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“I DON’T NEED PREP RIGHT NOW”: A QUALITATIVE EXPLORATION OF THE BARRIERS TO PREP CARE ENGAGEMENT THROUGH THE APPLICATION OF THE HEALTH BELIEF MODEL

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Abstract

The Health Belief Model has been useful for studying uptake of HIV prevention behaviors and has had limited application to understanding utilization of pre-exposure prophylaxis (PrEP), a biomedical strategy to reduce HIV acquisition. We recruited 90 persons undergoing HIV screening and educated them about PrEP. We followed up with 35 participants approximately 3 weeks later and quantitatively assessed PrEP uptake. No participant had initiated PrEP. We conducted in-depth interviews with 15 participants to explore situational factors impacting this decision. In this paper we provide an overview of PrEP-related engagement using qualitative data to contextualize (in)action. While participants perceived PrEP as beneficial, perceived benefits did not outweigh real- and perceived barriers, such as financial and time-related constraints. In order to promote PrEP uptake, cues to action that increase the benefits of PrEP during seasons of risk, and interventions that reduce real and perceived barriers are needed.

Keywords

HIV; pre-exposure prophylaxis; health belief model

Pre-exposure Prophylaxis (PrEP) is a bio-behavioral HIV prevention strategy that involves the use of antiretroviral medications to reduce HIV acquisition (Centers for Disease Control and Prevention, 2014). PrEP trials have demonstrated PrEP efficacy among men who have sex with men (MSM; Grant et al., 2010), heterosexual men and women (Baeten et al., 2012; Thigpen et al., 2012), and people who inject drugs (PWID; Choopanya et al., 2013). Although the U.S. Food and Drug Administration approved PrEP in 2012, adoption of PrEP in real-world clinical settings has been slow (Eaton, Driffin, Bauermeister, Smith, & Conway-Washington, 2015). There are an estimated 1.2 million Americans who might benefit from PrEP, but only 130,000 individuals have received PrEP prescriptions thus far (Mera Giler, Trevor, Bush, Rawlings, & McCallister, 2017; Smith et al., 2015).

In order to understand PrEP implementation challenges, research has been conducted to identify possible barriers and facilitators to PrEP uptake, including from the perspective of potential PrEP consumers (Auerbach, Kinsky, Brown, & Charles, 2015; Golub, Gamarel, Rendina, Surace, & Lelutiu-Weinberger, 2013; Mayer, Oldenburg, Novak, Krakower, & Mimiaga, 2014; Philbin et al., 2016; Rucinski et al., 2013). To date this research has generally focused on hypothetical barriers and facilitators to accessing PrEP care from the perspective of people who have yet to engage in PrEP care. For example, Auerbach et al. conducted focus groups with 144 women at risk for HIV and found potential barriers to PrEP uptake to include concerns about cost, side effects, and mistrust of the medical establishment (Auerbach et al., 2015). In an additional study among 31 Black MSM, a population for which rates of new HIV infections are particularly high (Centers for Disease Control and Prevention, 2017; Koblin et al., 2012), potential barriers included side effects and stigma related to taking PrEP (Philbin et al., 2016). Among 184 MSM and transgender women in New York City, potential barriers to PrEP included fears of the longterm effects of PrEP on health, and concerns that PrEP will render antiretroviral medications ineffective in the event that the individual does become infected (Golub et al., 2013).

This research has been an important first step in the roll out of community-based PrEP programs and implementation studies. However, individual behaviors around PrEP initiation and use may differ from the hypothetical preferences and intentions described in the literature. For example, participants in Arnold and colleagues' study to assess factors influencing retention in PrEP care among 30 MSM in Mississippi describe that while many participants initially perceived the high cost of PrEP as a potential barrier to use, cost barriers were overcome with industry-sponsored medication assistance programs (Arnold et al., 2017). Therefore, to better understand barriers to PrEP engagement and ways to address these barriers, studies that focus on the reasons why individuals initiate or do not initiate PrEP care after PrEP has been recommended to them by healthcare personnel are needed.

The Health Belief Model (HBM; Becker, 1974) could provide a useful framework for understanding individual factors and decisional processes that influence initial engagement in PrEP care. This model posits that a person's health behavior, in this case, engaging

in PrEP care, depends on their perception of four areas: (1) the severity of a potential illness (i.e., their perception of how bad it would be to acquire and live with HIV); (2) their susceptibility to that illness (i.e., perceived risk of acquiring HIV); (3) the benefits of taking a preventative action (i.e., benefits of PrEP uptake); and (4) perceived barriers to taking the preventative action (e.g., lack of insurance). Additionally, the HBM suggests that behavior is influenced by cues to action that move people to change their behavior (e.g., reminder postcards). Given HBM's focus on individuals' beliefs, perceptions, and concerns, HBM may help elucidate cognitive factors that impact decision making around PrEP. Other studies have found HBM useful as a guiding framework for understanding the role of PrEP and HIV-related beliefs, concerns, and perceptions of risk as it relates to prior PrEP use and PrEP use intentions (Halkitis et al., 2018; Holloway et al., 2017). The purpose of this study was to assess PrEP uptake among individuals who are educated about and received a recommendation for PrEP after completing rapid HIV screening, and to use the HBM as a framework for understanding their interest in PrEP, as well as barriers to PrEP uptake.

METHODS

PARTICIPANTS AND STUDY DESIGN

Between January and July 2017, we enrolled 255 women and men into a study designed to estimate the number of PrEP eligible persons undergoing community-based HIV counseling and testing in Philadelphia. In this larger study, participants were 18 years or older, able to read English or Spanish, and not currently taking PrEP. Those who endorsed sex with a partner of positive HIV status; sex with a partner of unknown HIV status; engagement in sex work; diagnosis of sexually transmitted infection; use of methamphetamines; or sharing of needles or drug preparation equipment all within 6 months, were educated about PrEP.

Participants who consented to be contacted for a follow-up study on PrEP engagement were called to complete a brief quantitative telephone survey. Using binary (yes/no) items we assessed engagement in critical endpoints in PrEP care including: scheduling an appointment, attending an appointment, receipt of a PrEP prescription, filling a PrEP prescription, and PrEP initiation. Phone surveys were approximately 5 minutes in duration. We contacted participants weekly for 3 weeks. After three failed contact attempts, participants were considered lost to follow-up and removed from the recruitment list.

All participants completing the telephone survey were invited to participate in a qualitative interview to explore the context of participants' decisions to access any PrEP-related health care after the larger baseline study, as well as to elucidate barriers that they had experienced. Interviews occurred in person in a private room/office at a local university or hospital. Participants were first asked to describe in depth their experiences at multiple steps in the process of accessing PrEP-related care, including deciding whether or not to seek PrEP, calling to make an appointment with a health care provider, attending a healthcare appointment, talking to a health-care provider about PrEP, obtaining a PrEP prescription, and filling the PrEP prescription. Participants were probed to describe the challenges they faced during each step. Participants were also asked to describe their perceived risk of acquiring HIV, as well as their perceptions of the benefits and harms of taking PrEP. On average, semistructured interviews lasted one hour.

ANALYSIS

We used descriptive statistics to describe the sample and PrEP engagement from baseline, the brief quantitative telephone survey, and the in-depth interviews using SAS version 9.4. In-depth interviews were transcribed verbatim and managed using Dedoose qualitative software (Dedoose Version 8.0.42, Los Angeles, CA). Transcripts were double coded and analyzed using content analysis methods (Miles, Huberman, & Saldaña, 2013). First, a priori or structured codes corresponding to the domains in the interview guides were developed. Second, three to five transcripts were read by three separate team members to develop a framework of emergent codes reflecting unanticipated themes from the interviews. Third, two research assistants independently applied the coding framework to the qualitative texts. Discrepancies in coding were discussed until an appropriate code was agreed upon. In subsequent readings of the text, we grouped codes into themes with sub-themes. In the final phase of analysis, exemplars of each theme were selected, participants' ID numbers were changed to self-selected pseudonyms, and constructs from the Health Belief Model were used as a theoretical framework for understanding barriers to PrEP uptake. All quotations are identified by participants' self-selected pseudonyms.

RESULTS

The overview of the study design is displayed in Figure 1, Study Design. Two hundred fifty-five participants completed the parent study. Of these, 35% ($n = 90/255$) were considered to have a PrEP indication and received PrEP education and information about local care providers. Most (86%; $77/90$) consented to be contacted for follow up to assess PrEP uptake. We were able to reach 45% ($n = 35/77$) of these for a brief quantitative follow-up phone survey and 43% of those who completed a telephone survey ($n = 15/35$) returned for an in-person qualitative interview.

Table 1 describes characteristics of the samples during the parent study, the follow-up telephone survey, and the in-depth qualitative interviews. Participant characteristics were similar across all three study visits. In all study waves, participants were predominately male, heterosexual, and unemployed. However, there are notable differences from the baseline interview and first follow-up compared to the qualitative sample. White participants comprised a larger proportion of the qualitative sample as did those who were younger, had greater education attainment, and income.

Of the 35 participants reached for the telephone follow-up survey, 8 (23%) had scheduled an appointment to discuss PrEP with a health care provider, and 4 (11%) had attended the appointment at the time of the in-depth interview. Two (50%) of the four participants who saw a provider received a prescription for PrEP. No participant initiated PrEP at the time of the telephone follow-up survey. We subsequently conducted 15 qualitative interviews with a subsample of those who completed the telephone survey in order to explore barriers to engagement in PrEP care. Among these 15, 3 (20%) were the participants who reported during the telephone interview to have seen a provider about PrEP and 2 (13%) were those who reported during the telephone interview to have received a PrEP prescription. No participant initiated PrEP at the time of the qualitative interview. The following five sections

represent descriptions of the major themes relating to HBM domains that occurred in the qualitative data to explain engagement in PrEP care or lack thereof.

THEME 1: PERCEPTIONS THAT HIV WAS A SERIOUS CONDITION MOTIVATED INDIVIDUALS TO ENGAGE IN PREP CARE

Of the 15 participants interviewed, 3 had seen a provider to discuss PrEP. All 3 participants perceived HIV to be highly severe, and described getting HIV as devastating. The perceived severity of HIV may have played a part in motivating these participants to seek PrEP care. For example, Aaron, a 25-year-old Black heterosexual male, described getting HIV as “devastating.” He reported, “Oh my God, I don’t know what I would do [if I got HIV]... thank God I haven’t. I just don’t want it ... For me, PrEP is an opportunity to have a safer sexual experience.” Similarly, Frank, 51-year-old White MSM male, reflected, “I’m really afraid of catchin’ any disease, especially HIV and so it makes me you know, kinda want to live that ... safe life ... And we now have this tool [PrEP] and I’m excited about it.”

Among those who did not seek PrEP care, many perceived that getting HIV would not be highly severe. For some, this may be attributed to knowing others who live with HIV and who lead long, healthy lives. This may in turn have decreased their perceived need for ways to avoid HIV infection via PrEP. For example, Martin, a 57-year-old Hispanic heterosexual male, said,

[If I was diagnosed with HIV] I would be sad, but I wouldn’t really worry too much about it these days. My sister and a lot of my friends have had it for like twenty years or more, and they are alive. They take care of themselves, they take medications ... to stop the virus. So getting HIV, I wouldn’t be really concerned or worried. I usually have protected sex. I don’t think I need the extra layer of protection of PrEP.

Similarly, Andrea, a 44-year-old heterosexual Black woman, questioned the need for PrEP, given that she perceived HIV to be less severe. She reported,

I’m not afraid of HV anymore because you are able to live with it and there are so many people that have it and are living with it. I’m glad it is not the lot of death that it used to be. So why would I need to take PrEP?

Thus, participants varied in their perception about the seriousness of HIV, with those who sought PrEP care generally describing HIV as more serious.

THEME 2: PERCEIVED SUSCEPTIBILITY TO HIV ACQUISITION IS CONTEXT-DEPENDENT AND DYNAMIC

Participants’ perceived susceptibility to HIV was context-dependent (e.g., based on relationship status and current use or nonuse of injection drugs) and evolved over time. In our sample, participants who sought PrEP care were more likely to have a sustained perceived susceptibility to HIV. For example, Shawn, a 22-year-old Asian MSM male who attended an appointment to discuss PrEP with a health care provider, describes that despite using condoms consistently, he perceived that getting HIV was small but nonetheless a real

possibility. For him, this small chance of acquiring HIV was sufficient for him to want to use PrEP. He said,

I've always used condoms with hookups ... but [HIV] has always been ... in the back of my mind. Even if you think about playing it safe the whole time, it's always just that chance of getting [HIV] Honestly, getting [HIV] is a constant worry. Because of that worry, I think I should be on PrEP.

Similarly, Patricia, a 55-year-old White heterosexual female, described her sustained elevated HIV risk:

I consistently have unprotected sex, I've had multiple partners, and I don't know what their [HIV] status is. I never ask those questions about HIV, and then we get involved, and then later I'm like, "Oh my gosh," but it is too late. So for me, I think PrEP would help.

Alternatively, many participants reported that their susceptibility to HIV had decreased since their baseline study visit, due to decreases in sex-and drug-related risk behavior. These participants attributed their non-engagement in PrEP care to their lower susceptibility to HIV. For example, Ben, a 25-year-old White MSM male, described that his HIV risk decreased when he entered a monogamous relationship: "I have a different relationship to [PrEP] now that I'm in in a relationship I've even had friends that said, 'Well, you probably don't need to worry about [getting PrEP] so much because you're seeing [name of boyfriend] now.'" Andrea, a 44-year-old heterosexual Black woman, explicitly tied her decrease in perceived HIV risk to cessation of sex work, "PrEP would be a waste on me.... As far as the necessity of having sex for money, I'm no longer in that position of need. I don't need PrEP right now," and Vincent, a 41-year-old White heterosexual male, echoed this when he stopped using heroin:

I'm clean now, but I wasn't clean [when I did the baseline survey]. That's why I was interested in calling and making an appointment [for PrEP] because I knew I was at danger for catching something. But then after getting clean, I feel like now [PrEP] wouldn't even help me ... But I think if I ever relapse, [PrEP] will come to mind.

In this sample, perceived susceptibility varied as the context of participants' lives changed. Those with sustained perceptions of HIV susceptibility noted this as a driving force in PrEP-seeking behavior and those whose perception changed were less interested in PrEP care.

THEME 3: PREP IS PERCEIVED TO BE BENEFICIAL BUT CONFUSION REMAINS OVER INTERPRETATION OF EFFICACY

Participants nearly all perceived PrEP to be highly effective and potentially useful in decreasing HIV risk. Shawn, a 22-year-old Asian MSM male, said, "If more people knew and had access to [PrEP], this can have a big impact. Both the spread and the worry of HIV will be reduced by a lot." Aaron echoed the perceived benefit of PrEP when he stated, "PrEP would be helpful for me because I wanna live Anybody that has common sense, anybody

that wants to live, will try to learn more about PrEP as much as they can. Like I said, I'm willing to do anything to live" (25-year-old Black heterosexual male).

Jack, a 22-year-old multiracial MSM male, was the only participant whose comments did not suggest a perception that PrEP would be useful in preventing HIV. This may be attributed in part to inaccurate interpretation of PrEP's efficacy measures. When assuming that PrEP was about 92% effective at reducing HIV transmission, he explained his concern that PrEP is less useful in HIV prevention than others may think: "I think a lot of people are bad at math. They think 92% [effectiveness] is really high, and they don't think about how if you [have sex] 10 times without protection with someone who has HIV, you are going to get it." Despite the perceived benefit of PrEP, the majority of participants did not seek PrEP care.

THEME 4: EXPERIENCED AND ANTICIPATED BARRIERS LIMITED PREP UPTAKE

Despite the almost unanimous agreement that PrEP is a valuable HIV prevention tool, participants described a variety of barriers that prevented them from accessing care. The most commonly described barriers were related to insurance coverage and the perception that the process of getting PrEP would be burdensome. Many of these concerns were due to misinformation. Many participants did not initiate PrEP care because they believed their insurance would not cover PrEP or because they were unable to pay a monthly co-pay. Alicia, a 49-year-old Hispanic heterosexual female, worried, "I get public service for my health [insurance]. So, if they're gonna pay for PrEP, it's not gonna be a problem. But I didn't know if I had to have private insurance so didn't make an appointment [to talk to a health care provider about PrEP]." Andrea said, "If I got to pay for PrEP right now, I'm not in a position. I can't afford to do that, so I didn't think I should get it" (44-year-old Black heterosexual female).

Two participants in this study who received a PrEP prescription described being unable to fill it due to insurance-related barriers, including the potential for inadvertent disclosure of PrEP use due to use of parental insurance. Shawn, a 22-year old Asian MSM male who received medical coverage through his parents, did not fill his prescription due to fear of his parents seeing that he was taking PrEP. He said, "I thought that I could get PrEP through Gilead ... since I didn't feel safe using [my parents' insurance] But they said that I am required to use [my parents'] health insurance, and that's what stopped me from moving forward." Frank described his own cost barriers: "To fill my prescription, [PrEP] is \$400 a month. I don't have an extra \$400 a month, and my insurance doesn't cover it" (51-year-old White MSM male).

Participants were also deterred by the perception that the process of obtaining PrEP would be burdensome. Vincent stated, "If they made PrEP really accessible, I would probably [get PrEP], but I can't see myself going out of my way to get PrEP because of my chaotic lifestyle" (41-year-old White heterosexual male). Anna, a 35-year-old Hispanic heterosexual female, was specifically concerned about having to travel far to obtain PrEP:

If I got to go all the way across town somewhere to see a doctor, and then I have to go all the way across the other side of town to get it, it would just be too much.

That don't make no sense. It is too much trouble so I didn't even want to learn more about PrEP.

Two participants described experiencing logistical challenges that limited PrEP uptake. Lisa, a 37-year-old White heterosexual female, said, "I keep calling my doctor's to make an appointment but they don't get back. I have medical coverage but they just don't get back to me." Similarly, Corey, 24-year-old White MSM male, stated,

I've spoken to two or three of my like primary care physicians and we talked about risk factors. They encouraged me to really consider [PrEP] But then I couldn't get back in for an appointment with him because of his limited appointments available and it just became a struggle to talk to my doctor.

In summary, insurance, cost, and the perceived practical challenges with obtaining PrEP represented both an anticipated and previously experienced barrier. Some participants' concerns were rooted in inaccurate understanding or misinformation about insurance coverage and financial assistance options. For many, paying any amount of co-pay would make PrEP unattainable.

THEME 5: THE SALIENCE OF PREP DECREASED OVER TIME

For many participants, the salience of PrEP faded over time (i.e., they tended to forget about PrEP after their baseline survey), and they attributed their lack of engagement in PrEP care to this lack of salience. Participants suggested that having a reminder about PrEP would have been helpful. Vincent stated,

[PrEP] just slipped my mind. Out of sight, out of mind If I had a sign on the wall, or if there was an advertisement out on the Avenue or somethin' about PrEP, a poster, billboard, then I would have seen it and be like "Oh yeah, I gotta look into that." (41-year-old White heterosexual male).

A few participants commented that follow-up interviews served as a reminder about PrEP, and potentially motivating them to make an appointment to talk to a health care provider about PrEP. Vincent commented, "You've informed me about PrEP today. Even though I forgot last time, I think this time I'm going to remember because of repetition. It might make things stick" (41-year-old White heterosexual male). Furthermore, Aaron said, "Talking to you [during this interview] made me more aware of [PrEP], and now that's one thing on my to-do list—give this health center a call and set up an appointment to talk about [PrEP]" (25-year-old Black heterosexual male).

DISCUSSION

Data from this study show that despite the overall high value of PrEP for its effectiveness at preventing HIV, engagement in PrEP care was minimal. The perceived and experienced barriers of getting PrEP, the shifting nature of perceived HIV risk, and a lack of follow-up reminders about PrEP may have contributed to low PrEP uptake. Following participants for one month after a PrEP recommendation allowed an exploration of the experienced barriers that limited PrEP uptake among a diverse sample. Using the HBM to guide the narrative

surrounding the context of participants' lives after the PrEP recommendation was useful for understanding why PrEP uptake was low.

In this sample, screening for PrEP eligibility was not sufficient to engage potential PrEP candidates into care. Real and anticipated barriers such as misinformation about insurance coverage, cost, and the perceived hassle of obtaining PrEP may have been a challenge to PrEP uptake. Thus, reducing misinformation will be integral for increasing PrEP uptake. Like other studies (Auerbach et al., 2015; Golub et al., 2013; Goparaju et al., 2017), one of the most commonly cited barriers to PrEP uptake was the anticipated and experienced concern that insurance would not cover PrEP and that participants would be unable to afford a co-pay. Thus, it is integral that potential PrEP users are provided adequate information about financial resources available to them. For example, PrEP is often fully covered by most major insurance plans (Plushcare, 2017). However, if co-pays are cost-prohibitive, Gilead, the biopharmaceutical company responsible for branding the PrEP medication Truvada, offers payment assistance through its Gilead Advancing Access program (Plushcare, 2017). Additionally, PrEP is often more affordable for individuals who qualify for Medicaid, however there are restrictions to coverage depending on the state one resides in (Plushcare, 2017). For those without insurance and have income under 500% of the poverty line for their area, Gilead offers financial support that makes PrEP free of charge through their Patient Assistance Program (Plushcare, 2017).

Given the FDA's recent expansion of PrEP indication to adolescents at risk for HIV infection (Gilead Sciences Inc., 2018), insurance as a barrier to PrEP uptake may increase among adolescents who are concerned about maintaining confidentiality about PrEP use to parents. These adolescents may not be able to utilize health insurance coverage for PrEP due to fear of inadvertent disclosure of PrEP use to parents via benefits statements sent by the insurance company. While this is an emerging focus of research, one study has examined parental insurance coverage as a potential barrier to PrEP uptake among adolescents and found that among 151 urban adolescents and young adults aged 13–25, 91% reported having health insurance, with 46% reporting being on parent's insurance policy (Moore et al., 2018). The study found that while dependence upon parental insurance was not significantly associated with willingness to take PrEP, individuals who indicated that they would not want their parents to know that they are taking PrEP had a 59% lower odds of using PrEP than those who would. This suggests that parental insurance may not be a direct barrier to PrEP use, but may be associated with concerns related to disclosure. More studies are needed to assess insurance and confidentiality concerns as potential barriers to PrEP uptake among adolescents, and to identify the resources that will be needed to best support these adolescents navigating potential funding sources for PrEP.

Participants in this study also experienced logistical barriers that limited PrEP care engagement, such as difficulties scheduling appointments with medical providers, lack of responsiveness of providers, and limited number of sites where PrEP can be accessed. One way to decrease these barriers may be through PrEP patient navigation services, which is a model of care coordination to help individuals navigate the health system. Patient navigators used in HIV care have been found to be successful in reducing barriers to linkage, decreasing patient worries and stigma, and increasing the amount of care patients

receive (Bradford, Coleman, & Cunningham, 2007). In translating HIV patient navigators to PrEP patient navigators, these providers would deliver focused counseling for high risk patients about PrEP, elucidate the process of receiving PrEP care, clarify the expenses involved in PrEP and financial resources available to them, and assist patients with setting up appointments.

Like in other samples, participants acknowledged the importance of a “season of risk,” which is the idea that risk taking behaviors are episodic (Elsesser et al., 2016). This concept has mostly been applied to the dynamic nature of sexual risktaking behaviors among MSM, and has supported the usefulness of intermittent PrEP in this population (Elsesser et al., 2016). Our study uniquely identifies how seasons of risk is also relevant among heterosexual samples including those who inject drugs. Intermittent PrEP use, based on engagement in risk, is effective for MSM (Molina et al., 2016), however the efficacy of this strategy for penile-vaginal and intravenous exposures is unknown. Thus, it is pivotal to educate heterosexuals with episodic HIV risk about PrEP so that they can use PrEP when they anticipate engaging in periods of risky behaviors. Furthermore, cues to action, such as posters about PrEP in high HIV prevalence neighborhoods and organizations that serve high risk heterosexuals (i.e., syringe exchanges, sex worker advocacy organizations) could be instrumental to remind potential PrEP users about PrEP during seasons of risk behavior. Other more personalized cues to action could include follow-up phone call reminders from health care providers or PrEP patient navigators, or text message-based programs to increase the saliency of PrEP, both of which have been used to successfully modify HIV prevention behaviors in other interventions among diverse samples (Mugo et al., 2016; Reback, Fletcher, Shoptaw, & Manswergh, 2015).

As with any exploratory study, findings should be interpreted with caution. Data are derived from a convenience sample of persons accessing rapid HIV testing in Philadelphia. It is possible that people accessing rapid HIV testing are at higher HIV risk than the general public, which limits the generalizability of our findings. Further, our retention rate is low. The telephone follow-up sample and the qualitative sample represents 45% (35/77) and 19% (15/77) of those persons considered eligible for PrEP and who consented for follow-up, respectively. Attempts were made to obtain a representative sample but retention rates were lower among participants of color, those who were older, and with lower income. While there were few demographic differences in the samples, it is important to note that selection bias may be at play with those staying in the study have more likelihood of engaging in PrEP care. While the qualitative sample represents less than 20% of persons considered to be eligible for PrEP, findings from the 15 interviews allowed for a fine-grained and in-depth inquiry into the multiple barriers to PrEP uptake, and reached a point of saturation, which is where data collection does not shed any further light on the issue under investigation.

CONCLUSIONS

Data from this study suggest that the perceived benefit of PrEP may be insufficient for PrEP uptake. The episodic nature of perceived HIV risk, as well as anticipated and experienced barriers in accessing PrEP care outweighed the benefits for many participants, and may have contributed to low PrEP care engagement in this sample. Taken together, while screening for

PrEP is pivotal, it is not sufficient to ensure PrEP uptake. In order for PrEP to be utilized among diverse at-risk populations in the real-world setting, strategies are needed to increase the relevance of PrEP among heterosexuals with episodic HIV risk, and to reduce real and perceived barriers related to cost and insurance.

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REFERENCES

- Arnold T, Brinkley-Rubinstein L, Chan PA, Perez-Brumer A, Bologna ES, Beauchamps L, ... Nunn A (2017). Social, structural, behavioral and clinical factors influencing retention in pre-exposure prophylaxis (PrEP) care in Mississippi. *PloS One*, 12, e0172354. [PubMed: 28222118]
- Auerbach JD, Kinsky S, Brown G, & Charles V (2015). Knowledge, attitudes, and likelihood of pre-exposure prophylaxis (PrEP) use among US women at risk of acquiring HIV. *AIDS Patient Care and STDs*, 29, 12–110.
- Baeten JM, Donnell D, Ndase P, Mugo NR, Campbell JD, Wangisi J, ... Partners PrEP Study Team. (2012). Antiretroviral prophylaxis for HIV prevention in heterosexual men and women. *New England Journal of Medicine*, 367, 39–410.
- Becher M (1974). The health belief model and personal health behavior. *Health Education Monographs*, 2, 324–373.
- Bradford JB, Coleman S, & Cunningham W (2007). HIV System Navigation: An emerging model to improve HIV care access. *AIDS Patient Care and STDs*, 21(Suppl 1), S49–S58. [PubMed: 17563290]
- Centers for Disease Control and Prevention. (2014). Pre-exposure prophylaxis for the prevention of HIV infection in the United States-2014: A clinical guideline. Retrieved from <https://www.cdc.gov/hiv/pdf/prepguidelines2014.pdf>
- Centers for Disease Control and Prevention. (2017). Diagnoses of HIV infection in the United States and dependent areas, 2016. *HIV Surveillance Report* 2017, 28. Retrieved from <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2016-vol-28.pdf>
- Choopanya K, Martin M, Suntharasamai P, Sangkum U, Mock PA, Leethochawalit M, ... Tenofovir Study Group. (2013). Antiretroviral prophylaxis for HIV infection in injecting drug users in Bangkok, Thailand (the Bangkok Tenofovir Study): A randomised, double-blind, placebo-controlled phase 3 trial. *The Lancet*, 381, 2083–2090.
- Dedoose. (2015). 8.0.42., web application for managing, analyzing, and presenting qualitative and mixed method research data. Los Angeles, CA: SocioCultural Research Consultants.
- Eaton LA, Driffin DD, Bauermeister J, Smith H, & Conway-Washington C (2015). Minimal awareness and stalled uptake of pre-exposure prophylaxis (PrEP) among at risk, HIV-negative, black men who have sex with men. *AIDS Patient Care and STDs*, 29, 423–429. [PubMed: 26083143]
- Elsesser SA, Oldenburg CE, Biello KB, Mimiaga MJ, Safren SA, Egan JE ... Mayer KH (2016). Seasons of risk: Anticipated behavior on vacation and interest in episodic antiretroviral pre-exposure prophylaxis (PrEP) among a large national sample of US men who have sex with Men (MSM). *AIDS and Behavior*, 20, 1400–1407. [PubMed: 26538056]
- Gilead Sciences Inc. (2018). U.S. Food and Drug Administration approves expanded indication for Truvada® (Emtricitabine and Tenofovir Disoproxil Fumarate) for reducing the risk of acquiring HIV-1 in adolescents [Press release]. Retrieved from <https://www.gilead.com/news/press-releases/2018/5/us-food-and-drug-administration-approves-expanded-indication-for-truvada-emtricitabine-and-tenofovir-disoproxil-fumarate-for-reducing-the-risk-of-acquiring-hiv-1-in-adolescents>.

- Golub SA, Gamarel KE, Rendina HJ, Surace A, & Lelutiu-Weinberger CL (2013). From efficacy to effectiveness: Facilitators and barriers to PrEP acceptability and motivations for adherence among MSM and transgender women in New York City. *AIDS Patient Care and STDs*, 27, 248–254. [PubMed: 23565928]
- Goparaju L, Praschan NC, Warren-Jeanpiere L, Experton LS, Young MA, & Kassaye S (2017). Stigma, partners, providers and costs: Potential barriers to PrEP uptake among US women. *Journal of AIDS & Clinical Research*, 8, 730. [PubMed: 29201531]
- Grant RM, Lama JR, Anderson PL, McMahan V, Liu AY, Vargas L, ... iPrEx Study Team. (2010). Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. *New England Journal of Medicine*, 363, 2587–2599.
- Halkitis PN, Jaiswal J, Griffin-Tomas M, Krause KD, D'Avanzo P, & Kapadia F (2018). Beliefs about the end of AIDS, concerns about PrEP functionality, and perceptions of HIV risk as drivers of PrEP use in urban sexual minority men: The P18 Cohort Study. *AIDS and Behavior*. Advanced online publication. 10.1007/s10461-018-2218-y
- Holloway IW, Tan D, Gildner JL, Beougher SC, Pulsipher C, Montoya JA, ... Leibowitz A (2017). Facilitators and barriers to pre-exposure prophylaxis willingness among young men who have sex with men who use geosocial networking applications in California. *AIDS Patient Care and STDs*, 31, 517–527. [PubMed: 29211513]
- Koblin B, Mayer K, Eshleman S, Wang L, Shoptaw S, del Rio C, et al. (2012). Correlates of HIV incidence among black men who have sex with men in 6 US cities. *Journal of the International AIDS Society*, 15, 94–95.
- Mayer KH, Oldenburg C, Novak DS, Krakower D, & Mimiaga MJ (2014). Differences in PrEP knowledge and use in US MSM users of a popular sexual networking site surveyed in August 2013 and January 2014. *AIDS Research and Human Retroviruses*, 30, A91–A92.
- Mera Giler R, Trevor H, Bush S, Rawlings K, & McCallister S (2017, 7). Changes in truvada (TVD) for HIV pre-exposure prophylaxis (PrEP) utilization in the United States: (2012–2016). Paper presented at the 9th International AIDS Society Conference on HIV Science, July 23–26, Paris, France.
- Miles MB, Huberman AM, & Saldaña J (2013). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Thousand Oaks, CA: Sage
- Molina J, Charreau I, Spire B, Cotte L, Chas J, Capitani C, ... Pasquet A (2016). Efficacy of on-demand PrEP with TDF-FTC in the ANRS IPERGAY open-label extension study. *Journal of the International AIDS Society*, 19.
- Moore K, Dell S, Oliva M, Morgan A, Rothman R, Hsieh Y, & Arrington-Sanders R (2018). Does parental insurance impact willingness to take prep in adolescents & young adults? *Journal of Adolescent Health*, 62(Suppl 2), S23–S24. 10.1016/j.adohealth.2017.11.047
- Mugo PM, Wahome EW, Gichuru EN, Mwashigadi GM, Thiong'o AN, Prins HA, ... Sanders EJ (2016). Effect of text message, phone call, and in-person appointment reminders on uptake of repeat HIV testing among outpatients screened for acute HIV infection in Kenya: A randomized controlled trial. *PloS One*, 11,e0153612. [PubMed: 27077745]
- Philbin MM, Parker CM, Parker RG, Wilson PA, Garcia J, & Hirsch JS (2016). The promise of pre-exposure prophylaxis for Black men who have sex with men: An ecological approach to attitudes, beliefs, and barriers. *AIDS Patient Care and STDs*, 30, 282–290. [PubMed: 27220036]
- Plushcare. (2017). Getting PrEP with or without insurance. Retrieved from <https://www.plushcare.com/blog/getting-prep-without-insurance-or-uninsured/>
- Reback CJ, Fletcher JB, Shoptaw S, & Mansergh G (2015). Exposure to theory-driven text messages is associated with HIV risk reduction among methamphetamine-using men who have sex with men. *AIDS and Behavior*, 19, 130–141. [PubMed: 25563501]
- Rucinski KB, Mensah NP, Sepkowitz KA, Cutler BH, Sweeney MM, & Myers JE (2013). Knowledge and use of pre-exposure prophylaxis among an online sample of young men who have sex with men in New York City. *AIDS and Behavior*, 17, 2180–2184. [PubMed: 23479003]
- Smith DK, Van Handel M, Wolitski RJ, Stryker JE, Hall HI, ... Valleroy LA (2015). Vital signs: Estimated percentages and numbers of adults with indications for preexposure prophylaxis to

prevent HIV acquisition—United States, 2015. Morbidity and Mortality Weekly Report, 64, 1291–1295. [PubMed: 26606148]

Thigpen MC, Kebaabetswe PM, Paxton LA, Smith DK, Rose CE, Segolodi TM, ... TDF2 Study Group. (2012). Antiretroviral preexposure prophylaxis for heterosexual HIV transmission in Botswana. New England Journal of Medicine, 367, 423–434.

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FIGURE 1.
Study design.

TABLE 1.

Socio-demographic Characteristics Among Baseline Sample, Follow-Up Quantitative Survey, and Qualitative Interview, Philadelphia

	Sample Characteristics	Quantitative Baseline (N = 255)	PrEP-eligible (n = 90)	Follow-up Quantitative Survey (n = 35)	Qualitative Interview (n = 15)
Age	Median (interquartile range)	41.0 (31.0–51.0)	38.0 (29.0–47.0)	39.0 (29.0–50.0)	33.0 (25.0–44.0)
Sex at Birth					
	Male	178 (69.8%)	71 (78.9%)	20 (57.1%)	9 (60.0%)
	Female	77 (30.2%)	19 (21%)	15 (42.9%)	6 (40.0%)
Self-Identified Sexual Orientation					
	Homosexual	27 (10.6%)	16 (17.8%)	12 (34.3%)	6 (40.0%)
	Heterosexual	202 (79.2%)	62 (68.9%)	23 (65.7%)	9 (60.0%)
	Bisexual	15 (5.9%)	7 (7.8%)	—	—
	Other	11 (4.3%)	5 (5.6%)	—	—
Race					
	White	43 (16.9%)	28 (31.1%)	10 (28.6%)	6 (40.0%)
	Black or African American	130 (51.0%)	37 (41.1%)	18 (51.4%)	4 (26.7%)
	Hispanic or Latino	67 (26.3%)	20 (22.2%)	5 (14.3%)	3 (20.0%)
	Other	15 (5.9%)	5 (5.6%)	2 (5.7%)	2 (13.3%)
Country of Birth					
	U.S. born	202 (79.2%)	69 (76.7%)	29 (82.9%)	11 (73.3%)
	Non-U.S. born	53 (20.8%)	21 (23.3%)	6 (17.1%)	4 (26.7%)
Primary Language					
	English	164 (64.3%)	58 (64.4%)	27 (77.1%)	10 (66.7%)
	Spanish	73 (28.6%)	27 (30.0%)	7 (20.0%)	4 (26.7%)
	Other	18 (7.1%)	5 (5.6%)	1 (2.9%)	1 (6.7%)
Employment Status					
	Unemployed	192 (75.3%)	69 (76.7%)	25 (71.4%)	11 (73.3%)
Education Attainment					
	Less than 12th grade	101 (39.6%)	33 (36.7%)	7 (20.0%)	1 (6.7%)
	12th grade	80 (31.4%)	23 (25.6%)	6 (17.1%)	3 (20.0%)
	College or beyond	74 (29.0%)	34 (37.8%)	22 (62.9%)	11 (73.3%)
Annual Income					
	< \$10,000	167 (65.5%)	58 (64.4%)	18 (51.4%)	6 (40.0%)
	\$10,001	88 (34.5%)	32 (35.4%)	17 (48.6%)	9 (60.0%)
Duration of Health Insurance					
	Never insured	28 (11.0%)	13 (14.4%)	3 (8.6%)	1 (6.7%)
	Sometimes insured	102 (40.0%)	34 (37.8%)	13 (37.1%)	10 (66.7%)
	Always insured	125 (49.0%)	43 (47.8%)	19 (54.3%)	4 (26.7%)