it into a preexisting coding frame or the researcher's analytic preconceptions [26]." This process included identifying important and relevant sections of transcribed focus group text and attaching codes to these sections, then indexing them as they related to a theme or data issue. Once the coding structure and themes were identified, the transcribed data was reviewed in its entirety to index data into the established codes. The data was reviewed a second time and in the case of relevant issues in the text not included in an existing code, a new code was inserted. Some codes were branched under other relevant themes and data was ultimately reduced into a set of significant themes that could be summarized to adequately describe the findings. The software package NVivo was used to organize and describe the focus group findings.

**Table 1:** Description of the Focus Groups

Group Location	Number of Attendees	Setting	Participant Gender Identity	Group title
Alabama	7	AIDS Services Organization	Mixed gender group	AL
Mississippi	10	Housing for women in substance use recovery	Female group	MS1
Mississippi	6	Participants in an HIV prevention education	Male group	MS2
Mississippi	7	Participants in an HIV prevention education	Male group	MS3
South Carolina	16	Substance abuse treatment center	Female group	SC
North Carolina	8	AIDS Services Organization	MSM/2 transgender women	NC

## Results

The study results are grouped into broader subject categories and themes, with more specific topics contained therein, including: lack of accurate information about HIV, high levels of HIV-related stigma in the community, the faith community's response to HIV, greater need for HIV testing and prevention, and ideas for addressing HIV and HIV-related stigma.

### Lack of knowledge and accurate information about HIV

Participants were asked to describe the first words or images that came to mind when they heard the word "HIV." This question generally elicited very negative images from participants including "fear," "death sentence," and "dirty." Regarding fear associated with HIV, one participant said:

*"I think in general, a complete ambiguity or ignorance to what HIV and AIDS is. I think I can agree, when you hear it you just become afraid, you become terrorized by the word. And then you realize that you don't know very much about it at all."*(NC group)

Another participant talked about HIV being associated with death, stating

*"That's [death] the first thing that comes to my mind. I know there's a lot more to it that I don't know and I can learn a lot more about it."*(MS1 group)

Some participants' impressions of HIV focused on transmission categories and stereotypes such as "gay," "lifestyle," "transgender," "drugs," and "prostitution."

Participants described a pervasive lack of knowledge about HIV in their communities and reported a dearth of accurate information available about HIV. One participant said, *"I think people are dying because of their lack of knowledge, their lack of understanding..."* (MS3 group).

Misinformation and myths about HIV were reported to be common such as the potential to transmit HIV through spitting or *"by mosquitos or wiping toilet seats."*(MS3 group). Another participant noted that *"Some people think just you talking and breathing you can catch AIDS."* (SC group).

Age differences in HIV perception were noted, with older individuals still believing HIV to be a "death sentence" rather than a chronic illness and younger individuals having less fear of HIV because they had not witnessed the early years of the epidemic.

Several participants believed that while some individuals do have accurate knowledge of HIV, they do not get tested or reduce risk behaviors because of denial of personal risk or because they think HIV only happens to “others.” For example, one participant stated:

*“I think people just usually think it won’t ever happen to me. People don’t willingly go get tested. They don’t get tested until they’re in a hospital or treatment facility where they’re made to get tested, and then they find out and it goes all downhill from there. That’s just another something else they’re going to have to deal with.” (MS1 group)*

When asked where people obtain information about HIV, participants primarily named sources such as word of mouth, the Internet and social media outlets, while a few participants reported obtaining information from service providers including health departments and substance use treatment/recovery organizations. Focus group participants consistently lamented a lack of sufficient HIV education in the community, which they believed could assist in dispelling HIV myths and resultant stigma.

An additional theme that emerged relating to HIV discourse within the community was a lack of HIV status disclosure due to fears of stigma and discrimination. This lack of disclosure was thought to result in less conversation overall regarding HIV and less opportunity for HIV-related education. A participant described the consequences of the lack of disclosure, responding that:

*“It also comes back to that we don’t have proper discussions so we don’t know. Even those that are HIV infected don’t really talk about it. So, if you’re not talking about it, how can you make a person or persons aware when there’s no conversations, there’s no dialogue? So, abstinent dialogues and those kind of wrong ideas are going to continue.”(NC group)*

### High Levels of HIV-related stigma in the community

An additional theme that was consistently described by participants was a high level of HIV-related stigma in their communities. For example, one participant reported that *“people who have AIDS are treated like the plague.”(MS1 group)* Another participant described HIV-related stigma in the Deep South, emphasizing that *“We’re in the Bible Belt. There’s not much more to say than that.”(MS1 group)*. There was a general consensus among participants that people living with HIV often avoid disclosing their status for fear of rejection and discrimination. One participant described reasons people may not disclose, noting:

*“Fear of rejection. I mean, I’ve known a couple people who have had HIV and they don’t like to talk about it because as you say it people start to cut you off as if it’s a disease you’re going to catch just by walking by somebody. You know, you sneeze on somebody and all of a sudden it’s like oh my god I got to go get tested. It’s the fear, you know.”(NC group)*

Another participant said that after revealing an HIV diagnosis, *“people are going to treat you different no matter what, family included.”(MS2 group)*. Another participant summed up the anticipation of stigma on delays in testing and subsequent care by saying *“The stigma is greater than wanting to be healthy.” (AL group)*

One participant described witnessing stigma following disclosure, saying:

*“I could see where they have tried to make friends with other people or they’ve been friends with somebody and then for whatever reason it comes out and then all of a sudden there’s like they have the bubonic plague, you know? It’s like they stop talking to you, they treat you differently, it’s just like people that you hung out with, you’ve known all your life and all of a sudden they don’t want to talk to you because of ignorance.” (NC group)*

Public shaming on Facebook and other social media was also described, particularly instances when social media was used to disclose an individual’s status without their consent, often by posting pictures of HIV medication bottles.

Discrimination based on sexual orientation was discussed as a substantial concern in the South as well, with one participant stating:

*“I just feel like Mississippi don’t care about gay people enough to educate them... Only reason I say that is because they just passed the new law to discriminate against gay people.” (MS1 group)*

Discrimination related to HIV in health care settings was also mentioned as a concern, with one individual who worked in a health care setting describing observations of stigma from co-workers and others worrying about stigmatization resulting from a lack of health care providers’ training regarding HIV.

**HIV-related stigma affects HIV testing:** A consistent theme regarding HIV testing was a reluctance to participate in testing, often because of fears of the consequences of receiving a positive result, including concerns about being identified as HIV positive and the potential resulting stigma and discrimination that may occur after this revelation. Participants connected the fear of being associated with HIV to delays in testing, with one participant describing this phenomenon as **“test shunning.”** Participants described multiple layers of stigma experienced by individuals in their communities including racial and sexual orientation/gender identity stigma along with stigma regarding HIV from within the LGBT community. One participant described the effect of multi-layered stigma in relation to HIV testing, responding that *“Some kids won’t get tested at the doctor because they may be gay and haven’t come out to their parents. Once I ask for this test, I’m officially admitting that I’m gay.”(AL group)*

Others spoke about stigma surrounding sexual orientation as limiting the opportunities for HIV education, stating that:

*“I think the challenge with that is if I talk to you and if you have HIV and then I assume that you’re gay and I’m saying I’m*

straight, I don't want to be assimilated with you. So there goes another divide, so I don't want to talk to you about it because I shouldn't have any interest in it because it doesn't affect me because it's a gay person's disease. That's how it's viewed, and it's not a gay person's disease." (NC group)

### Stigma in the faith community

An additional HIV stigma-related theme that arose from the focus groups was a lack of positive response to HIV from the faith community. Most churches were said to stigmatize HIV and the LGBT community. One participant described the following experience within their faith community:

*"This is your pastor, your first lady, your nurse, your whatever and you go there for sanctuary because church is where you're supposed to go for love or for sanctuary, for counseling, whatever you [inaudible] and you pour it out and that person says well you know you're going to hell. Really?" (AL group)*

Some participants discussed hearing very negative sermons concerning HIV in church, particularly related to sexual orientation. On this topic, a participant noted:

*"Because you hear these things across the pulpit where no one wants to be against God or do something that's wrong, and so that's the first thing you hear. And then, as he said, it's almost a punishment if you are gay and then you will get AIDS, it's almost like a punishment, like that's the greatest sin so God punishes people by giving them AIDS. So you hear all those kinds of wrong kinds of teaching, but they come from very powerful sources that impact who we are and how we believe and how we think. And also how our elders and our parents and how people that are around us, our society thinks, as well. So, culture plays a lot into it." (NC group).*

This information was thought to contribute to internalized stigma and self-loathing among individuals living with HIV and individuals in the LGBT community and decrease likelihood of disclosure of HIV status to members of these faith communities, including within families who are involved in these churches. Participants reported that most churches they were familiar with did little in the way of HIV prevention. This general approach of churches regarding HIV and LGBT issues was thought to translate into a lack of education in the home as well as a lack of discussion of sex and sexuality, especially in the African American community.

However, some participants described increasing support from their local churches. For participants who attended an affirming church, the experience was relayed as positive and supportive.

### Need for additional HIV testing and prevention resources

As noted previously, participants talked about a general lack of HIV education and prevention programs available in their community, including through schools, church, media, family, and peers. However, the focus group participants receiving

substance use treatment and those involved with a CDC evidence-based prevention program (3MV) had been exposed to some HIV education through these programs.

Several participants noted that medical care providers do not routinely test for HIV unless an individual is pregnant or is known to be gay; rather individuals often had to ask to be tested. Some participants perceived that individuals are often afraid to ask for testing for fear of their sexual orientation being exposed or other confidentiality breaches, rendering medical provider visits a missed opportunity for HIV testing and education. One participant described barriers to testing among youth, explaining:

*"Yeah, you see in the media get tested and they're being real upfront about it but it's not as easy to get tested. Like depending on the type of parents you have and like the people behind you. If you have good support that will be that for you then yeah, it's easy to go and get tested but when you have like judgmental people and stuff, it's not so easy for people to just go to the doctor and get tested." (AL group).*

Other barriers to HIV testing mentioned in the focus groups included difficulty finding places to get tested and lack of availability of rapid tests, requiring individuals to return for their results thereby increasing travel costs and exposure to potentially stigmatizing situations. Additionally, participants shared concerns about what happens after testing, noting that media campaigns focus on the act of getting tested, but don't relay what to do once you have your results. This was described by one participant that stated:

*"When it comes to AIDS, most times you see in the media that says get tested, get tested, go be tested, be tested. They don't educate them anything further as to what you should do, even if you're tested. There's nothing in the media, and the media is very powerful." (NC group).*

Another described similar concerns, saying: *"I think people need to be educated on if the test is not favorable what they can expect." (NC group).*

**PrEP:** The consensus among participants in all focus groups was that there exists a lack of information and knowledge about PrEP in their communities, both in the general population and among minority MSM and other higher-risk groups. Among those familiar with PrEP, lack of access to and knowledge about where to obtain PrEP were also universally identified. Most of the African American men participating in the 3MV intervention reported that they knew little or nothing about PrEP until learning about it in a recent session. In the focus groups with women who were receiving substance use treatment, little or no knowledge of PrEP was also reported and some participants confused PrEP with post-exposure prophylaxis (PEP).

Since PrEP programs are often co-located with ID clinics, a few individuals expressed concern that they would be assumed to be HIV-positive if seen at the clinic. One participant shared similar worries about picking up PrEP at a pharmacy, explaining:

*"I ended up knowing everybody in the pharmacy because I was there every 30 days getting a prescription filled. And you're wondering, do they know what this is for, you know? And of course on the tag there's all this information about HIV PrEP. PrEP is also a part of the regimen that's used for HIV meds, yeah, so you're looking and they know you in church, they know you in the post office, they know in the grocery, they know you and you're like is my information going to get out? Is someone going to know?"(NC group).*

Additionally, participants from the group consisting primarily of individuals taking or considering PrEP mentioned encountering stigma surrounding taking PrEP, which one person described, stating: *"Because people feel like well if I'm taking PrEP then I'm only taking PrEP just to go out and screw everybody... so that's PrEP shaming."*(MS2 group).

### Ideas for Addressing HIV and HIV-related stigma

Focus group participants were asked to offer suggestions on ways to reduce HIV-related stigma in the South. Their responses fell into the following thematic categories:

**HIV testing and prevention:** A recurrent theme addressing reduction of HIV stigma was the need to expand HIV testing opportunities. Suggestions for expanding testing efforts included increasing testing availability in jails, pharmacies, and mobile vans. Another idea for testing that was suggested by a participant in one focus group and well-received among participants in that group was to include HIV testing as part of a more comprehensive wellness program in conjunction with other health topics.

There was broad agreement amongst the focus group participants regarding the need for additional HIV education and prevention messages, particularly in high poverty and minority communities. Specific suggestions included a media barrage, which would involve advertising about HIV and HIV prevention on buses, bus stations, billboards, at public services agencies, and through other media. Regarding increasing media advertising, one individual said:

*"I definitely think it brings into attention something we push in the back of our mind. Regardless of if you did see it -- whether you do anything about it, that would be something different, but I think it makes you aware."*(MS1 group).

Another person discussed the need for widespread education, saying:

*"I'm saying I think if people have education they'll fear less and if they fear less they'll be more, I won't even say accepting because you have to be tolerant first, because I think they'll be tolerant first and they grow to accept, but educations is lacking."*(NC group).

There were also suggestions about having trusted individuals in the community or celebrities offer accurate messages about HIV to increase credibility. Participants discussed how disseminating messaging aimed at gaining a better understanding of HIV as a chronic disease rather than a terminal

illness could assist in increasing HIV testing, as individuals may not be as afraid of the repercussions of a positive test. Lastly, education in cultural competence for health care professionals was also identified as a need, with one individual reporting:

*"Healthcare providers need more cultural competency, they need to know how to treat people, you know what I'm saying? People go to clinics here and the receptionist like frown their face up or like it's real subtle things."*(MS3 group).

**Support groups and opportunities:** Some focus group participants thought that having opportunities for social support for enhancing PLWH coping with HIV-related stigma would ultimately help to reduce feelings of stigma and isolation. In a similar vein, participants reported a need for additional support opportunities for LGBT youth who were described as often isolated from families. They believed additional support could assist youth to cope with living with HIV or encourage those who are HIV-negative to attend to their health. One participant noted:

*"And the one thing I will honestly say is if there was an organization for kids to actually go to that's in an LGBT community that's lesbian, bi, whatever, reaching out to the parents so they can get their kids there, so they can actually speak to people and learn and get the education about it."*(MS3 group)

**Faith communities:** Participants believed that including the church in prevention strategies was critical to effectively address HIV-related stigma. A participant stated that:

*"If there was a support system...within the black church, then a lot of things would be different, people would be more able to be open with who they are, who they choose to love, and with their sexual activity, and then you can also start some other dialogues there because I think the thing about HIV is that we're not working with the inner person, and the inner person, the inner core of the individual is being missed. And I think that's why HIV prevention in the south is not actually taking shape the way it should take shape because of that inner, dealing with the social determinants of health, social economic."*(MS3 group).

Several participants mentioned that it would be a missed opportunity to assume that churches would not want to partner in some way regarding HIV education and testing.

### Discussion

The participants in the qualitative study of community level HIV-related stigma in the Deep South describe substantial levels of stigma in the region. Reports of perceptions of HIV as a death sentence and as transmitted through casual contact reflect a lack of accurate understanding of HIV disease. There are a number of drivers of this lack of understanding that were consistently described by participants including a dearth of accurate information about HIV from sources perceived as reputable. In addition, the reported fear of and experiences with HIV-related stigma and discrimination from family, community, and church breed a silence about HIV and

reluctance to disclose HIV status by people living with HIV and those close to these individuals. This lack of disclosure in turn may continue the cycle of HIV-related myths and lack of honest discussions about HIV and sexuality.

The significant fear of HIV and HIV-related stigma described by participants was reported to result in reluctance to participate in HIV testing, a finding substantiated in other studies in the US and internationally [14-17]. Greater perceived HIV-related stigma has also been associated with lower levels of perceived risk [15]. This denial of risk and perception of HIV as affecting “others” was consistently described by study participants and associated with not participating in testing or reducing risk behavior.

Lack of trust in the integrity of HIV prevention messages was raised as a concern that may result in denial of risk and not seeking HIV testing or treatment. This finding is consistent with other studies that linked a lack of trust in the medical system and government with health behaviors, including a study situated in the Deep South that found lack of trust in government and health providers to influence health outcomes [27-30]. In addition, participants reported that churches, which are often highly influential in shaping community and personal perceptions in the Deep South, particularly in the African-American community, are offering messages regarding HIV and sexual orientation and gender identity that are often stigmatizing, such as the idea that HIV is a punishment from God. In addition, messages in the media that would raise attention on HIV and offer HIV-related education are largely absent, leaving this void to be filled with inaccurate myths and stigmatizing messages.

The high level of HIV-related stigma and discrimination reported by individuals at higher risk for HIV documented in this study are consistent with the high levels of HIV-related stigma reported by individuals who are living with HIV in the Deep South that have been documented in studies situated in the region [12,23,24,31-33]. These previous studies of the perceptions of stigma among individuals living with HIV report prevalent and persistent HIV-related and LGBT-related stigma that influences willingness to disclose HIV status, participate in HIV testing, and seek treatment for HIV. These studies along with the current study of individuals at higher risk for HIV reflect the palpable levels of HIV-related stigma in Southern communities and document the damaging effects of stigma on HIV prevention and care [32].

Most participants reported little personal and community knowledge of PrEP, with stigma and misinformation about PrEP reported as prevalent. When asked about solutions for addressing lack of knowledge regarding HIV and HIV prevention and HIV-related stigma in the Deep South, a number of suggestions were consistently reported by participants. These included a barrage of messaging about HIV in various media, especially presented by reliable and trusted sources in

the targeted community. Other suggestions focused on support services including support groups for individuals living with HIV to assist them in coping with stigma and support for young LGBT regardless of HIV status, who are often isolated and stigmatized.

Expanding HIV testing availability in the community was mentioned, however, reducing community-level stigma will be important to assure that individuals would feel comfortable utilizing expanded testing. Participants also discussed that faith communities have a key role to play in raising HIV awareness and reducing HIV-related stigma, with affirming churches aiding education expansion to other factions of the faith community where outreach has as yet been unsuccessful.

The findings from this study need to be taken in context of the study’s limitations. These limitations include a potential lack of generalizability to individuals at high risk for HIV because of the small sample size and the non-random manner used to identify participants. The study findings may not be generalizable to women not participating in substance use treatment and minority MSM not connected with prevention services. However, despite these limitations, the study provides important information from individuals at higher risk for HIV regarding substantial HIV-stigma related concerns and the negative ramifications of HIV-related stigma and lack of accurate perceptions about HIV on HIV risk behavior and participation in testing in the US Deep South. The suggestions for addressing HIV-related stigma raised by participants are critical to formulate into specific programming to address HIV, with continued input from the individuals living with and at high risk for HIV to best ensure the maximum outcome from implementation.

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