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ORIGINAL PAPER

Accessing Pre-exposure Prophylaxis (PrEP): Perceptions of Current and Potential PrEP Users in Birmingham, Alabama

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Abstract
Limited studies to date assess barriers to and facilitators of PrEP uptake and utilization using a patient-centered access to care framework, among diverse socio-demographic groups, or in the U.S. Deep South, an area with disproportionate HIV burden. We examine perceptions of PrEP access in qualitative interviews with 44 current and potential PrEP users in Birmingham, Alabama. Participants were 32 years old on average, 66% Black, 66% gay or lesbian, 70% male, and 66% single. Perceived barriers to PrEP access included: lack of PrEP awareness and advertisement; sexuality-related stigma; time and resource constraints; and concerns about the adequacy and technical quality of PrEP services. Perceived facilitators to PrEP access were: PrEP-related information gathering and sharing; increased dialogue and visibility around PrEP; social, programmatic, and clinical support; and, lastly, self-preservation; personal motivation; and treatment self-efficacy. Results point to opportunities to address complex barriers to equitable PrEP access using multilevel and multimodal solutions.

Keywords Pre-exposure prophylaxis (PrEP) · Access · HIV prevention · Continuum of care

Introduction

Rates of HIV infection, HIV-related illness, and death are higher for the southern United States (U.S.) compared to other regions [1]. The onus of the HIV epidemic in the U.S. South is largely borne by lower income and racial, ethnic, and sexual and gender minority groups in this region [1–3]. Population groups at the intersection of these social group identities, particularly black men who have sex with men (MSM), black transgender persons, and Black women in the U.S. South, are disproportionately affected by poorer HIV-related health outcomes, such as higher rates of HIV diagnoses [4, 5], lower likelihood of viral suppression [6], and higher risk of all-cause mortality [7], relative to their counterparts. The health outcomes of minority groups in the U.S. South are shaped by the greater social and economic contexts of the region, which include historical legacies of discrimination (manifested in income inequality [8], racial residential segregation [9], medical, ethical, and other injustices [10]). This social positioning also affects the ability of

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minority communities to take advantage of prevention tools, to include medical advancements like HIV pre-exposure prophylaxis (PrEP) [11].

Pre-exposure prophylaxis, a highly efficacious tool for the biomedical prevention of HIV among individuals at high risk of HIV infection, was U.S. Food and Drug Administration (FDA) approved for use as a once daily oral pill in 2012 [12]. Compared to other regions, the U.S. South has the lowest levels of PrEP use overall (21.0 users per 100,000 vs. 25.8 nationally), and relative to epidemic need (PrEP-to-need ratio of 1.0 vs. 1.8 nationally) [13]. States within the Deep South (Alabama, Georgia, Louisiana, Mississippi, North Carolina and South Carolina [14]) had especially low prevalence of PrEP use overall (ranging from 9.7 to 21.7 users per 100,000 people) and PrEP-to-need ratios (0.5–1.2) [13]. A recent analysis of PrEP utilization in Alabama identified significant racial disparities in the uptake of PrEP. Specifically, results suggested that PrEP uptake was scarce among black men, black women, and black MSM, populations most heavily impacted by the HIV epidemic in the region [15]. In-depth understanding of the issues that preclude uptake of PrEP in the U.S. Deep South may inform efforts to facilitate more equitable PrEP use nationally.

Limited studies have examined barriers and facilitators of PrEP uptake in the U.S. Deep South. Kelley and colleagues proposed a theoretical model for a PrEP continuum of care and identified factors relevant to uptake at each point along this framework based on data from MSM in Atlanta, Georgia [16]. The proposed continuum includes awareness and willingness, access to health care, likelihood of receiving a prescription for PrEP, and adherence and self-efficacy—all critical sequential points of intervention upon the achievement of protection from HIV with PrEP for which there exist barriers and facilitators. Barriers to seeking PrEP included risk/benefit perception, cost and ability to pay, side effects, and PrEP-related stigma. Similarly, Arnold and colleagues examined factors affecting PrEP use and retention in PrEP care among young MSM in Mississippi [17]. Results identified cost and access to financial assistance for medications and clinical services, sexual risk behaviors, and perceived and actual side effects as determinants of PrEP utilization.

Though not regionally specific, a recent systematic review of values and preferences related to PrEP uptake provides valuable insights to acceptability, barriers, and facilitators of PrEP uptake [18]. Specifically, this review highlighted study findings from different populations most affected by the HV epidemic, and reported that most socio-demographic groups welcomed the use of PrEP as an important tool to prevent HIV transmission. Despite high acceptability of PrEP as a prevention tool, several barriers to PrEP uptake were identified across studies with the most commonly cited barriers being concerns about safety [19, 20], side effects [21, 22], cost [23, 24], and effectiveness [25, 26]. Other barriers identified included stigma related to HIV and use of antiretroviral therapy (ART) [27, 28], low risk perception [29, 30], lack of access (i.e., discontinued supply PrEP medication) [31, 32], and lack of provider knowledge [33, 34]. Importantly, this review revealed a significant lack of research on PrEP outside of MSM, sero-discordant couples, and drug using populations [18]. The authors concluded that there is a need for further research on PrEP among women, heterosexual men, and transgender persons.

In this qualitative study, we explore perceptions of PrEP access among current and potential PrEP users in Birmingham, Alabama. We apply a conceptualization of patient-centered access to health care by Levesque et al., which integrates and builds upon various earlier access to care models [35]. The Levesque et al. framework takes a broad view of access to care in that it considers population and system-level processes and determinants of access to care in addition to the more commonly theorized patient, provider, and health care facility-level factors. In other words, it considers barriers and facilitators to access on the demand-side (patient and population -level ability to access care) and on the supply-side (provider, health care facility, and health care system—level accessibility of care). As such, the concept of access is redefined by Levesque and colleagues as, "the opportunity to reach and obtain appropriate health care services in situations of perceived need for care" and "is seen as resulting from the interface between the characteristics of persons, households, social and physical environments and the characteristics of health systems, [organizations] and providers." The Levesque access to care conceptualization also encompasses domains beyond the availability of health services, a predominant focus of previous conceptualizations.

Patient-centered access to care is conceptualized as comprising five major dimensions: approachability, acceptability, availability and accommodation, affordability, and appropriateness. Approachability refers to a person's knowledge of the availability of services, which may vary by social or geographical position. Acceptability refers to cultural and social factors that affect the perceived appropriateness of seeking out a service. Availability and accommodation relate to the ability to access services both physically, and in a timely manner. Affordability refers to a person's ability to pay for services. Finally, appropriateness refers to the fit between client needs and the services offered, to include such factors as the type of services provided and the quality of services provided.

This framework has seldom been explicitly drawn upon in prior studies of HIV treatment and prevention [36–39]. The application of this framework to understanding the process through which someone may move from unaware of, uninterested in or unempowered to use PrEP to PrEP uptake and beyond can inform strategies to overcome experienced or

perceived barriers to access. Considering the multifaceted nature of the PrEP care continuum and of the challenges observed in implementation thus far [40, 41], this characterization of access lends well to the empirical assessment of progress in improving PrEP uptake, use, and equity. Particularly in the U.S. Deep South, where the HIV disease burden is high and where PrEP service provision is lagging as compared to other regions [42, 43].

Methods

The present analysis is part of a larger exploratory sequential mixed-methods study to assess the effects of stigma on PrEP uptake and adherence. First, individual in-depth qualitative interviews were conducted to identify perceptions of PrEP and related experiences among current and potential PrEP users. We then created survey measures of these attitudes and experiences and pre-tested them through cognitive interviews before revising the items and administering the survey to a larger group of similar participants. The analysis described here includes qualitative data from the individual in-depth and cognitive interviews, collected from June 2017 to March 2018. The study protocol was approved by the University of Alabama at Birmingham Institutional Review Board.

Our study team recruited potential participants via referrals from PrEP providers and posted study flyers at PrEP clinics and community organizations serving populations at risk for HIV in the Birmingham, Alabama area. In order to capture a spectrum of participant experiences in the qualitative interviews, we purposively recruited potential participants in various age, PrEP use, gender, sexual orientation, and racial/ethnic groups. Trained graduate and undergraduate research assistants subsequently screened interested individuals for eligibility by phone. Individuals were eligible to participate in the study interviews if they were HIV-negative, over the age of 18, not employed as staff at the PrEP clinic recruitment locations, and if they were either on PrEP or PrEP eligible on the basis of high current or prior risk of acquiring HIV infection, as follows. We assessed current or prior risk of acquiring HIV infection using criteria that we created, informed by U.S. Public Health Service guidelines [44]. Specifically, participants were considered to have high current or past HIV risk if they: were in a sexual relationship with a person living with HIV, ever had condom-less sex, ever had a diagnosis of a sexually transmitted infection, ever engaged in sex work, ever engaged in intravenous drug use sharing needles, or were ever in a methadone or medication-based drug treatment program.

We invited eligible individuals to select from prearranged interview times (which included options in the day and early evening) and locations. Options for interview location included private rooms at PrEP clinics, community organizations, the local university, a public library, or other locations with public access of the participant's choosing. Interviews were conducted by four qualitative research experienced study team members (WSR, KBC, GCA, and DSB), and were guided by the use of semi-structured interview guides. The initial in-depth interviews included open-ended questions about how participants first learned of PrEP (if at all prior to this study); regarding PrEP use within the interviewees' social networks (if at all); on perceptions of PrEP within participants' communities; assessing perceptions and experiences of PrEP-related stigma; about experiences, interests, and motivation related to PrEP; and about actual or anticipated PrEP adherence (Table 1). In the cognitive interviews, we asked participants to respond to survey items that we created to measure the concepts that emerged from the initial interviews, and these quantitative responses were then self-reported by participants on a paper version of the survey. We then asked participants to verbally reflect upon those items out loud and had discussion of their reflections.

The individual qualitative interviews were audio-recorded and transcribed, and the data were coded using thematic analysis [45]. Three research team members (WSR, KLS, and KBC) developed the codebook used in analyses through an inductive and deductive process. A priori codes were informed by review of literature regarding PrEP implementation, the interview guide, and a review of initial transcripts. Additional codes that emerged from the data were added to the codebook during the data analysis process. Two research team investigators (WSR and KLS) double-coded the same initial few transcripts and then reviewed the percentage of coding agreement (similarities and discrepancies in our coding application) across those transcripts. We next held meetings to discuss discrepancies in the initial coding and divergence in our interpretation of codes and to reach consensus about the coding definitions and process before revising the codebook and proceeding to divide and code remaining transcripts.

We used NVivo 11 qualitative data analysis software for coding and to generate excerpt reports for themes broadly related to PrEP access [46]. Three research team members (WSR, KLS, and MS) reviewed the coded excerpts and assigned fine codes reflecting the five major categories of patient-centered access to care (approachability, acceptability, availability and accommodation, affordability, and appropriateness) conceptualized by Levesque, et al. [35]. The first author presented preliminary findings to individual research team members and other colleagues iteratively as a method of peer debriefing and incorporated their feedback into final analyses and reporting.

Table 1 Sample questions from semi-structure qualitative interview guide by interviewee category

Interviewee category	Interview guide question
Both PrEP users and potential PrEP users	What can you tell me about PrEP? What have you heard about PrEP? What can you tell me about use of PrEP within your community? By community, I mean the people who live in your area *and* people close to you (who may not live close by) Probes: Are people in your community open to talking about using PrEP? What are some reasons that people might not talk about PrEP? Can you please describe what you have heard about experiences with trying to get on PrEP that you or others that you know have had? What kinds of opinions or attitudes do people within your community have about PrEP users? How are people who are on PrEP treated in your community?
PrEP users only	Can you tell me about how you began using PrEP? What were your experiences with getting on PrEP? Can you tell me about your experiences with taking PrEP? How did things go when you first started taking PrEP? What about now (i.e., how are your experiences with taking PrEP now)? What helps you to take PrEP as your doctor recommended? What things might make it hard for you to take PrEP as your doctor recommended?
Potential PrEP users only	Tell me about your interest in using PrEP What do you think about taking a pill every day to prevent HIV? Probes: Do you think PrEP is useful? What challenges would you have with taking PrEP? What things could help you to take the PrEP pill every day? Do you think there are any risks of taking PrEP?

Results

Out of 73 total individuals recruited, 44 were both eligible and participated in the study interviews. Interviewees largely identified as male; black; and lesbian, gay, bisexual, or pansexual; single; and not currently using PrEP (Table 2). A total of 45 interviews were completed, with a single study participant having completed both the initial in depth interview and survey pre-test cognitive interview. Interviews were 56 min in duration on average (standard deviation = 18 min). The qualitative findings are presented by dimension of access to care below (and in summary form in Table 3).

Approachability

The interviewees indicated several barriers and facilitators to their own personal and their community's knowledge of the availability of PrEP services (approachability). Many participants shared the perception that knowledge of PrEP differed by social status. Accordingly, interviewee perceptions regarding the degree to which they themselves and their communities were aware of PrEP, how they might access it, and of how the use of PrEP may benefit them varied. When asked to elaborate, we heard a participant response that was echoed by many others, "I would determine my community [to be] black, gay men. I don't think that it's used often in our community. I don't think it's accessible. I don't really believe that people know about it" (black MSM, age 20–24, not on PrEP).The concept that PrEP services were more known to specific social groups was not only observed across racial and ethnic groups, but participants also observed that knowledge of PrEP differed across geographic areas and by sexual orientation. One participant states about PrEP promotion across locations, "I know in the larger cities I've seen a lot more, [advertisement], literature and things like that" (White MSM, Age 30+, On PrEP). Another participant shared about sexual orientation:

> When I think of PrEP, I predominantly think of a gay relationship. I haven't really thought of it in a straight relationship … even though I know that it's something that other people can take… It is something that affects men and women and heterosexuals and homosexuals. I feel like the education of it more is to the gay community (white MSM, age 20–24, on PrEP).

Table 2 Socio-demographic and health characteristics of the study sample (n = 44)

Characteristics	*n*	%
Gender identity		
Female	8	18.2
Male	31	70.4
Transgender	5	11.4
Race		
Black	29	65.9
Other	13	29.6
White	2	4.5
Sexual orientation		
Bisexual	6	13.6
Gay/lesbian	29	65.9
Other	2	4.5
Straight/heterosexual	7	16.0
Relationship status		
In a relationship/not living together	9	20.5
In a relationship living together	2	4.5
Other	4	9.1
Single/not in a relationship	29	65.9
Currently using PrEP[a]		
No[b]	25	56.8
Yes	19	43.2
	Mean	SD[c]
Age (years)	31.8	10.7

[a] *PrEP* pre-exposure prophylaxis

[b] Two participants previously discontinued use of PrEP

[c] SD standard deviation

Participants called for more equity and transparency of information about PrEP and in outreach activities. One of the women in the study shared, "I would like to see more advertisement with people of color and I would like to see it more—the information more readily available in our community and the benefits of it. Then, also geared toward women because our HIV rates are as high, as well" (black, heterosexual, age 30+, not on PrEP). Another participant stated, "If anything that may prevent people from using PrEP … it's not understanding the drug and what it is. It needs to be this broad communication and education about the drug and more advertisement of the drug or getting it out there" (black, transgender and heterosexual, age 25–29, not on PrEP).

Interviewees also shared the processes by which they themselves became aware of PrEP, the social institutions or groups that facilitated their awareness, and offered suggestions for improved awareness of PrEP across population groups. White participants and participants who worked in HIV-related clinical or advocacy settings more commonly expressed that information about PrEP was accessible through community-based and health care organizations that engage in health promotion efforts within the local metropolitan area. As an interviewee (black MSM, age 25–29, not on PrEP) who worked in HIV prevention stated:

> I think with PrEP, right now, at least definitely in the city of Birmingham in between the different agencies and clinics and things that we work with, I think we're doing a really good job at informing … at getting the information out there … and at least touching on the subject with people.

For many participants, initial awareness of PrEP was facilitated by word of mouth within their social networks, and many of the study participants since acted as facilitators of PrEP information access for others: "I think that when you're willing to share your knowledge and open up to people, they learn and they become interested" (black MSM, age 30+, On PrEP). Seeking and exchange of information about PrEP online and via social media were also commonly reported: "I learned everything I know about [PrEP] literally just, like, either online, social media, because someone posted and asked questions or I met someone, they told me they were on it, told me a little bit about it" (multiracial MSM, age 25–29, not on PrEP). One participant advocated for PrEP information dissemination through, "AIDS fairs, school systems, whether it's pamphlets being sent out, whatever. Social media, advocates, people that have a big social impact, not just on straight, not just on gay, but people that have an impact period" (black MSM, age 25–29, not on PrEP).

Acceptability

Participants reported that a number of cultural and social dynamics affect the perceived appropriateness of PrEP use (acceptability). Cultural and social norms that silence discussions concerning sexuality were perceived barriers to PrEP knowledge dissemination:

> Southern Baptists drink just like the Episcopal people do, but they sneak to the liquor store or have somebody else go in for 'em rather than go in and buy their liquor. I think the same thing is true about sex. They're supposed to be all conservative and "Ooh, you shouldn't have sex outside of marriage" and all this kind of stuff, but when I first came out in the small town I was raised in, I had more married men callin' me than gay men. Maybe I'm tainted that way, but I don't think that people would sit in church and swap pamphlets about PrEP, but I think it's information that they would like to have (white MSM, age 30+, On PrEP).

These norms were perceived to negatively affect the level of encouragement and other social support that one

Table 3 Current and potential PrEP users' perceived barriers and facilitators to accessing PrEP in Birmingham, AL

Dimension of access to care[a] (definition)	Perceived barrier or facilitator	Major sub-themes
Approachability (knowledge of the availability of services, which may vary by social or geographical groups)	Perceived barrier(s)	Lack of awareness of PrEP and limited advertisement of PrEP within non-white communities and among non-MSM populations
	Perceived facilitator(s)	PrEP-related information sharing via internet, social media and close interpersonal connections
Acceptability (the cultural and social factors that affect perceived appropriateness to seek out a service)	Perceived barrier(s)	Cultural and social norms that silence discussion concerning sexuality Fear and experiences of sexuality-related stigma
	Perceived facilitator(s)	Increased dialogue and visibility concerning PrEP in some social groups
Availability and accommodation (the ability to access services both physically, and in a timely manner)	Perceived barrier(s)	Long travel distances to access PrEP Time conflicts with available PrEP clinic appointments Repeated clinic visits needed to begin and receive cost assistance for PrEP
	Perceived facilitator(s)	Assistance from social support networks, employers, and others
Affordability (the ability to pay for services)	Perceived barrier(s)	High prescription and co-pay costs Lack of awareness of financial assistance programs Lack of resources for health insurance and cost-related challenges
	Perceived facilitator(s)	Financial and logistical support from assistance programs and clinic staff Assistance from peer navigators
Appropriateness (the fit between client needs and the services offered, including the type and quality of services provided)	Perceived barrier(s)	Lack of awareness of PrEP by primary care and family practitioners Preference for other modes of PrEP delivery (i.e., injectables) Low perceived HIV risk relative to the resources required for PrEP use Concern about side effects
	Perceived facilitator(s)	Interpersonal quality of interactions with PrEP providers Self-motivation and treatment self-efficacy

[a]As defined by Levesque et al. [35]

may receive from others around use of PrEP, especially for black MSM:

> I don't have any gay friends, but I assume that if I were to expand my horizons, and meet new people that they probably would know what PrEP [is] from another culture. Just because it's easier for them to talk about it in the community…. I think about all the references I have to anyone that's black that's come out, and it's like the backlash that I've seen from just the Black people…. I feel like if you mention [PrEP] to anyone of any other culture, they're so much more open, and it would be something that you should know about. That kinda thing (black MSM, age 20–24, On PrEP).

Fear of judgement regarding sexual orientation and sexual behavior, as shared by participants—particularly interviewees of color—were perceived as barriers to the acceptability of PrEP health care seeking:

> MSM are not seeking help because, if I do, people are going to find out, like someone sees me at that clinic, there's going to be gossip about me being gay … so they're scared … they obviously are still having sexual relations but they're not doing anything about it … they're not looking for answers about what they should to do to stay healthy or what they should be aware of … white people, they do still have some of that stigma, especially in the south, you're gonna have that whole, gay is not okay and all that … [but] they also have that ability to go out to different clinics and people won't really question them … once they do come out, you know, like, they accept it and then they still don't have any backlash … (Hispanic MSM, age 20–24, on PrEP).

In a more specific example, "[A friend] was still on his parent's insurance because he was in college, and I was like '…you're 24 years old, [because of] HIPAA [—the Health Insurance Portability and Accountability Act], you don't

have to let them know. I mean, the charge will show up, but he [has a] very, very conservative family, so he just didn't even want to have that discussion" (white MSM, age 30+, on PrEP).

Participants perceived that social norms and stigma around sexuality additionally pervade the health care institutions where people seek PrEP. In particular, participants commonly commented about perceptions and experiences of stigma from doctors and pharmaceutical companies:

> I think that there's a lot of negative stigma and political push from a lot of different sides, and I feel that our political influences are being influenced … by extreme Christian people who do not want any of it to be there, including birth control. They're making it very, very difficult for people like us to acquire the things that are useful and helpful (white, transgender and bisexual, age 30+, not on PrEP).

On the other hand, we heard from participants that some accepting social norms and the common use of PrEP in some social groups facilitate the acceptability of seeking and using PrEP: "getting the process starting is the toughest part… The more people you talk to about it, the more regular it becomes because it's not something that you're concerned about. No judgement. If you know that you're being exposed to HIV potentially, why would you not go and protect yourself" (white MSM, age 20–24, on PrEP)?

Availability and Accommodation

Many interviewees described barriers and facilitators to their and others' perceived ability to access PrEP physically and in a timely manner (availability and accommodation). Some participants had to travel long distances to access PrEP services: "I did have to travel … about an hour and 20 min [for initial and return PrEP visits] … it was kind of a hassle having to go out that far … but whenever doctors just aren't open about that, and sometimes they're just not aware, you just have to go to an open [or accepting] society like [other cities]" (Hispanic male, age 20–24, on PrEP). Participants also reported difficulty with attending several clinic appointments to initiate the use of PrEP, considering their work, class, or other schedules: "I would like to get on PrEP, and I've tried before. It's just the scheduling doesn't align" (black MSM, age 20–24, not on PrEP).

An interviewee spoke about reasons that he perceives that his close friends are not on PrEP:

> Because they gotta take time out of their day and go to the doctor. It only took about 3 days of me coming to the clinic to get to where I was able to finally take PrEP. It was mostly a scheduling thing because I had showed up on a Monday when I had the day off. Then I came back on a Thursday for another test and then Friday was when they ended up doing the actual PrEP work here. I came back like 3 days in a week (white MSM, age 20–24, on PrEP).

Many of the interviewees who had used PrEP initiated PrEP as part of research or other programs that assisted with the cost of PrEP. However, attendance at study visits or other check-ins required by such programs were burdensome to some participants:

> The clinic here, they provide some type of program that pays for it, as long as you participate in something… The scheduling that they had for it was very limited … I work two jobs, so it was like, okay; well, I also ride the bus to work. I have to figure out how would I get here, then the bus stop, then work. Just the planning of it all was not good. It's just kind of delayed the process (black MSM, age 20–24, not on PrEP).

Additionally, there was variability in the perception of the convenience of PrEP users' existing pharmacy arrangements. Some interviewees found mail order pharmacy services to be less convenient than visiting a pharmacy, as stated by one participant, "Now, with my new insurance, I have to get a mail order. I'm dependent on them getting the shipment to me on time, and stuff like that, as opposed to just coming here and getting it when I'm down here" (black MSM, age 30+, on PrEP). On the other hand, most participants on PrEP were happy with their present pharmacy arrangements:

> I called on Monday to get it refilled because it was my off day and I knew that I had—I thought I had more pills left than I did so I'm glad I did call. It was super easy. Walgreens is great. Amazing. I just typed in my prescription, they verified that it was me, and they told me that it would be ready tomorrow or Tuesday at 11:00. I got a call saying that it was ready. Awesome (white MSM, age 20–24, on PrEP).

Some participants were able to manage other priorities while seeking PrEP as facilitated by support from friends, family members, co-workers or supervisors: "I needed to get on PrEP, and I also didn't wanna take any sick time to go to the doctor to take away from work because I didn't want to explain to work about my situation, which I ended up doing. I talked to my boss, and it was great. I'm glad that I ended up talking to my boss cuz it makes it easier" (white MSM, age 20–24, On PrEP). Responses by participants who were using PrEP largely suggested that the "hassle" of arranging and traveling to repeated appointments was worth the time spent for HIV prevention and peace of mind.

Affordability

Participants shared perceived barriers and facilitators of their own and others' ability to pay for PrEP (affordability). Both current and potential PrEP users identified cost as a significant impediment to PrEP uptake. For interviewees yet to use PrEP, many had heard from friends or acquaintances that prescription costs are prohibitive to uninsured persons seeking PrEP: "I heard, you don't have insurance, it's really expensive or something … if it's as expensive as I heard it can be, that is absolutely a barrier" (multiracial MSM, age 25–29, not on PrEP). While many participants were unclear about what the actual cost of PrEP would be for them, many interviewees shared the sense that the cost of PrEP could be onerous even for people who have insurance. Some current PrEP users complained of high prescription costs even after supplemented by insurance: "My insurance was iffy about it. They made me pay a lot more than my insurance plan usually covered for prescriptions cuz there's no generic or anything. It was more expensive than I wanted to pay" (white MSM, age 25–29, not on PrEP).

Others were concerned that their insurance providers may not cover PrEP and were not sure whether the expense would be worth the cost without insurance coverage or alternate assistance:

> I don't know if my current health insurance would [cover PrEP]. It's expensive from what I understand. That would be a determining factor… Is it extremely expensive? Can I afford it? Weigh the options … am I sexually active enough to warrant paying for this?… $25 or $20 wouldn't be an issue for me (white MSM, age 20–29, not on PrEP).

A few participants identified pharmaceutical companies as the drivers of high PrEP cost:

> If they made it more cost-efficient for people, then I think it might actually be covered by the insurance companies, but in all shades of light, I think I can see part of the reason an insurance company wouldn't want to cover it. They don't want to pay $6000 a month for a pre-exposure pill. That's an awful lot of money. I think our pharmaceutical companies kinda gouge a little too much in their prices. They want people to take it, but they don't want to budge on their prices (white, transgender and bisexual, age 30+, not on PrEP).

Interviewees also perceived a general lack of awareness of financial assistance programs, lack of resources for navigating enrollment in prescription cost reduction programs, and lack of resources to navigate insurance-related challenges as barriers to PrEP uptake in their communities. However, for some participants on PrEP, payment by insurance plans and PrEP assistance programs was facilitated smoothly by clinic staff members. Many participants themselves acted as peer navigators to friends, family, or others. One interviewee who worked at a pharmacy shared:

> I have one customer that came in. He had the copay card, but he was clueless as to what it even was or what they even do with it. I asked permission from the pharmacist to take him to the back to educate him on what he needs to do (black MSM, age 25–29, On PrEP).

Appropriateness

The interviewees also relayed reflections about the degree to which PrEP services fit their needs as patients, including barriers and facilitators concerning the form and quality of health care provided (appropriateness). Generally, participants who had used PrEP spoke highly of the quality of interpersonal interactions with PrEP service providers. However, current PrEP users shared with us experiences with unwanted disclosure of PrEP use in other health care settings, and other interactions with health care providers that the participants viewed as inappropriate or subpar:

> …any time I go to, like, a doc in the box or something like that and presumably the people I interact with are straight or straight-identifying, once I get there, they ask about medications, and I tell them I take Truvada and so if they know what Truvada is they immediately ask "Are you HIV positive?" … usually I'm very disappointed in that because … I feel like people should know, and they always want to give me an HIV test immediately, too (white MSM, age 25–29, on PrEP).

Potential PrEP users expressed concern about whether their care providers would be knowledgeable about PrEP and accepting of their desire to use PrEP:

> I need to find a new doctor … [My doctor is] more like a family practitioner type person. I don't feel that he would be the best resource for me. I don't know that I would even feel comfortable. I think I'd probably feel some judgment. Clearly I haven't at this point—I would kind of feel a little awkward asking him about that. I would hope that he knows, but I don't even know for sure that he would, cuz I'm younger than most of his other patients (white MSM, age 25–29, on PrEP).

Participants who were not on PrEP also considered whether the relatively more frequent and sustained health care utilization required to begin and continue PrEP would be worth it at this time, given that they were rarely or not currently engaged in HIV risk behavior:

> Even if you get an injectable, do you still have to come in every month to get your liver checked? Do I still have to go through all of that, even though I'm not

> engaging in X behavior? … If it's something that I'm not engaging in, then—Is it worth the headache of setting up an appointment every month, you know what I mean? It just depends on what your level of sexual health importance is, I guess you could say (black MSM, age 25–29, not on PrEP).

Most participants did not perceive that they have or would have trouble taking PrEP as recommended or prescribed. Many interviewees felt that their motivation for HIV prevention superseded any other barriers to taking a daily medication that they have or would encounter. Participants who were taking other daily medications perceived that the addition of PrEP would be or has been easy. A few of the potential PrEP users expressed heightened concern about side effects of PrEP, particularly as it relates to liver and kidney function. Another small group of the potential PrEP users also doubted their ability to adhere to PrEP in its presently approved pill form. For a few participants, this was because they have difficulty swallowing pills. Others didn't think that they had the self-discipline or the ability to remember to take a pill daily and would prefer other modes of delivery such as a monthly injection.

Discussion

Among current and potential PrEP users in Birmingham, Alabama, we apply a multidimensional model by Levesque, et al., to assess patient-centered access to PrEP, considering the entire process of obtaining and benefiting from PrEP information and services [35]. Notably, disparate perspectives were provided by participants engaged in HIV education and prevention programs and their counterparts from the general population regarding the availability of PrEP knowledge, resources, and other forms of access to PrEP in the greater Birmingham metropolitan areas. Interviewees perceived various challenges to uptake and use of PrEP, including: lack of awareness and limited advertisement of PrEP, particularly within communities of color, among non-MSM populations, and outside of cities (approachability); social norms that produce sexuality-related stigma (acceptability); the time and resource demands of initial screening for PrEP and follow-up clinic visits (availability and accommodation); lack of economic capacity to pay for PrEP, even with cost sharing (affordability); and concerns about the adequacy and technical quality of PrEP services (appropriateness). The participants also discussed several perceived facilitators to their uptake or use of PrEP, such as: internet, social media, and close interpersonal connections that facilitate PrEP-related information gathering and sharing, making PrEP more approachable; increased dialogue and visibility around PrEP was said to promote its acceptability; social support networks, cost assistance programs, and clinical support staff helped many participants to navigate time and resource constraints (availability and accommodation; affordability). Lastly, participants reported that self-preservation, personal motivation, and treatment self-efficacy helped them to navigate these barriers to accessing PrEP (approachability and other domains). Taken together, these data point to various opportunities to address individual, community, and structural barriers and facilitate equitable PrEP access in a region where risk of HIV infection is disproportionately high [1, 13].

Several of the barriers and facilitators to PrEP uptake and adherence highlighted within the present study have been identified by earlier studies as key impediments or solutions to improving the PrEP care continuum [40]. Prior qualitative studies in this field draw primarily from the perspectives of individuals in other U.S. regions and states [17, 21, 47–49]. Thus, the results presented here contribute to the scientific literature about the experiences and perceptions of individuals residing in the less studied area of the U.S. Deep South, as it pertains to PrEP access. The U.S. Deep South is characterized by a unique combination of social, structural and policy positions that present distinct challenges to PrEP access [2]. For instance, Deep South states have higher levels of structural stigma related to sexual minority status (an indicator of environments less supportive of sexual minority rights and respect) relative to other states, which is in turn associated with lower odds of awareness and use of PrEP at the state-level [50]. Deep South states also rank among the lowest 30% of U.S. states on indicators of health system performance, a composite of indicators such as health insurance coverage, out-of-pocket health care expenses, cost of health care, receipt of preventive care, quality of care, and other health risk factors; which, taken together, are directly relevant to multiple PrEP access domains [51]. These and other characteristics of the U.S. Deep South (e.g., transportation inaccessibility [52], high rates of poverty [53], etc.) are reflected in the perceptions of access to PrEP that were shared by the current study participants.

Existing PrEP care continuum models view "PrEP access" as a limited part of the PrEP uptake process, consisting of the ability to reach and pay for PrEP services [16, 40]. Other indicators (i.e., PrEP awareness) that represent dimensions of access in the Levesque model (i.e., approachability) are generally conceptualized as separate from PrEP access and sequentially precede PrEP access in PrEP care continuum models. Additionally, more patient-centered determinants of PrEP uptake and utilization, including the personal and cultural acceptability of PrEP and whether PrEP services are delivered with appropriate quality, are not customarily included in PrEP care continuum models. Our application of an expanded conceptualization of access to the study of PrEP implementation is an attempt to more

comprehensively assess not only perceptions of the capacity to obtain and reach PrEP among individuals in the U.S. Deep South, but also to assess perceptions of the ability to identify a need for PrEP, to seek PrEP, and to have needs and preferences for PrEP fulfilled in this region [35]. Accordingly, our research findings suggest opportunities to improve PrEP uptake, utilization, and service delivery for each domain of patient-centered PrEP access.

As it pertains to PrEP approachability, interview participants reported that PrEP awareness was higher among white men, sexual minorities, and those residing in more urban areas. Knowledge that PrEP awareness is limited [54] and that awareness of PrEP is lower among certain social and geographic groups has been previously documented in other settings [21, 55], though lower HIV prevention knowledge may be more prominent in the U.S. Deep South [56]. Promising approaches to address these information gaps by improving PrEP awareness include clinic or social service organization-based educational sessions as part of sexual risk counseling [57], integration of current PrEP users as peer educators [58], and community-based social marketing campaigns [59]. The latter modes of PrEP promotion draw upon facilitators to PrEP approachability suggested by our study participants (i.e., information sharing through interpersonal connections, internet and social media). As a whole, these interventions may contribute to PrEP uptake and use by increasing knowledge of personal and community HIV risk around what PrEP is, around what the benefits of PrEP are, and around the process of obtaining PrEP, which may in turn facilitate recognition and fulfillment of personal and community PrEP interest and preferences. The current study results and the extant literature suggest the need for tailored implementation among population groups with low PrEP awareness and knowledge [60], particularly among racial minority and heterosexual individuals, in order for efforts to achieve more equitable PrEP uptake to be successful.

In regards to acceptability, participants reported that cultural norms and community level stigma constrained conversations about PrEP among family and peers, particularly within communities of color, and anticipating stigma within health care settings constrained patient-provider discussions about HIV prevention strategies including PrEP. These findings are in accord with previous studies which have identified social norms and stigma as significant barriers to PrEP uptake in the Deep South, also conducted predominantly among Black MSM [15, 17, 61]. These findings point to the potential usefulness of multilevel stigma reduction interventions targeting both community members and primary care staff, and centering racial and ethnic minority populations. Education, social marketing, and mass media interventions have shown effectiveness at reducing stigma at the community level [62], and could be leveraged to improve PrEP acceptability. On the health care provider level, the Finding Respect and Ending Stigma around HIV (FRESH) stigma intervention, piloted and adapted in Birmingham, Alabama, could be adapted to target the stigma surrounding PrEP and intersecting stigmas related to HIV and sexuality [63]. Previous scientific work has also identified a need for training and guidance to facilitate patient-provider discussion of PrEP for at risk populations [64]. Each of these potential intervention efforts serve to increase PrEP acceptability, and ultimately PrEP uptake, via mechanisms such as increased contact between stigmatized individuals (current or potential PrEP users) and potential enactors of stigma (ex. health care providers), by confronting misinformation regarding PrEP, challenging stereotypes about PrEP users [63], and through increased dialogue around and visibility of PrEP, as also suggested by the present study participants.

Concerning availability and accommodation, we found that the "hassle" of clinic visits and laboratory tests could limit uptake of PrEP among some, though our participants generally reported that they felt the benefits from PrEP outweighed the hassles related to PrEP uptake and use. Clinical practice guidelines for PrEP require follow up visits at least every 3 months to test for HIV, other STIs, and pregnancy (for individuals who may become pregnant); as well as to assess side effects and to provide patient assistance and support [12]. These frequent clinical visits may be particularly burdensome for clients living in rural areas of the Deep South and for those with limited transportation resources [65]. Recent innovative intervention approaches show promise in improving PrEP availability and accommodation, including home-based PrEP services, which can reduce the PrEP-related clinic visit burden from quarterly to annually [66]. For example, PrEP@home is an integrated system of participant self-collected specimens, centralized laboratory testing, and behavioral surveillance which has high user satisfaction to date [67]. Other interventions may include the integration of PrEP into pharmacies which may have more capacity to offer PrEP services during flexible hours of the day and night [68]. Additionally, as the participants in this study suggested and as noted by other HIV prevention studies, members of a patient's social circle, clinic staff and resources, social service programs and their staff, and the health care and public health systems can aid in availability and accommodation through the provision of free or reduced-cost transportation [28], by allowing for flexible timeframes in which to access PrEP-related clinical care, through diversification of the clinic and non-clinic settings in which to perform routine PrEP-related laboratory and other monitoring [69], and through other patient-centered options.

Regarding affordability, the findings of the present study corroborate those of previous studies which indicate that worries about lack of insurance coverage inhibit PrEP utilization [70], and, regardless of insurance status, the cost of PrEP can be burdensome [71]. While financial assistance

programs exist and many participants reported taking advantage of them, participants reported a general lack of awareness of financial assistance programs and lack of resources for navigating enrollment in prescription cost reduction programs. Thus, to improve affordability, it is critical to continue to offer programs designed to reduce financial burden, to raise awareness of such programs, and to offer support for enrollment in cost assistance programs, so that all individuals who require financial support can take full advantage. Interventions that involve the use of peer or other navigators to increase PrEP uptake and use should consider aiding with navigation of financial assistance services as an intervention component [72, 73]. Particularly in states that expanded Medicaid coverage through the Affordable Care Act (ACA), community health centers have been able to develop solutions to help patients address financial and related logistical barriers such as the use of systems navigators with government support [41, 74]. In states like Alabama, that did not adopt the Medicaid expansion, such health centers may face greater challenges in meeting diverse patient needs. However, a variety of privately funded initiatives, such as the Gilead COMPASS Initiative seek to provide financial resources to local organizations in such states [75].

Furthermore, our results echoed findings from other studies that perceived HIV risk impacts perceived appropriateness of PrEP as a tool for sexual health promotion [76]. Public health clinical guidelines recommend that patients consult with clinicians to determine whether to initiate or continue use of PrEP, considering an assessment of the patient's current risk of HIV acquisition [12]. However, participants reported uneasiness about seeking PrEP from providers whom they anticipated would not be knowledgeable about the method and were concerned about poor quality interactions with clinicians surrounding PrEP (particularly in non-HIV care settings). These findings contextualize prior reports of low PrEP awareness among providers nationally [77], of lack of informative discussion about PrEP between persons at risk for HIV and health care providers, and of stigmatizing attitudes that some members of the health care community hold toward PrEP users and sexual risk behavior [78]. Emerging innovative intervention approaches to improve PrEP appropriateness have been developed and piloted in other settings, but could potentially be adapted for use in the U.S Deep South. One pertinent example is provided by the PrEP Optimization Intervention, which offers health care providers a web-based tool that: aids in the comprehensive assessment of patient HIV risk; provides automated reminders to perform clinical laboratory monitoring, other check-ups, and patient counseling; and includes PrEP educational material for ongoing training [73]. The intervention also includes the integration of a PrEP coordinator into clinic flow, who serves as a liaison between health care providers, patients, and the health care system. In an intervention pilot within a safety net health care system in California, the PrEP Optimization Intervention improved PrEP provider knowledge, enhanced communication with patients, and improved patient engagement in care.

The present study results should be considered in the context of the following limitations. First, our study team performed a secondary data analysis, therefore, the data were not collected primarily to examine perceptions of access to PrEP. Nevertheless, the interview guide included questions relevant to PrEP access that were assessed systematically across interviews. Second, though we purposively recruited individuals from select sociodemographic and health groups for study participation, the individuals who agreed to participate in the interviews may have different perceptions of access to care than those who did not participate. The inclusion of potential PrEP users in this study in addition to individuals currently on PrEP was intended partly to capture diverse perspectives. However, we did not have the capacity to include a sufficient number of participants for group stratification. Specifically, we did not have even representation by race, ethnicity, gender, and sexual orientation, and we did not have sufficient resources to purposively sample for other characteristics relevant to PrEP access, such as insurance status, and sociodemographic status; thus, precluding comparison by socio-demographic characteristics.

Notwithstanding limitations, this study offers a theoretically driven qualitative investigation of perceived access to PrEP from the perspective of current and potential PrEP users in a city in the Deep South. By applying the patient-centered access to care framework [35], we take an integrative approach to understand opportunities to achieve more equitable access to PrEP in this region, informed by lived experiences. Findings reinforce the need for implementation of combination and multilevel strategies to enhance PrEP uptake and utilization in diverse contexts [79].

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Compliance with Ethical Standards

Conflict of interest Whitney S. Rice declares that she has no conflict of interest. Kristi L. Stringer declares that she has no conflict of interest. Maira Sohail declares that she has no conflict of interest. Kaylee B. Crockett declares that she has no conflict of interest. Ghislaine C. Atkins declares that she has no conflict of interest. Kachina Kudroff declares that she has no conflict of interest. D. Scott Batey declares that he has no conflict of interest. Joshua Hicks declares that he has no conflict of interest. Janet M. Turan declares that she has no conflict of interest. Michael J. Mugavero has served as a scientific advisor for Gilead Sciences, Inc. Bulent Turan declares that he has no conflict of interest.

Ethical Approval The human subjects protocol for this study was approved by the Institutional Review Boards at the University of Alabama at Birmingham and at Emory University.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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