Role of Structural Marginalization, HIV Stigma, and Mistrust on HIV Prevention and Treatment Among Young Black Latinx Men Who Have Sex with Men and Transgender Women: Perspectives from Youth Service Providers

Renata Arrington-Sanders, MD, MPH, ScM,¹ Kimberly Hailey-Fair, MPH,¹ Andrea L. Wirtz, PhD,² Anthony Morgan,¹ Durrelle Brooks, PhD,² Marne Castillo, PhD,³ Connie Trexler, RN, CPN, BSN, MSHS,⁴ Jennafer Kwait, PhD, MHS,⁵ Nadia Dowshen, MD, MSHP,⁶ Noya Galai, PhD,² Chris Beyrer, MD,² and David Celentano, ScD²

Abstract

Young black and Latinx men who have sex with men (YBLMSM) and transgender women (YBLTW) are disproportionately impacted by HIV. Structural and social marginalization, the social barriers, and structures that unevenly distribute benefits and burdens to different groups, may contribute to inability for youth to access prevention and treatment care services. Yet, few reports have examined the community and health care experiences of social marginalization among youth service providers who have multiple roles in the community (i.e., serve as a service provider and are a member or prior member of the YBLMSM and YBLTW population). Eighteen key informants (KIs), defined as youth, young adults, or adults who were members of or connected to the YBLMSM and young black and Latinx transgender (YBLTG) community, participated in a one-time, face-to-face, or telephone key informant interview (KII) lasting ~45 min. KIs were defined as youth service providers because they described working with the target population and either being a member of or closely connected to the target population. KIs described key themes related to marginalization: lack of competent care among health care providers and both clinical and community spaces that left out key populations. HIV stigma and medical mistrust continues to create a barrier to care in this population and for interventions to be effective interventions will need to use an intersectional approach that simultaneously address all identities, and the social and structural needs of youth.

Keywords: YBLMSM, YBLTW, structural marginalization, HIV

Introduction

YOUNG BLACK AND LATINX men who have sex with men (YBLMSM) and transgender women (YBLTW) are disproportionately impacted by HIV.^{1,2} Structural and contextual factors (e.g., stigma and discrimination),³ neighborhood environments (e.g., high crime and inadequate housing),^{4,5} and sexual networks (e.g., assortative and nonassortative mixing in high-prevalence networks) have been thought to play a role

in the HIV disparities among YBLMSM and YBLTW in the United States and globally.^{6–10} There are also greater losses in the HIV prevention and treatment cascades among YBLMSM and YBLTW than other adolescent groups.¹¹ Some estimates suggest that only 41% of youth ages 13–29 are aware of their diagnosis, 25% linked to appropriate care, 11% retained in care, and 6% of youth are virally suppressed once stable in care.¹¹ Research has linked low uptake to pre-exposure prophylaxis (PrEP) among YBLMSM and YBLTW to issues of

¹Division of General Pediatrics & Adolescent Medicine, Johns Hopkins School of Medicine, Baltimore, Maryland.

²Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland.

³The Adolescent Initiative, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania.

⁴Adolescent Clinical Research, Burgess Clinic, Children's National Medical Center, Washington, District of Columbia.

⁵Whitman-Walker Health, Washington, District of Columbia.

⁶Perelman School of Medicine at the University of Pennsylvania, Philadelphia, Pennsylvania.

stigma associated with PrEP use and/or being black, Latinx, and gay or transgender, medical mistrust, culturally insensitive health care for gay men, limited access, and lack of discussion on topics of HIV prevention and sexual health in these communities.^{12–16}

Marginalization is defined as the process of making a group or class of people feel less important or of a secondary position.¹⁷ Structural marginalization results from structures and institutions that unevenly distribute benefits and burdens to different groups, and as a result, marginalize certain groups or people.¹⁸ Such structures reinforce advantages or disadvantages and can contribute to inadequate access to or provision of health care services. Social marginalization relates to the process through which persons are peripheralized based on social identities including, but not limited to, gender, class, race, sexual orientation, and socioeconomic status and is thought to be related to social determinants of health.¹⁹ Social marginalization among YBLMSM and YBLTW contributes to HIV disparities and poorer health outcomes.^{20,21} In a recent study of 21 HIV service providers in Chicago, multiple key informants (KIs) reported that societal marginalization intersected with HIV stigma and was thought to predispose youth to low engagement in HIV services.²² These findings represented the perceptions of HIV service providers, however, and may be distinctive from or omit critical insights that can be provided by those with lived community experiences.

In this study, the community is defined as encompassing youth who experience multiple intersecting sexual orientation and gender identities (e.g., black, Latinx, gay, transgender) and social contexts (e.g., social, neighborhood, income) that may further exacerbate feelings of marginalization and create barriers to care. The framework of intersectionality can be understood as the underpinning lens to examine this relationship. Intersectionality has been used to describe the compounding effects that having multiple marginalized identities (i.e., gender; sexual orientation; race/ethnicity) has on the health of those individuals.^{23,24} Previous research has also considered the importance of using this framework to explore disparities in HIV transmission rates.^{23,25,26} The purpose of using this framework for this study is to define a community not only by the social space that YBLMSM and YBLTW may exist in, but also the community factors that may impact experiences of stigma, mistrust, and marginalization.

HIV-stigma and anticipated HIV stigma have been described as barriers to HIV prevention and treatment care.^{27,28} HIV stigma reflects the endorsement of stereotypes and prejudice associated with an HIV diagnosis, whereas anticipated stigma is described as relating to individual's avoidance of adhering to an expected behavior, for example, avoiding HIV testing because of fear of the negative consequences associated with a positive result.^{27,29} As such, HIV stigma may act as a structural barrier to care. Others have documented the associations between stigma and insufficient HIV testing and less than optimal treatment outcomes among those at high risk for HIV.^{30,31} Some reports suggest that gay and bisexual men who report sex with men and transgender women may avoid testing because of the social and psychological costs that may be associated with a positive test.²⁷ There may be other unmeasured structural barriers within clinical spaces that also marginalize groups and contribute to avoidance behavior.

Few reports have examined the community-level and health care experiences of social marginalization among YBLMSM and YBLTW and described how structural barriers (e.g., HIV-related stigma) intersect with marginalization to further reinforce disadvantages in care. Structural marginalization may exist particularly in clinic and community settings where service providers interact with youth at risk for HIV; this may further compound barriers to HIV prevention and treatment care. Prior work has explored experiences among YBLMSM and YBLTW as well as ancillary providers' views,^{22,32} but has failed to examine the experiences of those who serve youth and may also be members of the community. Youth service providers who have multiple roles in the community (i.e., serve as a service provider and are a member or prior member of the YBLMSM and YBLTW population) may experience unique challenges that exist both for service providers and also for the youth they serve as well. In this article, we sought to qualitatively understand—from a youth service providers' perspective—how community and societal marginalization intersect with HIV-related stigma and may result in barriers to the provision of HIV prevention and care among YBLMSM and YBLTW.

Methods

KIs, defined as youth, young adults, or adults who were members of or connected to the YBLMSM and young black and Latinx transgender (YBLTG) community. Informants included service providers (case managers, community outreach specialists, or volunteers) and youth who were members of the YBLMSM and YBLTG community that had served in an informal role (e.g., mentorship, peer recruiter, etc.). Youth community members were included with service providers, given that they had multiple roles in the community that included serving as sources of HIV prevention and care information to YBLMSM and YBLTG, peer recruitment, and support around HIV testing and prevention. KIs were defined as youth serving providers (YSPs) because they described working with the target population and either being a member of or closely connected to the target population.

KIs participated in a one-time, face-to-face, or telephone key informant interview (KII) lasting on average 45 min (range from 30 to 120 min). KIs were identified through partnerships with three large centers serving lesbian, gay, bisexual, transgender, and questioning (LGBTQ) adolescents in Baltimore, MD, Philadelphia, PA, or Washington, DC. KIs were reimbursed \$35 for their participation. Interviews continued until there was saturation of themes and no additional themes were identified. The study was approved by the Institutional Review Board of the Johns Hopkins Bloomberg School of Public Health.

The purpose of the interview was to explore barriers in treatment and prevention efforts of clients living with HIV or high-risk youth and the use of potential bidirectional mobile app to address those barriers. Formative data from KIs were collected to inform potential interventions to address inequities in the HIV prevention and care continuums for YBLMSM and YBLTW. KIs were eligible to participate if they currently resided or worked in Baltimore, MD, Philadelphia, PA, or Washington, DC; and were identified by LGBTQ-serving organizations as persons who were in or around the target age range and served YBLMSM/YBLTW or a part of the community.

Semistructured interview guides were created to facilitate discussion around the topics of community and societal barriers to accessing HIV treatment and prevention among YBLMSM and YBLTW and strategies (e.g., navigator, coach, mobile application) that could be used to address barriers. Interview respondents were not required to disclose age, gender identity, race, or ethnicity. Organizations who referred KIs were asked to confirm that they fit the eligibility criteria of the study. Participants, however, were asked to comment about how gender identity and/or race/ethnicity might impact the experiences of minority youth. Study staff members were trained to use the approved script to facilitate participant discourse on their own experiences or the experiences of the population targeted in this study. Interviews were audiorecorded and transcribed verbatim by an independent transcription company. Interviews progressed until saturation was determined by the absence of any new information arising from the data.³³

Initial codes were identified from the interview guide. The initial coding schema was based on predetermined questions and codes were then refined and elaborated during the process of analysis through the constant comparison method.³⁴ The constant comparison method consisted of first reading the first four interviews. The initial codes were used to review interviews. During the review, memos were written for each code and new codes identified. Next, one study staff conducted axial coding where data were combined in an excel spread sheet to allow for connections between categories and codes. Using memos, questions, and making comparisons, this process allows for the inductive and deductive thinking process of relating subcategories to a main category.³⁵ Once an initial coding scheme was identified, three team members met and discussed initial codes and incorporated any new codes that had been missed or identified through memos. Discussion occurred until a consensus was met. Once a consensus was met, the remaining interviews were subsequently coded.

Further coding and development of emergent themes relied on selective coding to identify and choose the core category and systematically connect it to other categories, validating similarities and relationships and further refinement and development of categories until no additional codes were identified. In this final stage of coding, the systematic approach to further validate and connect categories continued until the point of data saturation. Grouped and categorized codes were then examined for emergent themes.^{35,36} We further examined themes by relationship type (whether someone had a formal or informal relationship with YBLMSM and YBLTW) and intersectional identities, including race/ethnicity, sexual orientation, gender identity, and social context. Ten percent of interviews were double coded and then reviewed for inter-coder reliability/consistency to ensure high coder agreement ($\kappa > 0.80$). Transcripts were reviewed using NVivo 11 software and included analyses based on the presence of identified codes and emergent concepts.

Results

A total of 18 KIs participated in interviews with research staff from February to May, 2019. The available demographic profiles of participants are shown in Table 1. Most ($n = 15$, 83%) participants provided information on demographics. Among those who provided demographics, the

TABLE 1. KEY INFORMANT INTERVIEW
BY SELF-IDENTIFIED ROLE IN THE LESBIAN,
GAY, BISEXUAL, TRANSGENDER,
AND QUESTIONING COMMUNITY

<i>Characteristic (n = 18)</i>	<i>Formal role^a (n = 10)</i>	<i>Informal role^b (n = 8)</i>
Age (mean, standard deviation) ($n = 15$) ^c	24.3 (4.06)	20.1 (2.54)
Gender identity, n (%)		
Male	7 (70.0)	6 (75.0)
Transwoman	2 (20.0)	2 (25.0)
Female	1 (10.0)	
Race/ethnicity, n (%)		
Black, non-Hispanic	5 (50.0)	8 (100.0)
White, non-Hispanic	1 (10.0)	
Latinx, race not identified	4 (40.0)	
City, n (%)		
Baltimore, MD	5 (50.0)	2 (20.0)
Philadelphia, PA	2 (20.0)	3 (30.0)
Washington, DC	3 (30.0)	3 (30.0)

^aIncludes people self-reported as youth service providers, for example case managers or health educators.

^bIncludes people self-reported as young adult mentors or peer recruiters.

^cAge was not provided by three participants living in Washington, DC.

mean age of respondents was 22.3 years (standard deviation 3.9, range 18–31 years), with most (72.2%, $n = 13$) identifying as cisgender male and non-Hispanic black. All but one participant identified as being a member of the gay, bisexual, and transgender community. Most (55.6%, $n = 10$) described serving formally in a clinic or community organization as a service provider (case manager, community outreach specialist, or volunteer), while seven described working in an informal role (as a mentor or some other social role) in the community with other youth. There was no difference in themes among those with a formal or informal role in the community.

Inadequate information

Half (50.0%, $n = 9$) of the KIs expressed concern with the lack or absence of accurate knowledge pertaining to HIV transmission facts or prevention strategies among the among YBLMSM and YBLTW communities.

Five participants described that youth experienced fear from the HIV testing process and this fear originated from a lack of knowledge about HIV.

“Because some people they hear oh, HIV test and they get scared. So like when I, I remember when I first started engaging in sexual activity and things like that, probably about two or three years ago, once I—because I used to always take ‘em [HIV tests] regularly. But then and it’s on side when you start engaging in sexual activity—But then once I started getting into having sex and things like that every time I heard test, you know, I got scared because at that time I was out in the streets and doing a lot of stuff. So it’s like I guess you would have to make people feel comfortable and make people want to I guess, how can I say it? I guess give them more knowledge and I guess excitement about getting test and wanting to know their status.” (**Informal role, Transgender Black female, 20 years old, Washington, DC**)

The fear also stemmed from a lack of general health care knowledge and a lack of the post-testing process (what occurs after a positive test result). This, combined with the fear of being treated differently post-testing or an HIV diagnosis was described as contributing to people less likely to seek out care. The same participant describes it in this manner,

“I...think not only trans like just transwomen, Because I feel like a lot of black people kind of subject to HIV and they don’t know how to get care. Or sometimes they’re scared to go get tested and receive care. They think, oh, if they are positive or something like that or if they do have any type of disease, period, it’s the end. Or they can’t get help, people going to look at them differently or they’re scared. So I think it would be very helpful with not only the incentive, but the test itself and then the—before the test, just the knowledge of know how to go about testing and how to go about oh, what would happen after your test if you are positive, just giving them a update and information about how it will go.” (**Informal role, Transgender black female, 20 years old, Washington, DC**)

Education around the process of the HIV post-test procedure, natural history of the illness, and support provided, were described by this participant as key pieces of information that persons would need to engage in HIV testing.

Other participants described barriers around lack of knowledge around PrEP and how mistrust of the PrEP medication may result in youth being less likely to engage in HIV PrEP services.

“...Some people don’t really know what PrEP is for...They’ve heard of it but they haven’t informed themselves about it. I have one particular friend who I told in person that I was taking PrEP. This is for my benefit, for my own health. I asked him has he ever heard about it. He said, “Yeah. But I don’t really think you should. It’s a waste of time to get on it.” I’m like, “Do you know anything about it?” He said, “No, really, not really. I’ve heard a few people talk to me about it, but I’m not really”—[interested]” (**Informal role, Cisgender black male, 18 years old, Baltimore, MD**)

In the prior quote, the KI describes that his friend expresses that he should not take PrEP, but is unable to articulate why. Participants indicated concerns that PrEP may not prevent HIV in certain populations or even cause it. The following quote, puts words to the reasoning behind the hesitancy.

“Frequently we get those people who are like skeptical about the idea of taking something that is supposed to prevent them from HIV. They feel like if they don’t have it then there’s nothing they should be taking...the first place...there is a large portion of skepticisms surrounding PrEP where people felt like if they started taking it they actually may contract it somehow.” (**Formal role, Cisgender black male, 23 years old, Philadelphia, PA**)

Other reasons described for not taking PrEP were lack of insurance, knowledge about PrEP, and a supportive system to help with adherence. No one raised concerns that PrEP would result in increased risk compensation meaning increased risk behavior or condom nonuse. KIs described that a combination of miseducation around HIV transmission and the lack of knowledge about the medicines available to prevent youth from acquiring HIV has led to a delay in accessing PrEP services. This perception exists in the context of having to defy popular opinions of their peers, while simultaneously being responsible for personally overcoming the stigma of HIV testing and care.

Latinx serving KIs described that the lack of bilingual resources and the perceived need for documentation of immigration status to access medical care and treatment (i.e., documentation of legal residency) further created feelings of mistrust and hesitation to access HIV and PrEP-related services.

Cultural competency

Lack of cultural competency was described as being further exacerbated by perceived clinic barriers. While clinics were assumed to be a safe space, long wait times, combined with a sense of lack of concern by staff, was described as fostering an environment of unacceptance and noninclusion. Providers’ lack of physical touch contributed to KIs describing that youth were made to feel isolated or unaccepted. Informants described that such interactions further compounded difficult experiences navigating clinics, making appointments, and communicating effectively with staff.

...the fact that people have to come in—and definitely when it’s not a situation where you have to be physically there, coming in and sitting in front of somebody, having to wait for a hour 30 minutes to see a doctor, then having to wait another hour to talk to that doctor and deal with whatever you’re dealing with, only for them not to touch you, or check your heart rate and say, “Okay, well we’ll see you again in this amount of time.” (**Formal role, Cisgender black male, 26 years old, Baltimore, MD**)

Uncaring, rushed care was viewed as less personal and not tailored to address the youth’s needs.

KIs who were members of the gay ($n = 13$) or transgender community ($n = 4$) described clinical settings not being open and accessible to all groups. Three KIs described that health care excluded certain groups from HIV and prevention care by focusing only on “key populations.”

“So why is everything just for the gay male? Why can’t anything be for transgender or just the whole? Why are we in this LGBTQ circle and we all get picked apart differently. What about the bi people? What about the lesbian people? Things like that. Because if you hear studies now, all you hear is young black men, young black gay men of color, men who have sex with men. You never hear, like, women who have sex with women, because HIV can be transmitted that way, too, and a lot of people don’t even know that...It’s possible. It happens. It’s just not the biggest thing that everybody talks about because everybody usually talks about men who have sex with men getting it.” (**Formal role, Cisgender black male, 22 years old, Philadelphia, PA**)

The exclusion of one population segment over another created a sense of marginalization for one community member or group. KIs described that because youth often identify with multiple marginalized communities, focusing on just one group marginalized other aspects of their lived experiences. For example, the following participant described that working with youth requires considering the social context, which may also be marginalized.

“I work with clients who participate in sex work and oftentimes their main focus is stability and getting money and surviving this cruel sort of world...” (**Formal role, Cisgender black male, 25 years old, Philadelphia, PA**)

KIs felt that approaching HIV care and prevention with all target populations considered would provide greater overall acceptance and would be better received by youth.

HIV stigma

A sense of internalized stigma was one component of feeling different. Most KIs (61.1%, $n=11$) described that stigma originated from feelings of shame from acquiring HIV, uncertainty of the HIV testing process, and fear of how people will treat individuals following an HIV diagnosis. Stigma was tied to shame and an inability to forgive oneself for engaging in behavior that resulted in HIV. This participant describes it this way,

“You have to get past the fact that you have HIV... You have to forgive yourself and continue living your life. Knowing that you have HIV, you have to live, be okay that you’re living with that for the rest of your life. In order to stay in undetectable, then you make it that and take your darn pill.” (**Informal role, Cisgender black male, 24 years old Baltimore, MD**)

It was not uncommon for KIs to describe that taking a daily medication reminded them of their prior risky behavior and created a barrier for an individual to access care services. KIs explained adolescents’ perceived unwillingness, forgetfulness, or challenges in adhering to antiretroviral therapy (ART), PrEP, or routine clinic appointments as a result of an inner discourse associated with shame of engaging in perceived risky behavior, having HIV, or not achieving an undetectable viral load. Internalized stigma was compounded by lack of support from the larger LGBT community around HIV care.

“The community always has its ways of alienating people, even people in the LGBT community have a— they have a way of alienating people and making people feel that they don’t belong when they actually do. And sometimes it’s kind of frustrating because it’s like we have all these outside forces sort of putting this negative aspect around us, and the fact that in our own community, we still have all these biases, and especially with HIV... For something that should be so positive and should be rewarded in the sense of praising a person for taking care of their health, it’s still looked down upon.” (**Formal role, Cisgender black male, 25 years old, Philadelphia, MD**)

As demonstrated by these quotes, the internal battle to disengage in care due to internal stigma was further exacerbated by community nonsupport around HIV.

Internalized stigma was further exacerbated by misconceptions of HIV that were described as still existing within communities of color. One person said, “educating the community in general [is needed] because sometimes you hear HIV and you’re like, Oh, I don’t want to touch you, don’t touch me.” This view that HIV was contagious, from the larger community, combined with feelings of shame, created a barrier to accessing health care services. Such stigma also created a barrier to engage in HIV prevention and HIV testing. KIs described concerns about the necessity of offering confidential services or services in spaces where client identities would not be compromised. KIs described that it was common for youth to avoid clinics that were specifically identified as clinics for persons with HIV. One KI, who was also living with HIV, described it in the following manner,

“But having to sit in a waiting room with the stigma of everybody in here has HIV is like—okay, so anybody walking in here and them seeing me, knows that I have HIV and I know that they have it too, even if that’s not true...” (**Formal role, Cisgender black male, 26 years old, Baltimore, MD**)

Seven KIs who were members of the LGBT community described that HIV-related stigma prevented youth from being tested in public testing events. For example, some public community testing procedures (long testing times) was described as contributing to assumptions about individuals who were tested had an HIV diagnosis.

“...because it’s like this unsaid rule, like this... unsaid kind of logic where “Oh, well, we know a HIV test takes 10 minutes, so if they’re not out in 10 minutes that could mean something bad,” and honestly that’s how I’ve seen rumors get started, and I’ve literally seen fights break out.” (**Informal role Cisgender black male, 22 years old, Philadelphia, PA**)

Stigma existed around the test procedures (e.g., time), as described in the prior quote and also around the facilities that were known to provide HIV testing. One participant describes being in such facilities creates a barrier in this way,

“having that stigma around getting tested in the first place and having to cover your face walking into that testing facility because you don’t want anyone to see you.” (**Formal role, Cisgender black male, 18 years old, Philadelphia, PA**)

Such barriers were described as contributing to youth avoiding or delaying engaging in HIV testing. Providers described the need to better understand more subtle nuances of community stigma to ensure removal of structural barriers to testing and services. Organizational practices to increase patient privacy were greatly appreciated, and facilities that did not respect these viewpoints were at risk of losing participants that most needed to access their services.

Intersectional marginalization

Several KIs ($n=16$) described marginalization experiences that systematically prevent youth from accessing services. First, KIs described the challenge for youth to identify providers who treat patients with multiple identities that these youth endorse—across age, race/ethnicity, sexual orientation, and gender identity. The inability to find culturally competent providers that were relatable to queer youth was a common theme among all the KIs interviewed. This sentiment was expressed by a provider who described challenges with regard to finding a culturally competent psychological mental health provider.

“What I’m thinking of is psychological health, so therapists, counselors, psychiatrists, just not being very competent or relatable, or at least the young people not feeling like they’re—I can’t tell you how long it took me to find a psychologist that I think would work well with the demographic I work with to refer, because I was constantly going by calling their insurance and then the kids would do two sessions and come back and be like, “That was useless, I can’t talk about being black and queer or Latino and trans to this white man.” You know what I mean? So, I think that also—and that goes in general with health too, having—not feeling as a queer person being—having those services.” (**Formal role, Cisgender Latino male, 25 years old, Philadelphia, PA**)

The inability to find providers that could address people who exist within multiple identities may create a significant barrier to accessing HIV and preventive care.

Strategies

KIs indicated that more effort was needed to address the marginalization experienced by sexual and gender minorities

in community and clinical settings. They suggested that health care facilities serving this population need to focus on training providers, developing programs, and changing clinical spaces to accommodate the needs of youth with multiple intersecting identities. One suggestion was the introduction of programs that were youth centered and fun, but that did not always focus on HIV. Participants felt that programs that always focused on HIV further marginalized sexual and gender minority youth by equating gay and bisexual young men with HIV risk:

“...Because if it was all just one thing or if it was all saturated with the HIV and STD prevention stuff I think it would be off putting to folks at some point. They would feel like they reached a saturation point on that information. And if this is what it’s all about I’m not really here for it. So being able to, like I said, weave it in so it’s always there. Sometimes it’s in the forefront. Sometimes it’s background music. But being able to offer like a wide range of things and opportunities like the films that we choose, the games that we have, the trivia that we have. It’s all there. But it’s not always blaring in their faces the way I think they expect that it will be because that’s always been presented through other mediums like school and things like that.” **(Formal role, Cisgender white female, 31 years old, Washington, DC)**

Equating certain groups, in itself to HIV, is stigmatizing and misses seeing young people as whole, of which their sexuality is just one part.

KIs also described the need for colocated competent specialty services with primary care services. The following participant describes that geographically closest hospitals only provided limited care, whereas those that provided gender or HIV specialty care were further away.

“Well for starters, some clinics or hospitals don’t even have the staff who are actually experts in that field. Some of them may not even have resources to help out those who are dealing with AIDS or HIV, who are currently trying to keep up with their health, pretty much...Yeah, they don’t have people specialized in it. And I believe all hospitals and clinics should have that because some people live in some areas where they can’t—you don’t feel like going all the way across town to get that special care. It should be based in their own neighborhood or clinics or hospitals that are in their surrounding areas.” **(Informal role, Cisgender black male, 18 years old, Baltimore, MD)**

This quote exemplifies how geographic barriers to care (e.g., lack of accessible HIV specialty services) isolated youth and further prohibited access to perceived competent care. KIs also described that access was limited by Medicaid services, which was not accepted at all locations, but only limited to certain hospital settings.

Discussion

KIs described key themes related to marginalization: lack of competent care among health care providers and both clinical and community spaces that may prioritize one population over another. The intersection of existing in an already marginalized community (e.g., sexual or gender minority youth, communities of color) combined with HIV stigma further created barriers to engaging in prevention and treatment for HIV. Informants described that the sense of marginalization was closely related to HIV-related stigma,

fear of an HIV diagnosis, and mistrust of PrEP. The KIs described that youth experience both perceived internal and actual external stigma related to HIV.

In this study, KIs described experiencing or interacting with youth that experience individual and structural experiences of stigma. Such stigma was described as preventing engagement of YBLMSM and YBLTW along all aspects of the prevention and treatment cascade. KIs also related that youth had to navigate different intersectional identities—for example, black, gay, transgender; and social contexts—for example, low income and exchange sex that may further exacerbate feelings of marginalization and create barriers to care. These findings support prior work describing that an absence of an intersectional approach to providing HIV services creates a barrier to accessing needed health care services.²²

Earnshaw³⁷ has suggested that the interdependence of multiple co-occurring devalued social identities intersect to create a unique experience of stigma in marginalized communities. The Stigma and HIV Disparities Model by Earnshaw³⁷ is a framework that includes aspects of societal stigma and racial/ethnic HIV disparities, including components of risk, screening, and treatment. It can be used when addressing the intersection of HIV stigma and marginalization. This framework posits that individuals experience stigma at the individual, societal, and structural level and that an intersectionality framework addresses the interdependence of co-occurring devalued social identities and incorporates how structures further contribute to marginalization and risk. For example, despite evidence suggesting that black and Latinx populations are less likely to engage in high-risk sexual behavior and more likely to have *ever* been HIV tested than whites,^{38,39} black, and Latinx populations are more likely to test and access prevention services at a later stage in the HIV prevention and care continuum,^{28,40–42} suggesting that there may be unique factors among YBLMSM and YBLTW that may contribute to delay in HIV testing, prevention, and care. Similar to prior work, KIs in this study, described that youth anticipated that others would either discriminate against them or treat them differently after an HIV test or diagnosis.⁴³

Clinic environments may further intersect with experiences of stigma to result in youth feeling marginalized. KIs stated that YBLMSM and YBLTW experience clinic environments and low levels of cultural competency among providers further marginalize youth. Philbin et al., Adolescent Trials Network for HIV/AIDS Interventions,⁴⁴ and others⁴⁵ have described that meso-level factors, such as staff attitudes that often communicate larger social values of homophobia and HIV-related stigma, create barriers to care among adolescents. The findings from the KIs in this study suggest that community and clinical spaces that serve YBLMSM and YBLTW need to take into account how long wait times, testing approaches, and lack of culturally competent providers can further perpetuate feelings of stigma and marginalization in the youth being served. Such barriers may significantly impede access to HIV testing and related services.

Medical mistrust, in this sample, was described as contributing to youth being less willing to take PrEP, highlighting the need to address wariness with the health system among YMSM. Previous research documents medical mistrust among both racial/ethnic minority and sexual minority communities.^{46,47} For example, in a study of black MSM by

Eaton et al.⁴⁸ nearly one-fifth of participants reportedly did not trust doctors and other health care workers. Mutchler et al.⁴⁹ noted high levels of misconceptions and mistrust about PrEP among black YMSM and their close friends, including skepticism about the efficacy of PrEP and fears that PrEP might cause people to become infected with HIV. Misconceptions about PrEP and HIV research continue to perpetuate in the African American community and create barriers to engaging in HIV treatment and prevention.⁵⁰ Guidelines and effective ongoing training and education for providers are needed to assist community agencies in providing culturally competent care that addresses medical mistrust. The Fenway Institute has developed guidance for providers to increase the capacity to work with sexual minority and transgender and gender nonbinary youth.^{51,52}

This work suggests that youth service providers will need to be aware of how HIV stigma contributes to feelings of marginalization and how programs can address structures that further contribute to those feelings. Providers, for example, will need to simultaneously take into account multiple identities—sexual orientation, race/ethnicity, and socioeconomic status, and also address the cultural underpinnings of mistrust and the lack of employment and residential displacement that predispose some youth to HIV. Prior work has called for public health and medical practitioners alike to first acknowledge the historical mistrust, racial disparities, and lived experiences that may uniquely occur at the intersection of minority communities, and to provide an open forum to discuss concerns.⁵⁰ Programs that also include providers who are youth and members of the community being addressed, should seek to understand the intersectional factors that contribute to experiences of marginalization in clinical settings where youth are supporting other YBLMSM and YBLTW. However, acknowledgement and discussion may be insufficient. Such work will also need to attempt to address social marginalization, stigma, and anxiety related to the HIV/AIDS epidemic through structural changes in care to make it accessible, competent, and authentically YBLMSM and YBLTW centered.

Work is needed to better understand how structural and societal marginalization serves as critical barriers to care for YBLMSM and YBLTW who are seeking prevention and treatment services,⁵³ and develop programs that address such barriers. Technology-enhanced interventions, such as *we-Care* a social media intervention that uses a combination of Facebook, text messages, and Global Positioning System, found improvements in attendance of HIV care appointments and viral load suppression after the implementation of intervention.⁵⁴ In addition to employing technology-based methods, other expert consensus have identified peer-based approaches, holistic services, and making services more enjoyable as key crosscutting strategies to improving HIV service uptake among YBLMSM and YBLTW.⁵⁵

There are some limitations that should be noted in this study. This is a qualitative sample of young urban youth serving professionals of color who are also a part of the community. As such the findings may not generalize to rural or ethnically nondiverse communities that also identify as LGBTQ. Aspects of structural marginalization may change over time. The cross-sectional nature of these interviews limits our ability to examine such trends. Despite these limitations, the findings of this work suggest that YSP perceive

barriers to both preventive and treatment services for YBLMSM and YBLTW that may contribute to feelings of isolation and that potentially further leads to marginalization from preventive and treatment services.

For us to end the epidemic and reduce new HIV infections by 75%, we will need to address the perceived structural marginalization that YBLMSM and YBLTW experience in clinical and community settings. Approaches will need to take into account the interdependence of multiple co-occurring devalued social identities that occur in this group and simultaneously make HIV prevention and treatment programs readily accessible in their communities. Without thoughtful planning and approaches we risk further marginalizing communities of color from HIV treatment and preventive care.

Acknowledgments

The authors appreciate all of the input on this project from YSPs who participated and the community-based organizations who referred YSPs to the study.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

This work was supported by the National Institute of Drug Abuse (NIDA) R01DA043089.

References

- Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2010–2015. Available at: www.cdc.gov/hiv/library/reports/hiv-surveillance.html (Last accessed March 2018).
- Hess KL, Hu X, Lansky A, Mermin J, Hall HI. Lifetime risk of a diagnosis of HIV infection in the United States. *Ann Epidemiol* 2017;27:238–243.
- Adimora AA, Schoenbach VJ. Social context, sexual networks, and racial disparities in rates of sexually transmitted infections. *J Infect Dis* 2005;191 Suppl 1:S115–S122.
- Nunn A, Yolken A, Cutler B, et al. Geography should not be destiny: Focusing HIV/AIDS implementation research and programs on microepidemics in US neighborhoods. *Am J Public Health* 2014;104:775–780.
- Sullivan PS, Peterson J, Rosenberg ES, et al. Understanding racial HIV/STI disparities in Black and White men who have sex with men: A multilevel approach. *PLoS One* 2014;9:e90514.
- Birkett M, Kuhns LM, Latkin C, Muth S, Mustanski B. The sexual networks of racially diverse young men who have sex with men. *Arch Sex Behav* 2015;44:1787–1797.
- Krivitsky PN, Morris M. Inference for social network models from egocentrically sampled data, with application to understanding persistent racial disparities in HIV prevalence in the US. *Ann Appl Stat* 2017;11:427–455.
- Morris M, Kurth AE, Hamilton DT, Moody J, Wakefield S. Concurrent partnerships and HIV prevalence disparities by race: Linking science and public health practice. *Am J Public Health* 2009;99:1023–1031.
- Mustanski B, Morgan E, D'Aquila R, Birkett M, Janulis P, Newcomb ME. Individual and network factors associated with racial disparities in HIV among young men who have

- sex with men: Results from the RADAR cohort study. *J Acquir Immune Defic Syndr* 2019;80:24–30.
10. Poteat T, Wirtz AL, Reisner S. Strategies for engaging transgender populations in HIV prevention and care. *Curr Opin HIV AIDS* 2019;14:393–400.
 11. Zandoni BC, Mayer KH. The adolescent and young adult HIV cascade of care in the United States: Exaggerated health disparities. *AIDS Patient Care STDS* 2014;28:128–135.
 12. Elopore L, McDavid C, Brown A, Shurbaji S, Mugavero MJ, Turan JM. Perceptions of HIV pre-exposure prophylaxis among young, Black men who have sex with men. *AIDS Patient Care STDS* 2018;32:511–518.
 13. Cahill S, Taylor SW, Elsesser SA, Mena L, Hickson D, Mayer KH. Stigma, medical mistrust, and perceived racism may affect PrEP awareness and uptake in Black compared to White gay and bisexual men in Jackson, Mississippi and Boston, Massachusetts. *AIDS Care* 2017;29:1351–1358.
 14. García M, Harris AL. PrEP awareness and decision-making for Latino MSM in San Antonio, Texas. *PLoS One* 2017;12:e0184014.
 15. Marks SJ, Merchant RC, Clark MA, et al. Potential healthcare insurance and provider barriers to pre-exposure prophylaxis utilization among young men who have sex with men. *AIDS Patient Care STDS* 2017;31:470–478.
 16. Brooks RA, Cabral A, Nieto O, Fehrenbacher A, Landrian A. Experiences of pre-exposure prophylaxis stigma, social support, and information dissemination among Black and Latina transgender women who are using pre-exposure prophylaxis. *Transgend Health* 2019;4:188–196.
 17. Alakhunova N, Diallo O, del Campo IM, Tallarico W. Defining Marginalization: An Assessment Tool. The George Washington University, The Ellicott School of International Affairs, eds. *World Fair Trade Organization*; 2015. Available at: <https://elliott.gwu.edu/sites/g/files/zaxdzs2141/f/World%20Fair%20Trade%20Organization.pdf> (Last accessed October 14, 2019).
 18. Powell JA. Deepening our understanding of structural marginalization. *Poverty Race* 2013;22:3–4,15.
 19. Baah FO, Teitelman AM, Riegel B. Marginalization: Conceptualizing patient vulnerabilities in the framework of social determinants of health—an integrative review. *Nurs Inq* 2019;26:e12268.
 20. Mayer K. Old pathogen, new challenges: A narrative review of the multilevel drivers of syphilis increasing in American men who have sex with men. *Sex Transm Dis* 2018;45:S38–S41.
 21. Perez-Brumer A, Nunn A, Hsiang E, et al. “We don’t treat your kind”: Assessing HIV health needs holistically among transgender people in Jackson, Mississippi. *PLoS One* 2018;13:e0202389.
 22. Beach L, Greene GJ, Lindeman P, et al. Barriers and facilitators to seeking HIV services in Chicago among young men who have sex with men: Perspectives of HIV service providers. *AIDS Patient Care STDS* 2018;32:468–476.
 23. Bowleg L. The problem with the phrase women and minorities: Intersectionality—an important theoretical framework for public health. *Am J Public Health* 2012;102:1267–1273.
 24. Peek ME, Lopez FY, Williams HS, et al. Development of a conceptual framework for understanding shared decision making among African-American LGBT patients and their clinicians. *J Gen Intern Med* 2016;31:677–687.
 25. Bowleg L, Teti M, Malebranche DJ, Tschann JM. “It’s an Uphill Battle Everyday”: Intersectionality, low-income Black heterosexual men, and implications for HIV prevention research and interventions. *Psychol Men Masc* 2013;14:25–34.
 26. Freeman R, Gwadz MV, Silverman E, et al. Critical race theory as a tool for understanding poor engagement along the HIV care continuum among African American/Black and Hispanic persons living with HIV in the United States: A qualitative exploration. *Int J Equity Health* 2017;16:54.
 27. Golub SA, Gamarel KE. The impact of anticipated HIV stigma on delays in HIV testing behaviors: Findings from a community-based sample of men who have sex with men and transgender women in New York City. *AIDS Patient Care STDS* 2013;27:621–627.
 28. Hightow-Weidman LB, LeGrand S, Choi SK, Egger J, Hurt CB, Muessig KE. Exploring the HIV continuum of care among young Black MSM. *PLoS One* 2017;12:e0179688.
 29. Earnshaw VA, Smith LR, Chaudoir SR, Lee IC, Copenhaver MM. Stereotypes about people living with HIV: Implications for perceptions of HIV risk and testing frequency among at-risk populations. *AIDS Educ Prev* 2012;24:574–581.
 30. Basta TB, Shacham E, Reece M. Symptoms of psychological distress: A comparison of rural and urban individuals enrolled in HIV-related mental health care. *AIDS Patient Care STDS* 2009;23:1053–1057.
 31. Peretti-Watel P, Spire B, Pierret J, Lert F, Obadia Y; VESPA Group. Management of HIV-related stigma and adherence to HAART: Evidence from a large representative sample of outpatients attending French hospitals (ANRS-EN12-VESPA 2003). *AIDS Care* 2006;18:254–261.
 32. Wao H, Aluoch M, Odondi GO, Tenge E, Iznaga T. MSM’s versus health care providers’ perceptions of barriers to uptake of HIV/AIDS-related interventions: Systematic review and meta-synthesis of qualitative and quantitative evidence. *Int J Sex Health* 2016;28:151–162.
 33. Morse JM. The significance of saturation. *Qual Health Res* 1995;5:147–149.
 34. Glaser BG. The constant comparative method of qualitative analysis. *Soc Probl* 1965;12:436–445.
 35. Strauss A, Corbin J. *Basics of Qualitative Research*. Newbury Park, CA: Sage; 1990.
 36. Creswell JW, Clark VLP. Choosing a mixed methods design. In: *Designing and Conducting Mixed Methods Research*. 2nd ed. Los Angeles: Sage Publications; 2011: 53–106.
 37. Earnshaw VA, Bogart LM, Dovidio JF, Williams DR. Stigma and racial/ethnic HIV disparities: Moving toward resilience. *Am Psychol* 2013;68:225–236.
 38. Harawa NT, Greenland S, Bingham TA, et al. Associations of race/ethnicity with HIV prevalence and HIV-related behaviors among young men who have sex with men in 7 urban centers in the United States. *J Acquir Immune Defic Syndr* 2004;35:526–536.
 39. Marks G, Millett GA, Bingham T, et al. Understanding differences in HIV sexual transmission among Latino and Black men who have sex with men: The Brothers y Hermanos Study. *AIDS Behav* 2009;13:682–690.
 40. Chen NE, Gallant JE, Page KR. A systematic review of HIV/AIDS survival and delayed diagnosis among Hispanics in the United States. *J Immigr Minor Health* 2012;14: 65–81.
 41. Centers for Disease Control and Prevention. *CDC HIV Prevention Progress Report*, 2019. Available at: www.cdc.gov

- /hiv/pdf/policies/progressreports/cdc-hiv-preventionprogressreport.pdf (Last accessed October 8, 2019).
42. Kanny D, Jeffries WL, Chapin-Bardales J, et al. Racial/ethnic disparities in HIV preexposure prophylaxis among men who have sex with men—23 urban areas, 2017. *MMWR Morb Mortal Wkly Rep* 2019;68:801–806.
 43. Obermeyer CM, Osborn M. The utilization of testing and counseling for HIV: A review of the social and behavioral evidence. *Am J Public Health* 2007;97:1762–1774.
 44. Philbin MM, Tanner AE, DuVal A, et al. Understanding care linkage and engagement across 15 adolescent and clinics: Provider perspectives and implications for newly HIV-infected youth. *AIDS Care* 2014;26:12–19.
 45. Lichtenstein B. Stigma as a barrier to treatment of sexually transmitted infection in the American Deep South: Issues of race, gender and poverty. *Soc Sci Med* 2003;57:2435–2445.
 46. Malebranche DJ, Peterson JL, Fullilove RE, Stackhouse RW. Race and sexual identity: Perceptions about medical culture and healthcare among Black men who have sex with men. *J Natl Med Assoc* 2004;96:97–107.
 47. Eaton LA, Kalichman SC, Price D, et al. The role of stigma and medical mistrust in the routine health care engagement of Black men who have sex with men. *Am J Public Health* 2015;105:e75–e82.
 48. Eaton LA, Kalichman SC, Price D, Finneran S, Allen A, Maskut J. Stigma and conspiracy beliefs related to pre-exposure prophylaxis (PrEP) and interest in using PrEP among Black and White men and transgender women who have sex with men. *AIDS Behav* 2017;21:1236–1246.
 49. Mutchler MG, McDavitt B, Ghani MA, Nogg K, Winder TJ, Soto JK. Getting PrEPared for HIV prevention navigation: Young Black gay men talk about HIV prevention in the biomedical era. *AIDS Patient Care STDS* 2015;29:490–502.
 50. Heller J. Rumors and realities: Making sense of HIV/AIDS conspiracy narratives and contemporary legends. *Am J Public Health* 2015;105:e43–e50.
 51. Ard KL, Makadon HJ. Improving the Health Care of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Understanding and Eliminating Health Disparities. Boston, MA: The Fenway Institute; 2012. Available at: www.lgbthealtheducation.org/wp-content/uploads/Improving-the-Health-of-LGBT-People.pdf (Last accessed October 14, 2019).
 52. National LGBT Health Education Center. Transgender Health ECHO. Available at: www.lgbthealtheducation.org/transecho (Last accessed June 7, 2019).
 53. Dowshen N, Lee S, Franklin J, Castillo M, Barg F. Access to medical and mental health services across the HIV care among young transgender women: A qualitative study. *Transgend Health* 2017;2:81–90.
 54. Tanner AE, Song EY, Mann-Jackson L, et al. Preliminary impact of the weCare social media intervention to support health for young men who have sex with men and transgender women with HIV. *AIDS Patient Care STDS* 2018;32:450–458.
 55. Freese TE, Padwa H, Oeser BT, Rutkowski BA, Schulte MT. Real-world strategies to engage and retain racial-ethnic minority young men who have sex with men in HIV prevention services. *AIDS Patient Care STDS* 2017;31:275–281.

Address correspondence to:

Renata Arrington-Sanders, MD, MPH, ScM
Division of General Pediatrics & Adolescent Medicine
200 North Wolfe Street
Baltimore, MD 21287

E-mail: rarring3@jhmi.edu