ORIGINAL ARTICLE

"Who? What? Is that a test?" African Americans in non-metropolitan Midwest U.S. identify knowledge gaps and opportunities for PrEP for HIV prevention

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A substantive gap exists in understanding the knowledge and perception of Pre-exposure prophylaxis (PrEP) among African Americans overall and especially those in non-urban areas. Thus, this analysis explores these issues among heterosexual African Americans, who face high risks for acquiring HIV, in a non-metropolitan setting in the U.S. Midwest, to inform health care practitioners about increasing awareness and availability of PrEP. We used a qualitative design to explore awareness of and perspectives about PrEP in depth. After listening to a description of PrEP, participants reactions could be summarized in four themes: amazement, suspicion, disapproval, and in need of information. Three of our themes weaved together around African American's mistrust of the medical system. Recent prevention suggestions to highlight PrEP's importance for a range of people versus a strategy for particular groups only may lead to improved PrEP access if we know how to reach diverse and varied groups of people.

Keywords: PrEP, HIV prevention, Midwest, non-metropolitan

INTRODUCTION

Pre-exposure prophylaxis (PrEP) is an effective and approved HIV prevention tool (CDC, 2019; FDA, 2012) that remains unknown and inaccessible to too many at-risk Americans (Auerbach et al., 2015; Calabrese et al., 2017). Compared to studies of other HIV prevention methods such as contraception usage, research about PrEP focuses predominantly on select populations (Auerbach et al., 2015; Bien et al., 2017; Calabrese et al., 2016) because, by its nature, PrEP is for individuals who are deemed, by a health care provider, at high risk of contracting HIV. For instance, most existing PrEP research addresses the experiences of men who have sex with men (MSM) (Cohen et al., 2015; Hood et al., 2016; Hoots et al., 2016; Okafor et al., 2017). While MSM are a high risk group for HIV, PrEP can prevent HIV among anyone at risk for the virus (CDC, 2017b). For example, other sub-groups at high risk for HIV include heterosexual racial/ethnic minorities, youth, and drug users (CDC, 2020b). Recent recommendations to increase PrEP uptake stress the importance of framing PrEP for

overall wellness, and as appropriate for everyone who identifies as at risk for HIV (Rivet Amico & Bekker, 2019). Understanding how to promote PrEP among a broader range of at-risk populations is necessary to meet the National HIV Strategy goals to reduce the number of new U.S. HIV diagnoses by 25% (Office of National AIDS Policy, 2015).

HIV prevalence in non-metropolitan areas is growing too (Pellowski, 2013; Rural Health Information Hub, 2019), particularly in the Midwest and South (CDC, 2018). The escalating opioid epidemic, which has sparked HIV epidemics in non-urban areas, also calls attention to the need to understand HIV in non-metropolitan environments (Evans et al., 2018). Higher rates of HIV stigma and heterosexism, and lower opportunities for HIV testing or care in non-urban areas, further reiterate the importance of understanding the relationship between prevention and geographic location (Pellowski, 2013; Rural Health Information Hub, 2019).

Significant geographic disparities in the use of PrEP exist across the U.S. A study of family planning doctors found that providers in the Midwest, for example, had among the lowest knowledge of PrEP when compared with providers in other areas of the U.S. (Jones et al., 2021; Weiss et al., 2018). The Northeast had approximately twice the rate of PrEP use (47.4 PrEP users per 100,000 population) compared to the West (28.1/100,000 population), the South (22.6/100,000 population), and the Midwest in 2016 (23.5/100,000 population) (The Rollins School of Public Health, 2019).

As with most key livelihood outcomes in the U.S., racial disparities in HIV prevalence are stark. Nearly 40,000 new diagnoses of HIV were made in the U.S. in 2017; almost half of these (43%) were among African Americans, who comprise less than 15% of the U.S. population (CDC, 2017a). Studies of PrEP among non-MSM African Americans focus predominantly on participants recruited from city clinics (Flash et al., 2014; Kwakwa et al., 2016; Raifman et al., 2019). Yet, HIV racial/ethnic disparities are usually more pronounced in non-metropolitan areas (Rural Health Information Hub, 2019). While non-metropolitan settings are not necessarily all rural, CDC data from 2018 indicate that the Midwest has the second highest percentage of rural HIV diagnoses (7%), only next to the South (9%) and considerably higher than the Northeast (2%) and West (3%). In Missouri, where our study took place, there is indeed a disproportionate relationship between racial composition and new HIV diagnoses: Black/African American individuals have about a ten-fold higher HIV incidence, in any given year, between 2008 and 2019 (CDC, 2021). Missouri is not an outlier nationally; surveillance data from the CDC in 2018 (CDC, 2020a) indicate that Missouri was 26th out of 51 in new HIV infections (States and the District of Columbia) but data from the American Community Survey show that Missouri was 21st in the percentage of Black/African American residents (American Community Survey, 2021).

This paper explores knowledge and perceptions of PrEP, among heterosexual African Americans, in a non-metropolitan setting in the U.S. Midwest, through semi-structured interviews and thematic analysis. Our analytic method allows us to most effectively bridge the substantive gap that exists in understanding the knowledge and perception of PrEP among African Americans overall and especially those in non-urban areas (Ojikutu et al., 2018); by definition, this study adds to our knowledge of PrEP use among an understudied but at-risk population. Understanding the perspectives of diverse groups of African Americans such as those in non-metropolitan

areas, is important to fully using this effective and technically simple prevention tool.

MATERIALS AND METHODS

Study Design

A *Community-Based Participatory Research* (CBPR) approach was used to carry out this research study. CBPR methods actively engage community stakeholders to collaborate in the research process, from study design to dissemination (Minkler, 2005). Researchers worked closely with a staff member at Spectrum Health Care (fifth author), the leading organization in Central Missouri that provides HIV prevention programming, to set eligibility criteria, recruit participants, create the study interview, and disseminate the research findings. A qualitative design was employed to explore awareness of and perspectives about PrEP among people at risk for HIV, in a way that quantitative methods could not. All study activities were approved by the primary and second authors' (SA) university institutional review board prior to engagement.

Participants

Participants were recruited through flyers posted in public spaces, such as the public library, community centers, grocery stores, bus stops, and through word of mouth. Interested participants called the study team after receiving a flyer to review study consent and plan an interview. The study recruited English-speaking, African Americans, aged 35 years and older, who resided in the center of the state where the study took place. This demographic group was targeted for recruitment as they were identified by the researchers as a hard-to-reach population for HIV prevention efforts in this non-metropolitan area, in addition to being deemed at high-risk for HIV infection, nationally, by the CDC (2020a).

Procedures

Semi-structured, one-on-one, interviews with 25 participants were conducted by the second author (SA) who is a White female with 15 years of experience in HIV prevention programming and research. Although she had experience collaborating with the study site, participants did not know her before the interview. An interview guide was used to lead the question-asking process and was informed by prior research, the expertise of the research team, and input from Spectrum Health Care. Example questions included "What have you heard about PrEP?" "Tell me about your interest, or not in PrEP." "What are the pros and cons of PrEP?" Interviews lasted approximately 45-60 minutes and were conducted in-person and over the phone (at the preference of the participant) for several months during 2018-19. Interviews were audio-recorded and transcribed verbatim by a professional transcription company. Participants received a $20 gift card for participating in the study.

Analysis

The data were analyzed using strategies of theme analysis—the ideal appropriate approach to understand participants' perspectives towards PrEP. All interview transcripts were reviewed by the first author (FA) and SA, with particular focus on the questions addressing PrEP, to become familiar with the data. Next, key patterns/themes were identified in the responses that captured participants' opinions about the positive and negative aspects of PrEP. a codebook was created by the FA that defined each theme and code definitions were reviewed and revised with the SA. The codebook was then used by the FA to code the data and match text to themes. After coding, a matrix report was created that listed each theme and corresponding quotes. The report was used by the FA and SA to generate the results. The results were

subsequently reviewed by the fifth author, who works at the study site and is on the study team, to ensure that they resonated with the participants' ideas as he understood them.

RESULTS

All participants identified as African American and heterosexual (N=27). Over half of participants were women (n=15). On average, participants were 50 years old (range 37-64). Nearly 70% of participants reported earning less than $20,000 a year. Most participants had been tested for HIV (20/27) and the majority said they had not heard of PrEP (25/27). Table 1 provides more information about participants who are quoted in the results [Table 1 near here]. The most common response to the question "Have you ever heard of the medication called PrEP, P-R-E-P?" was some form of "Never heard of it" (voiced by over 75% of participants). Some respondents were so confused that they had to have the interviewer repeat the question or the spelling, or asked questions like, "Who is that?" or "Is that a test?" After listening to a description of PrEP ("It stand for Pre-Exposure Prophylaxis, and it's the use of anti-HIV medications to keep HIV negative people from becoming infected"), participants reactions could be summarized in four themes: amazement, suspicion, disapproval, and in need of information.

Amazement

Numerous respondents' first words after hearing a description of PrEP (e.g., P1, P26, P25, P8, and others) were "wow" or "that's amazing." Many participants like P7, P8, P27, P17, P11, and others, also said PrEP was "a good thing" or "helpful." These respondents implied they may seek more information for themselves or others. For instance, P1 said:

> Wow. That's something…Now that you have told me about it, I'm definitely going to look into it, because these are the types of things that I like to spread the word on…I know a lot of younger people that listen to me and trust me.

Similarly, P3 said:

> That [info about PrEP] was informative - information that I could pass along. I work as a marketing director for a not-for-profit, and we have a van that does HIV testing at our school fair. That's information that I can pass on to other board members, so that's cool.

P25 was pleasantly surprised about PrEP. He thanked the interviewer for "bringing him up" on PrEP and ended their conversation indicating he was going to look it up on the internet. P5 circled back to it at the end of the conversation and asked more questions about how to access PrEP. P11 said, "I didn't know nothing about this. Good thing I talked to you." He also said the conversation was "enough" to get him interested in PrEP.

Suspicion

Another key theme expressed by participants was suspicion of PrEP, which resulted in part from the fact that they did not know about such a "game-changing" drug. Participants' suspicions centered on distrust of the medical system due to racism or propensity to withhold information, or a general distrust of pills. P9 said he "wasn't a drug taker," mostly because he worried about long-term side effects. Other interviewees, like P14 and P5 agreed. P14 cited concerns about side effects and P5 said, "I just think that popping a pill, taking medicine, I only take what I have to take. It's scary on that part." P7 said he was cautious because he observed people being hurt by pills that they took. Some respondents doubted it really worked and P2 compared it to "experimental" drugs at the beginning of

the AIDS crisis. P5 compared PrEP to the flu and said he worried that he may be being injected with "full blown AIDS."

> I don't know how you take this medicine, but is [it] the HIV virus that you're putting in? Are you giving me something that my body can fight off? [Or] if my immune system is not the same…If some people's [immune system] might not be strong, then it might just give them AIDS.

Similarly, P3 said people were still in a "Tuskegee mindset."

> I probably would be leery of somethin' like that, because, like so many things in the past that affect the African-American and Latina communities, where there has been medicine that [was supposed to help but] actually exposed people to somethin'. I think that a lot of people in the community would be kinda stand-offish or something like that…If I don't have it, then why are you givin' me somethin' to prevent it? I think that there was somethin' years ago about syphilis, that exposed a lot of African-Americans, the Tuskegee thing, or whatever. I think a lot of people are still in that mindset.

P6 said that if health clinics would tell people about the drug, they would take it. He also told the interviewer of a location she could go to recruit more interview participants and added that if you tell them about [that drug], that they would do the study. He said, in surprise, "I have never heard of that drug." He also said, though, that he believed there was a cure for AIDS. Citing celebrities like Charlie Sheen and Magic Johnson, he said, "If you got money, then, yeah, there's a cure. Money cures anything. People that don't have money, they'll be the ones walking around looking like a skeleton and sick."

Disapproval

A minority of participants (n=5) did not approve of PrEP but it was a theme that could be key for health awareness initiatives. These people worried that PrEP could encourage risk behaviors. When repeating what they heard from the interviewer about PrEP, several responded concluded this was for people who took risks – "prostitutes," or people who used high amounts of drugs and alcohol. Instead of using PrEP, P27 said he thought people should "Don't share needles…Don't do it…No sex, none—eliminate all those risk factors." Similarly, P13 said that "if you know what can pre-stop something" [like condoms], that people should just do that." He said condoms were a more known factor than PrEP. He thought PrEP could make people more careless.

More information

In general, the study participants knew very little about PrEP and expressed need for more information centered on cost and access: many assumed that it would be expensive and difficult to access; a few people asked who would be eligible to get it; and others wondered who would prescribe PrEP, which often was a result of not knowing anything about the medication. Specific questions about how PrEP works were also common. P5 asked if PrEP would help prevent HIV transmitted by sexual and injection drug use transmission, or just one of these. He said, "It might work for a certain group of people that are doing certain things, but it might not work for the other group of people that are doing something different." In a similar vein, one woman asked if PrEP would help women who had other women as sexual partners.

DISCUSSION

PrEP is an integral part of future HIV prevention plans in the U.S (Office of National AIDS Policy, 2015); one pill per

day can prevent HIV from spreading. However, despite the existence and availability of this preventative technique since 2012, new overall cases of HIV in Missouri, and the Midwest more generally, remained largely stable from 2010-2016 (CDC, 2021). In this study of heterosexual African Americans, whom the CDC defines as at risk for HIV, we found that most participants did not know about PrEP and had both positive (e.g., amazement), negative (e.g., suspicious, disapproval), and more neutral (need more information) perceptions towards the medication.

Very little existing PrEP research focuses on African American women or heterosexual men, despite their risk for HIV. Additionally, few studies on PrEP have documented the needs of non-urban samples (Whiteside et al., 2011). This important because of the disproportionately high risk of acquiring HIV among African Americans compared to White Americans and unequal access to health care in rural or non-metropolitan areas of the Midwest where HIV incidence is high; thus, among African Americans living in non-metropolitan areas of the Midwest—as is the case among our Missouri participants—the risk of acquiring HIV is substantial and knowledge of PrEP and screening for HIV needs to be improved. The study findings add new information to our knowledge of PrEP and how to use this method for HIV prevention success.

One of the study's key themes, disapproval of PrEP based on the fear that it may encourage risk behaviors or stand in for safer behaviors (e.g., condom use), has been found in other studies (mostly geared towards MSM) and noted in the popular press (Calabrese & Underhill, 2015; Hogben & Liddon, 2008; Myers, 2012). The study findings confirm that these fears and misperceptions exist among heterosexual African Americans. Additional public health work is essential to reframe PrEP as safe, so that these misperceptions do not shape the judgment of medical providers, policymakers, insurers, and potential PrEP users (Calabrese & Underhill, 2015). Misperceptions may be more common in areas like the non-metropolitan Midwest where use of and exposure to PrEP is lower than other geographic areas.

Studies among other groups of African Americans (e.g., MSM, women in urban settings) commonly cite denial of risk as a reason for lack of knowledge and support for PrEP (Khawcharoenporn et al., 2012; Kwakwa et al., 2016; Ojikutu et al., 2018). Participants in this study did not discuss low risk as a reason for low PrEP acceptance or planned use. Moreover, they expressed wanting to know more about the medication so that they could access the medication and share the information with others. Participants were frequently amazed by PrEP, which again, may relate to living in a place with less PrEP access and visibility overall. Such amazement may be able to be channeled to develop excitement about and willingness to use PrEP.

Three of the study themes (e.g., amazement, suspicion, more information) weaved together around issues of African American's mistrust of the medical system. Participants were awed by PrEP and shocked that they had not previously heard about the medication—so shocked in fact, that they were suspicious that it actually worked or was there to support them, versus hurt them. As a result, they needed more information. HIV conspiracy beliefs have been associated with a higher likelihood of reporting unprotected sex (Bogart et al., 2011) and poor HIV medication adherence (Bogart et al., 2010; Gillman et al., 2013) among African Americans at risk for and living with HIV. Only a few studies have explored or found an association between the lack of willingness to use PrEP and belief in conspiracy theories about HIV (Brooks et al., 2018; Ojikutu et al.,

2018) or distrust of the medical system (Auerbach et al., 2015). These studies were carried out in urban areas. The findings from this study highlight the importance of this perception, however, and raise the idea that it may be even more important to address in non-metropolitan areas. Such areas have higher rates of discrimination and less access to care, which may exacerbate trust issues between patients and providers (Pellowski, 2013).

This study was subject to several limitations. The methods intended to explore the in-depth experiences of African Americans in non-metropolitan areas, which resulted in a non-representive, albeit heterogenous, sample. Findings may not reflect the opinions or experiences of other groups. The age range of study participants was 37-57 years, and their views could differ greatly from those of youth. Given the lack of knowledge about PrEP, it was hard for people to talk in-depth about their perceptions, as well.

These limits notwithstanding, the study findings suggest more research and interventions are needed to support HIV prevention using PrEP and translate such efforts into reduction in HIV incidence across the U.S. Recent prevention suggestions to highlight PrEP's importance for a range of people versus a strategy for particular groups only may lead to improved PrEP access if we know how to reach diverse and varied groups of people (Calabrese et al., 2016). Community-based research on PrEP, of which very little exists, may be helpful to accomplish these goals. This research could help practitioners and researchers better understand the community response to this prevention strategy. Of course, PrEP is only helpful if used by those who need it. Bridges between medical advances and community uptake of these advances, especially among African Americans, are crucial to the success of biomedical methods (Eaton et al., 2015).

African Americans in non-metropolitan communities want more information on PrEP, which could be actionable through low-cost health information advertising. Infographics in medical settings, with clear and easy to understand basic information, will help. A campaign with a simple message, such as "Worried about getting HIV? Ask your doctor about PrEP", placed in clinical settings would be a cost-effective starting point. Since the emergence of PrEP has changed how health departments and clinics talk about HIV prevention and offer prevention services (Weiss et al., 2018), providers may also need education and support to offer and prescribe PrEP; with such education, bringing up PrEP in conversation with potentially at risk patients could serve as a valuable entry-point to promoting this preventative technique.

Many participants expressed wanting to tell others about PrEP and suggested that they knew others who would benefit from PrEP. African Americans, in non-metropolitan areas, may be better able to reach their families and communities than public health or medical providers, particularly given the close nature of small towns and communities. A popular opinion model, where leaders in their community encourage others to engage in safe health behaviors, may work well in non-urban settings to spread information about PrEP (Valente & Pumpuang, 2007); health-oriented non-profit organizations could be effective at facilitating this model.

Lastly, a history of mistreatment, discrimination, and distrust affect African American's current engagement with the medical system. Providers need to be aware of these perceptions and experiences and how they may affect the intake of medical advice; providers openly acknowledging to patients that the medical community has been the cause of past injustices towards African

Americans—such as the Tuskegee Syphilis experiments—and recognizing African Americans' systemic unequal access to medical care in America, could help build trust in PrEP. Thus, when learning about how to prescribe PrEP, providers need awareness and training around addressing PrEP-related fears and conspiracy beliefs. Providers need to be ready to answer basic questions about PrEP and to take patient's suspicions seriously. An open dialogue about how PrEP works, a patient's anger, or confusion about a lack of awareness about PrEP, and discussion around conspiracy theories (e.g., PrEP has been hidden from me) may ultimately support PrEP use. Finally, identifying local African American leaders and collaborating with them in order to build patient—or even general community trust—in PrEP, would be a worthwhile effort for providers.

Notes

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