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Dismantling Barriers and Transforming the Future of Pre-Exposure Prophylaxis Uptake in Young Black and Latinx Sexual Minority Men and Transgender Women

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Abstract

Pre-exposure prophylaxis (PrEP) has the potential to transform HIV in young Black and Latinx sexual minority men (SMM) and transgender women (TW). Addressing low PrEP uptake in this population depends on the better understanding of barriers to PrEP use. This article uses an ecological framework to explore barriers to daily oral PrEP in a sample of young Black and Latinx SMM and TW in three geographically prioritized cities in the United States. In-depth interviews were completed with 33 young Black and Latinx SMM and TW (22 at risk for and 11 recently diagnosed with HIV), aged 17–24, participating in a randomized trial aimed at increasing PrEP and antiretroviral therapy (ART) uptake and adherence. Interviews were recorded and transcribed, and then analyzed using inductive and deductive coding. Coded transcripts were organized into individual, interpersonal, community, and structural categories, by PrEP use and HIV status. Among participants, nine reported having been prescribed PrEP, with five actively or recently taking PrEP, whereas only one participant diagnosed with HIV had been prescribed PrEP. Major themes related to barriers emerged across the individual, family, community, and structural level. Limited barriers related to partners, instead partners with HIV encouraged PrEP use. Participants commonly reported low perceived HIV risk, fear of disclosure, barriers relating to insurance/cost, and medication use as reasons for nonuse of PrEP. For youth to remain on a healthy life course, HIV preventative measures will need to be adopted early in adolescence for those at risk of HIV acquisition. Interventions need to simultaneously address multilevel barriers that contribute to nonuse in adolescents. Clinical trials registry site and number: ClinicalTrials.gov Identifier: NCT03194477.

Keywords: pre-exposure prophylaxis, young Black and Latinx sexual minority men and transgender women, HIV

Implications and Contributions

The experiences of young Black and Latinx sexual minority men and transgender women shared from these inter-

views are potentially transformative in learning how to address barriers to PrEP use. Understanding the complicated and interwoven themes along the ecological framework allows for areas of action to be identified.

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Introduction

PRE-EXPOSURE PROPHYLAXIS (PrEP) HAS the potential to transform HIV prevention in communities disproportionately affected by HIV, namely Black and Latinx sexual and gender minority youth, including sexual minority men (SMM), trans feminine youth, and transgender women (TW).^{1,2} Pharmacy data by race/ethnicity suggest that persons who are PrEP-eligible and Black and Latinx are disproportionately less likely to be prescribed PrEP (11.2% and 13.1%, respectively) than Whites (68.7%).³ Uptake among young Black and Latinx SMM and TW remains low despite the availability of PrEP for youth younger than 18 since 2018.^{4,5} There has been a call to increase research focused on the lived experiences of PrEP use in sexual and gender minority youth (SGMY) at risk for HIV to better understand barriers to use and to develop interventions that transform engagement in PrEP.⁶

Barriers to PrEP identified among Black and Latinx SMM and TW have included low perceived risk, HIV-related stigma, and medical mistrust.^{6,7} Research focusing on youth has demonstrated that perceived HIV risk may be a key determinant in the willingness to take PrEP.^{8–11} However, risk perception may not align with actual risk or awareness of PrEP.⁹ Furthermore, barriers can occur at multiple levels and may carry a different weight depending on the frequency of occurrence and significance. Focusing on one level is a missed opportunity to examine barriers across levels and how levels may intersect.

Prior work has highlighted HIV prevention factors that occur at each level of Bronfenbrenner's ecological systems,¹² including individual (fear of side effects), interpersonal (risk disinhibition), community (medical mistrust), and structural levels (stigma, access).¹³ However, this work has not specifically focused on barriers to PrEP among young Black and Latinx SMM and TW, nor included key components relevant to adolescents, parents, and families, which may influence uptake and use of PrEP. Other works on adult men who have sex with men (MSM) and persons living with HIV have described barriers such as stigma, poor patient-provider communication, lack of empathy, and cultural humility from providers as key barriers to preventive care.^{14,15} Findings from a systematic review have highlighted the need for interventions that address barriers at multiple ecological domains to improve PrEP access, uptake, and adherence.¹⁶ To develop interventions responsive to barriers, more work is needed to delineate barriers to PrEP uptake.^{17,18}

Despite studies showing equal levels of willingness to use PrEP between Black and White MSM and federal PrEP programs increasing access to PrEP, PrEP use continues to be significantly lower for Black and Latino MSM with 8.2% of at-risk Black MSM, 14.0% Latino MSM on PrEP, compared with 63.3% of at-risk White MSM in 2019, and TW.^{19,20}

A key gap in the literature is understanding barriers to PrEP through lived experiences of youth at risk for or recently diagnosed with HIV. Lived experience refers to the subjective experiences of a given person and the knowledge gained from those experiences.²¹ Understanding one's lived experience can identify gaps not otherwise evident in prior work and potentially reveal areas of prevention that have been overlooked. We used an ecological framework to examine the lived experiences of PrEP barriers reported by young Black and Latinx SMM and TW who are at risk for or recently (within 5 years) diagnosed with HIV.

Methods

In-depth interviews were conducted among 33 Black and Latinx SMM and TW (22 at risk for and 11 recently diagnosed with HIV), living in Baltimore, MD, Philadelphia, PA, or Washington, DC, and aged 17–24 years. Participants were selected from a pool of youth participating in the PUSH Study, parallel randomized-controlled trials aimed at using a coach-based motivational approach to increase PrEP and antiretroviral therapy (ART) uptake and adherence.²² Eligibility criteria for the trials included the following: living in one of the three study sites, aged 15–24 years, assigned male sex at birth, identifying as masculine, nonbinary, or along the trans feminine spectrum male sexual contact in the last 12 months, no current (<30 days) PrEP use (among youth at risk for HIV), and a detectable viral load in the prior 12 months (among youth living with HIV).

In each city, we sought to recruit up to 13 participants using maximum variation sampling who were at risk for HIV or living with HIV, or until informational redundancy was achieved. Participants were invited to participate in an in-depth interview following enrollment into the clinical trial. Participants were provided \$25 for participating in an interview. This study received Institutional Review Board (IRB) approval from the Johns Hopkins School of Public Health, Children's Hospital of Philadelphia, and Children's National Hospital in Washington, DC.

Interviews took place between May 2018 and January 2020. Interviews lasted 45–60 min and followed semi-structured guides, which focused on barriers and facilitators to HIV prevention and treatment (Table 1). Interviews were audio-recorded, transcribed verbatim, and deidentified. Transcripts were entered into qualitative data analysis software, Dedoose.²³ Interviews were analyzed using inductive and deductive coding methods. A directed content analysis²⁴ approach was used to investigate the questions of interest. The first step was to identify key concepts from the literature identified as PrEP barriers to create and categorize the interview questions used to assess barriers. The second step was to examine themes around barriers among PrEP users and nonusers to examine if similarities occurred across groups.

Then, the first author created deductive codes a priori from the literature capturing information relating to established barriers to daily oral PrEP use. Any topic that emerged consistently during the coding of participant interviews was integrated into the codebook.^{25,26} This provided a data-driven (inductive) set of codes for the codebook. After three interviews were coded, the first and last author met to discuss the coding scheme and group codes into categories, using the social ecological framework. Once codes were agreed upon, the remaining transcripts were coded in tandem by two coders (first and second authors). Codes in disagreement were reviewed and discussed between the first, second, and last author, until resolved. Coders met regularly to ensure consistent use of codes. Coded transcripts were reviewed using the constant comparative method and organized into PrEP users and non-PrEP users, then individual, the interpersonal (partner, family), community, and structural categories, and finally by HIV status.

Results

Demographics of participants are outlined in Table 2. Themes from PrEP users aligned around individual, family,

TABLE 1. INTERVIEW QUESTIONS

PrEP Barrier	<ol style="list-style-type: none"> 1. Describe whether you tried to get PrEP but were not able to. <ol style="list-style-type: none"> a. What was the reason you were not able to get PrEP? b. Describe any concerns you have about PrEP <ol style="list-style-type: none"> i. Probe around side effects, cost, and medical mistrust. c. Describe any barriers you experienced trying to get PrEP. (Probe around insurance, access, consent, etc.) d. What messages have you heard about PrEP? (Probe around people who use PrEP in their social circle. Positive/negative attitudes around PrEP. Any myths?) 2. Tell me about a time when you delayed or did not take PrEP because you were worried someone might find out you were taking it. <ol style="list-style-type: none"> a. Were you ever concerned your partner might find out? b. Were you worried your parents or guardian might find out? (Probe around explanation of benefits as a barrier.)
PrEP Facilitator	<ol style="list-style-type: none"> 1. Have you ever been prescribed PrEP? <ol style="list-style-type: none"> a. If yes, what were some reasons you wanted to take PrEP? b. Describe anything or any person who helped you to obtain PrEP. (Probe around facilitators—navigators, programs, etc.)

PrEP, pre-exposure prophylaxis.

community, and structural barriers, whereas among nonusers, themes centered around individual, partner, and structural barriers, with fewer family barriers. Most youth living with HIV described individual and structural barriers to PrEP. Table 3 describes barriers to daily oral PrEP among youth at the individual, interpersonal, community, and structural levels.

TABLE 2. DEMOGRAPHICS

N=33	Mean or frequency
City	
Baltimore	13
Washington, DC	8
Philadelphia	12
Age	20.9 years ±2.4
Racial identity	
Black/African American	28
Black/Latinx	2
Black/White	2
Black/Native American	1
Sexual identity	
Gay	21
Bisexual	8
Pansexual	3
Queer	1
Gender identity	
Cis-male	26
Gender nonbinary	4
Gender queer	2
Transgender woman	1
HIV status	
At risk	22
LWHIV	11
PrEP use, at-risk youth (n = 22)	
Ever	9
Never	13
PrEP use, youth LWHIV (n = 11)	
Ever	1
Never	10

LWHIV, living with HIV; PrEP, pre-exposure prophylaxis.

Individual barriers

Twenty-three participants described never using PrEP, including 13 at-risk youth and 10 youth recently diagnosed with HIV. Most of the at-risk youth described individual barriers to using PrEP including fear of side effects, lack of desire to be on a daily medication regimen, and having a low motivation to attend appointments and follow-up related to taking PrEP. The inability to remember to take a medication every day was commonly described among fewer participants. Participants described that theoretically they would not be able to remember taking medications because of prior experiences related to other medications.

“I don’t know. I just rather just not have sex before or after do everything else with it. Too much of a hassle, and go take it every day. I have trouble remembering to take the medications I have now.” (22-year-old Black bisexual cis-male, at-risk for HIV living in Baltimore)

Four participants described that they had worries about side effects such as nausea and headaches that would prohibit their daily activities. Fewer PrEP users described individual factors, such as remembering to take a pill daily, potential side effects of PrEP, and difficulty swallowing pills, as primary concerns for nonuse.

Half of the youth living with HIV described a low perceived risk of HIV that resulted in them not seeking out PrEP before their diagnosis (Table 3). Feelings of low risk were attributed to few lifetime sexual partners and the perception that PrEP was for persons who had multiple concurrent sexual partners. One participant’s comment demonstrates that positive views about PrEP were insufficient to support PrEP initiation.

“No. I thought PrEP was a really great idea. And I knew about it for so long. It was just, like, I wasn’t as sexually active. I would say before college, I had sex with about six people. And I was, like, I don’t have sex that much. <laughs> I was, like, I don’t really need it.” (20-year-old Black and Native American pansexual cis-male, living with HIV in Baltimore)

Other participants described feelings of invincibility, in regard to contracting HIV. The other five youth described a lack

TABLE 3. BARRIERS TO PRE-EXPOSURE PROPHYLAXIS (PrEP) USE

No.	Quote (age, race/ethnicity, sexual identity, gender identity, HIV status, city)
Individual barriers	
1	“I don’t know. I just rather just not have sex before or after do everything else with it. Too much of a hassle, and go take it every day. I have trouble remembering to take the medications I have now.” (22-year-old, Black bisexual cis-male, at-risk for HIV living in Baltimore)
2	“No. I thought PrEP was a really great idea. And I knew about it for so long. It was just, like, I wasn’t as sexually active. I would say before college, I had sex with about six people. And I was, like, I don’t have sex that much. <laughs> I was, like, I don’t really need it.” (20-year-old, Black and Native American pansexual cis-male, living with HIV in Baltimore)
3	“Because I was fine living like I was. I didn’t think that it was gonna happen like that, or it was gonna happen at all.” (23-year-old, Black bisexual cis-male, living with HIV in Philadelphia)
4	“Sadly and unfortunately, I was already positive by the time PrEP got big.” (23-year-old, Black gay cis-male, living with HIV in Philadelphia)
5	“I’m not the type of person to take anything or any similar medication, especially with all these new drugs that’s coming out, and then five, 10 years later they’re saying you can sue them for multimillion dollars for problems that you have, but it’s like how the Johnson baby powder messed people up 10, 20 years later, so therefore if I don’t know everything about it or do my personal research on every ins and outs of it I’m not gonna take it, because I believe certain type of medication is made to damage people. Yeah.” (22-year-old, Latinx, Black, Indian, and White bisexual cis-male, at-risk for HIV living in Philadelphia)
Interpersonal barriers	
1	“I didn’t want them to see the bottle because my mother is very nosy, as you can see, and she’ll start asking questions, and those are questions I can’t answer because my boyfriend don’t want me to answer those questions. So she’s going to be like, “Why you taking PrEP for?” I’m like—I just tell them, “To protect myself.” But like—but I don’t really like lying, so I don’t really like lying to my mother, so.” (21-year-old, Black bisexual cis-male, at-risk for HIV living in Baltimore)
2	“I knew that my dad was going to find out. How was I supposed to explain it to him? Like I said, he knows what the medication is for and that was going to bring up a conversation that I wasn’t ready to have and I didn’t even know how he would take it. So, I just told myself that I’m not going to be able to get it.” (20-year-old, Black and White gay non-binary person, at-risk for HIV living in Philadelphia)
3	“Yeah. I showed her (mother) the little pamphlets and stuff and she was like, “Yeah, I see everybody you be bringing up in here.” So she was like, “Yeah.” So she was all for it. But her being the same way I am about medicine, she started feeling uneasy about it, too. I don’t want that to have a side-effect on anything. Chemicals or anything ... It was always in the back of my mind, but she started asking more and more about it. She was like, “Do you even know what’s going on?” I was like, “I mean, you right.” That’s what she got me to thinking. She never told me “Get off of it,” but she got me thinking. That’s when I was like, “Yeah, I’m getting too smart for that.” That’s when I told her, like, “Yeah. I’d rather just...[stop it]” (18-year-old, Black pansexual cis-male, at-risk for HIV living in Baltimore)
4	“But it’s (PrEP) not something that we feel like we need to do but it’s something that [boyfriend name] is like, “If you decide to do it, then I’ll do it.” And so, yeah, I mean it’s not like a big deal to us, but you know, we definitely know—we know who we love, you know, what we’re doing, our status and all that stuff like that. And we both get tested regularly.” (23-year-old, Black gay cis-male, at-risk for HIV living in Philadelphia)
5	“When I hear people say I’m on PrEP it kind of makes me feel like they’re a little more knowledgeable to the situation, they’re a little more accepting to the situation that’s why they’re on the PrEP. It makes it a little easier, it does make it a little easier to say, hey, well, I’m HIV positive, because at that point I kind of know, well, they’re not putting up a wall to it and just not dealing with it, they’re dealing with it to make sure that they’re healthy.” (24-year-old, Black gay cis-male, living with HIV in Washington, DC)
6	“He (boyfriend living with HIV) explains a lot. He was like, “Yeah, but I’m at a low risk of getting it because these reasons,” and he feels as though I should go get on PrEP, and don’t tell him I’m not taking PrEP because then he’ll stop giving me sex. For real. If he finds out I’m not taking PrEP, we don’t have sex. It’s just that. Like, no. I’m like, “What?” He’s like, “Because you’re not taking care of yourself and you’re not—.” Because he said he would feel horrible if he finds out he gave me the illness. He would feel horrible. I guess that’s his fear. He doesn’t want that.” (21-year-old, Black bisexual cis-male, at-risk for HIV living in Baltimore)
7	“I had an ingrown toenail when I was younger and I had—was it ibuprofen? But even then, my mom was very like, “If you don’t need it, don’t use it.” And so I really didn’t need it, so I didn’t use it.” (22-year-old, Black gay cis-male, at-risk for HIV living in Baltimore)

(continued)

TABLE 3. (CONTINUED)

No.	Quote (age, race/ethnicity, sexual identity, gender identity, HIV status, city)
Community barriers	
1	“There’s this thing going on in social media, on Instagram. This lady was saying how—I think she’s also famous too. She was basically coming at people about people who use it. She was like—she was trying to make it seem like people who use PrEP are basically dirty people, they’re disgusting, and, ‘You shouldn’t be going around ho’ing around and then having to take a pill to protect yourself when you should just be more conservative about yourself and the people, and just your whole sex life.’” (20-year-old, Black and White gay non-binary person, at-risk for HIV living in Philadelphia)
2	“Friends have told me about it, and I see a lot of profiles on Grindr that are like, “Negative on PrEP. Negative on PrEP” And I’m not—I mean, I can’t—I’m not going to sit here and generalize, but I think—I know a lot of people are not actually on PrEP. And so they say, “Negative on PrEP,” and you’re supposed to trust that and not use a condom, but that’s not an excuse. You just still—there’s still other STDs besides HIV. You should still use condoms. I can only see myself taking PrEP if I’m in a relationship, and if I’m in a relationship, I intend to have unprotected sex.” (23-year-old, Black gay cis-male, at-risk for HIV living in Washington, DC)
3	“When I first heard about PrEP I felt like it won’t work, I don’t know, for some reason ... Because it was like this—there was like an article going around saying somebody had caught HIV when they was on PrEP, so it was like, what’s the point of taking it?” (24-year-old, Black gay trans-woman, living with HIV in Baltimore)
Structural barriers	
1	“Just being Black in America, like, that is a stress in itself, and so I don’t know. I feel like when we were talking about PrEP, like, we were talking about, like, you know, just being on it. But I’ve been on PrEP. I know how to take it. I know that I have to take it every day. But it’s about, you know, access, it’s about my insurance, and like all the other, like, big things that are coming into play that I can’t always access it, and it’s not like I don’t want to be on my medicine. Like, of course. I want to be on it every day, but a lot of things come up. Like, I was just off of PrEP for like a week and a half because I wasn’t able to go back downtown to get my medicine. But, I mean, I’m back on it now. I’ve been on for like another week, so things are just... Just everything, honestly.” (22-year-old, Black gay cis-male, at-risk for HIV living in Philadelphia)
2	“And like I haven’t before—like the last time I was here with [peer navigator] we hadn’t had that conversation. But we both have learned about it on our own.” (23-year-old, Black gay cis-male, at-risk for HIV living in Philadelphia)
3	“So I never got on PrEP, but I was almost on PrEP. I just missed my appointment.” (22-year-old, Black pansexual cis-male, at-risk for HIV living in Baltimore)
4	“I wanted to try it (PrEP) but someone told me it was like \$1000. I said hell no and I walked out of the room.” (18-year-old, Black gay gender-queer person, at-risk for HIV living in Washington, DC)
5	“I was, like, people, spermed on me, and it was, like, okay. So if I’m not going to use that protection, I need to use some kind of protection. And it was a little too late, because—I don’t know why it took me so long to get on PrEP. I wanted to get on it. My insurance didn’t cover it. But I was talking to my doctor about it and he called me the next day and he was basically, like, you have HIV. And I was, like, woah. So I don’t need PrEP after all.” (20-year-old, Black and Native American pansexual cis-male, living with HIV in Baltimore)

PrEP, pre-exposure prophylaxis.

of information before diagnoses. It was not uncommon for these participants to describe hearing about PrEP after their diagnosis of HIV.

Interpersonal barriers

Barriers to daily oral PrEP were identified at the interpersonal level (Table 3). Half of the prior PrEP users described experiencing a fear of telling their parents about PrEP use as a cause for either nonuse or discontinued use. The fear of talking about PrEP was centered around the fear of having to engage in a conversation about sexual orientation, and a general fear of “outing” oneself to potentially nonaccepting parents.

“I knew that my dad was going to find out. How was I supposed to explain it to him? Like I said, he knows what the medication is for and that was going to bring up a conversation that I wasn’t ready to have and I didn’t even know how he would take it. So, I just told myself that I’m not going to be able to get it.” (20-year-old Black and White gay non-binary at-risk for HIV living in Philadelphia)

Potential PrEP use also was viewed as leading to a conversation about sexual behavior in which youth reported feeling they were not ready to engage. This intersection between the participant’s individual views around disclosure and perceived family response was described as having the greatest influence on PrEP-related behavior. This was followed by perceived views of the medications by parents, community influence, and structural barriers. Parental mistrust of medications was described by other participants as leading to a hesitancy to discuss with parents and use PrEP.

“Yeah. I showed her (mother) the little pamphlets and stuff and she was like, “Yeah, I see everybody you be bringing up in here.” So she was like, “Yeah.” So she was all for it. But her being the same way I am about medicine, she started feeling uneasy about it, too. I don’t want that to have a side-effect on anything. Chemicals or anything ... It was always in the back of my mind, but she started asking more and more about it. She was like, “Do you even know what’s going on?” I was like, “I mean, you right.” That’s what she got me to thinking. She never told me “Get off of it,” but she got me

thinking. That's when I was like, "Yeah, I'm getting too smart for that." That's when I told her, like, "Yeah. I'd rather just... [stop it]" (18-year-old Black pansexual cis-male at-risk for HIV living in Baltimore)

The fear of disclosure and perceived parental response led to the belief that avoidance of PrEP was a more reasonable approach than use.

Two participants described partner-specific barriers (Table 3). One participant described nonuse because of perceived trust in his relationship and how perceived trust and partner type (main partner) played into his decision not to take PrEP. This quote also exemplifies how he and his partner relied on regular HIV testing in place of PrEP use.

"But it's (PrEP) not something that we feel like we need to do but it's something that [boyfriend name] is like, "If you decide to do it, then I'll do it." And so, yeah, I mean it's not like a big deal to us, but you know, we definitely know—we know who we love, you know, what we're doing, our status and all that stuff like that. And we both get tested regularly." (23-year-old Black gay cis-male at-risk for HIV living in Philadelphia)

Another participant, who was at risk for HIV, described that familial views around medication use prevented use, particularly a perception that regular medication use was in contrast to views of being healthy and should only be used when absolutely needed.

One participant described nonuse attributed to partnerships, specifically in that they were in a monogamous relationship, whereas other participants described that PrEP in relationships facilitated disclosure.

"When I hear people say I'm on PrEP it kind of makes me feel like they're a little more knowledgeable to the situation, they're a little more accepting to the situation that's why they're on the PrEP. It makes it a little easier, it does make it a little easier to say, hey, well, I'm HIV positive, because at that point I kind of know, well, they're not putting up a wall to it and just not dealing with it, they're dealing with it to make sure that they're healthy." (24-year-old Black gay cis-male living with HIV in Washington, DC)

Six youth living with HIV described that availability of PrEP encouraged disclosure of their HIV status to new sexual partners, and two youth at risk for HIV described that being in a serodiscordant relationship encouraged their partner who was living with HIV to utilize PrEP services. One participant described the care that the participant's boyfriend gave to maintaining his partner's negative status, and how PrEP was viewed in the relationship.

"He (boyfriend living with HIV) explains a lot. He was like, "Yeah, but I'm at a low risk of getting it because these reasons," and he feels as though I should go get on PrEP, and don't tell him I'm not taking PrEP because then he'll stop giving me sex. For real. If he finds out I'm not taking PrEP, we don't have sex. It's just that. Like, no. I'm like, "What?" He's like, "Because you're not taking care of yourself and you're not—" Because he said he would feel horrible if he finds out he gave me the illness. He would feel horrible. I guess that's his fear. He doesn't want that." (21-year-old Black bisexual cis-male at-risk for HIV living in Baltimore)

This participant described an intersection between individual barriers (not wanting to take a pill daily) and interpersonal facilitators (encouragement from partner to engage in sex in their relationship).

Community barriers

Community themes centered around negative PrEP messaging on social media. This included social influencers describing PrEP users as promiscuous and such negative views led to nonuse.

"There's this thing going on in social media, on Instagram. This lady was saying how—I think she's also famous too. She was basically coming at people about people who use it. She was like—she was trying to make it seem like people who use PrEP are basically dirty people, they're disgusting, and, 'You shouldn't be going around ho'ing around and then having to take a pill to protect yourself when you should just be more conservative about yourself and the people, and just your whole sex life.'" (20-year-old Black and White gay non-binary person at-risk for HIV living in Philadelphia)

Four participants described not using PrEP because of tension between condom use and PrEP, where condoms were viewed as a preferred method for protection and perceived as being universally used by all persons to prevent against sexually transmitted infections (STIs)/HIV, regardless of the number of partners. Another participant described that posting on sexual network sites about PrEP status and community messaging around PrEP were a turnoff.

"Friends have told me about it, and I see a lot of profiles on Grindr that are like, "Negative on PrEP. Negative on PrEP" And I'm not—I mean, I can't—I'm not going to sit here and generalize, but I think—I know a lot of people are not actually on PrEP. And so they say, "Negative on PrEP," and you're supposed to trust that and not use a condom, but that's not an excuse. You just still—there's still other STDs besides HIV. You should still use condoms. I can only see myself taking PrEP if I'm in a relationship, and if I'm in a relationship, I intend to have unprotected sex." (23-year-old Black gay cis-male at-risk for HIV living in Washington, DC)

As exemplified by this quote, posting about PrEP on sexual partner meeting sites led to PrEP nonuse because such posts were negatively viewed as false or advertising condom nonuse, which, for some, was viewed as risky behavior. Two participants (one living with HIV and one at risk for HIV) described community barriers around mistrust that prevented PrEP use.

"When I first heard about PrEP I felt like it won't work, I don't know, for some reason ... Because it was like this—there was like an article going around saying somebody had caught HIV when they was on PrEP, so it was like, what's the point of taking it?" (24-year-old Black gay trans-woman living with HIV in Baltimore)

This quote exemplifies that for some youth, rumors around PrEP led to nonuse.

Structural barriers

Structural barriers were described as preventing participants from getting appointments and staying on the medication. One participant described that these barriers intersected with challenges associated with being Black in America, which led to periods of nonuse.

"Just being Black in America, like, that is a stress in itself, and so I don't know. I feel like when we were talking about PrEP, like, we were talking about, like, you know, just being on it. But I've been on PrEP. I know how to take it. I know that I

have to take it every day. But it's about, you know, access, it's about my insurance, and like all the other, like, big things that are coming into play that I can't always access it, and it's not like I don't want to be on my medicine. Like, of course, I want to be on it every day, but a lot of things come up. Like, I was just off of PrEP for like a week and a half because I wasn't able to go back downtown to get my medicine. But, I mean, I'm back on it now. I've been on for like another week, so things are just... Just everything, honestly." (22-year-old Black gay cis-male at-risk for HIV living in Philadelphia)

Other barriers centered around challenges, with follow-up required and the process of making appointments for PrEP. Missed appointments were described as a key barrier to starting PrEP.

The second structural barrier included cost and insurance. Among the five youth who described not using PrEP before their diagnosis, one youth described having attempted to receive PrEP services but being denied for reasons including lack of insurance.

"I was, like, people, spermed on me, and it was, like, okay. So if I'm not going to use that protection, I need to use some kind of protection. And it was a little too late, because—I don't know why it took me so long to get on PrEP. I wanted to get on it. My insurance didn't cover it. But I was talking to my doctor about it and he called me the next day and he was basically, like, you have HIV. And I was, like, woah. So I don't need PrEP after all." (20-year-old Black and Native American pansexual cis-male living with HIV in Baltimore)

Others described cost, access, a general difficulty getting a prescription, and other insurance challenges, including concerns that explanation of benefit information would reach parents or the primary policy holder, as reasons for nonuse.

"I wanted to try it (PrEP) but someone told me it was like \$1000. I said hell no and I walked out of the room." (18-year-old Black gay gender-queer at-risk for HIV living in Washington, DC)

This participant demonstrates that the perceived cost to receive the prescription resulted in PrEP being inaccessible. One participant described not receiving information about PrEP in a medical setting as a barrier. This participant also described having learned about PrEP on their own because of difficulty connecting with a navigator.

Discussion

Among participating youth, there were intersecting barriers to PrEP use across multiple domains of the ecological framework. Most commonly, barriers occurred at one or more of three levels: individual, including low perceived risk; family, including disclosure and perceived response to disclosure; and structural level, inability to access PrEP.

Low perceived risk of HIV due to a limited number of partners or the feeling that PrEP was intended for those who are "more sexually active" was a common theme among PrEP nonusers and youth recently diagnosed with HIV. Low perceived risk of HIV in young Black Latinx SMM and TW has been tied to low adherence and willingness to take PrEP,^{8,27-31} whereas high perceived risk has been associated with high willingness.^{7,10} Little data have explored how this intersects with the complexity of partnership factors, such as trust in relationships and perceived monogamy within relationships.

Earlier work has demonstrated that for young Black men who have sex with men (BMSM), condom use can be tied to feelings of intimacy, trust and commitment with a partner, and not STI risk perception.³² Furthermore, low perceived risk, combined with one's potentially limited ability to plan ahead within and during relationships, may not create a space for young Black and Latinx SMM and TW to appropriately titrate PrEP use based on the level of risk.³³

Participants also described daily pill regimens as a barrier to use, with daily use leading to cessation of PrEP among prior PrEP users. Nondaily oral and injectable regimens may promote PrEP uptake and adherence in youth. Long-acting injectable PrEP medications have been demonstrated to be effective and acceptable in this age range.³⁴ Likewise, intermittent PrEP has been shown to be effective in MSM³⁵ and is potentially cost-effective among SMM who engage in sex one or more times per week.³⁶ More work is needed to examine the use of nondaily oral PrEP use in this population, including whether youth have the planning capacity, clinical support, and logistical awareness to engage in nondaily PrEP use.

Youth living with HIV predominantly described lack of PrEP information before diagnosis; however, the lack of information was also prevalent among youth at risk for HIV. This is consistent with other work demonstrating that lack of information, especially around potential side effects, creates a barrier to use.^{9,17,37} We found that lack of information can promote suspicion of medication and foster feelings of anxiety among youth. To get ahead of anxiety, views and beliefs around medications, providers, community programs, pharmaceutical companies, and entities such as local health departments will need to address concerns, such as pill size and side effects up front. Newer regimens,³⁸ with potentially fewer side effects, may need to be provided first to alleviate concerns and fears in this age group.

Fears around inadvertent disclosure and assumptions of one's sexual orientation were a family barrier described by PrEP users. This is consistent with previous research that young SMM have concerns that taking PrEP medications and engaging in sexual health services may potentially "out" them to parents,³⁹ and prior work that suggests that youth may be less likely to be willing to take PrEP if parents know about their use or if confidential protections are not in place that prevent disclosure.⁴⁰ More will be needed to ensure privacy and confidentiality, including specific directions for providers on how to advocate for youth to prevent release of information without written authorization.⁴¹

Medical mistrust was described by both users and nonusers of PrEP. Medical mistrust refers to the discomfort and suspicion toward health care systems and personnel, originating from historical medical mistreatment and HIV conspiracy theories to kill Black and gay populations.^{14,42,43} Mistrust has been identified as a barrier for both Black and Latinx populations.⁴⁴ This work suggests that medical and nonmedical practitioners will need to address potential areas of mistrust and views around medications that occur in the families and communities that youth exist in, especially given that such mistrust may be further perpetuated by recent litigations.⁴⁵ Health navigators/coordinators, certified peer specialists, public service/community messaging, and the use of social influencers to dispel rumors and increase the quality of interactions with the health care system are a few interventions that have the potential to address mistrust.^{46,47}

We may also need to consider how we market PrEP to youth. Currently, most advertisements are generated from pharmaceutical manufacturers. Recent work focused on vaccine acceptability suggests that pharmaceutical manufacturers are not seen as trustworthy as government agencies, and trust in the government varies often by race/ethnicity.⁴⁸ Furthermore, some work has suggested that the pharmaceutical push toward newer regimens, combined with lawsuit advertisements about the safety and efficacy of older regimens, may generate misconceptions about PrEP and undermine use, particularly in younger populations.⁴⁹ More community messaging, such as the PrEP4Love Campaign developed by the AIDS Foundation of Chicago PrEP Working Group, that is noncoercive, avoids generating mistrust, and is sex-positive is needed.⁵⁰

Structural barriers, including overall challenges related to insurance coverage, ability to access PrEP services, and appointments, were key barriers identified in this population. Other works have demonstrated that trouble attending provider's appointments and loss of insurance coverage may be two of the most common reasons for PrEP discontinuation in this population.⁵¹ The Ready Set PrEP program provides free PrEP HIV-prevention medications and access to PrEP to youth, regardless of age.⁵² However, providers may be unaware of this program or are simply not making use of it, further limiting access to youth.⁵³ Also, even aware, providers may not be willing to prescribe PrEP.⁵⁴

In one study of adolescent specialists, while 93% of providers had heard of PrEP, only 78% were willing to prescribe to young adults (>18 years) and 65% were willing to prescribe it to youth younger than 18 years.⁵⁵ Despite the existence of federal programs, evidence demonstrates that without health care-level solutions, such as health insurance expansion, financial assistance for laboratory monitoring, expanded visit types, and appointment times to improve access to PrEP across multiple settings, structural barriers will continue and expansion of PrEP among Black and Latinx youth will be limited.⁵⁶

There are limitations in this work that should be acknowledged. This population focused on young Black and Latinx SMM and TW and may not be reflective of the views of other populations. Only two youth described themselves as Latinx, while seven youth described themselves as gender nonbinary, queer, or transgender, limiting the ability to specifically look at group differences. The qualitative nature of this work limits the ability to draw casual associations between barriers and nonuse. Furthermore, these interviews were performed once, thus limiting the ability to assess barrier impact on PrEP use over time.

Despite these limitations, this work suggests that PrEP barriers exist at multiple levels impacting young Black and Latinx SMM and TW. To end the HIV epidemic in this population, it is important to address the individual, interpersonal, and structural barriers that exist around PrEP, including how HIV risk perception is incorporated into decision-making, concerns around disclosure, and access to PrEP in a youth-centered meaningful way that dispels misinformation.

More is needed to reduce HIV- and PrEP-related stigma at the community and partner level to allow for disclosure between partners and open conversations that are sex positive and PrEP inclusive. Changing the public's perception of the

course of HIV and the measures one can take to protect oneself and loved ones begins with comprehensive education from trusted medical providers, educators, and community and family members. Leveraging known facilitators to improve PrEP uptake can help normalize conversations about risk and distribute the burden of protection to more than just youth who are living with HIV, but all youth as well.

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