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ORIGINAL PAPER

"Just the Stigma Associated with PrEP Makes You Feel Like It's HIV Itself": Exploring PrEP Stigma, Skepticism, and Medical Mistrust Among Black Cisgender Women in Urban and Rural Counties in the U.S. Deep South

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Abstract

Despite its effectiveness in HIV prevention, PrEP use among Black women is suboptimal. Notably in the Deep South, Black women have the lowest PrEP uptake rates among all US regions. To increase PrEP engagement, research suggests the implementation of structural and social interventions particular to the needs of Black women. The state of Alabama is of priority to federal HIV prevention initiatives; therefore, this study conducted focus groups among 47 cis-gender Black women in rural and urban Alabama counties, with the highest statewide HIV incidence rates, to understand perceptions of PrEP and decision-making processes. Deductive coding analysis was conducted and themes were finalized based on consensus among the two coders. Four themes were identified. Findings show stigma undergirds Alabaman Black women's decisions to engage in PrEP care. Moreover, women reported stigma stifled community-level education about PrEP. Despite these experiences, education was regarded as a strategy to decrease stigma and PrEP skepticism, the latter of which emerged as a prominent theme. Medical mistrust and healthcare engagement were the other emergent themes influencing participation in PrEP care. To ensure PrEP efforts meet the needs of Black cisgender women in Alabama counties, interventions must address longstanding stigma, increase educational initiatives, and ensure interventions consider women's experiences with medical mistrust and health care engagement.

Keywords Preexposure prophylaxis (PrEP) · Black women · Medical mistrust · Stigma · Deep South

Introduction

Black women represent 67% of all women newly diagnosed with HIV in the Southern United States (CDC, 2019). Due to disparate and persistent high HIV incidence rates in rural and urban areas, Alabama is among the 7 states prioritized by the federal initiative *Ending the Epidemic* (EHE) (Fauci et al., 2019). Black women in urban and rural counties of Alabama have the highest HIV incidence rates compared to other women and are 8 times more likely to acquire HIV than White women (Alabama Department of Public Health, 2019). Despite these disparities, engagement in preexposure prophylaxis (PrEP) care for HIV prevention among Southern Black women is suboptimal. The Deep South has the lowest rates of PrEP uptake compared to other US regions (Siegler et al., 2018). Moreover, Black women in the Deep South continue to be underserved by the implementation of PrEP

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(Chandler et al., 2022; Elopre et al., 2017; Patel et al., 2019). As such, there is a need for an in-depth understanding of social and cultural perceptions of PrEP engagement among Black women in the Deep South.

Black women in the Deep South particularly in rural counties face disproportionate social and structural barriers to HIV prevention services compared to those in other regions, with stigma, medical distrust, and perception of risk being important factors in HIV care engagement (Aholou et al., 2016; Ahrens et al., 2021; Brown & Van Hook, 2006; Gant & Gant, 2008; Hill et al., 2022; Reif et al., 2017; Willie et al., 2021, 2022). A growing body of literature indicates that PrEP uptake among Black women in the Deep South include limited awareness of PrEP, concerns about the cost of PrEP as well as side effects, and the need for tailored marketing for Black women in the Deep South (Willie et al., 2022). Furthermore, engagement in PrEP occurs in a larger ecosystem of social norms, cultures, and beliefs, signaling a need to enhance our understanding of Black women's perceptions of PrEP through an exploration of their lived experiences. The current study extends this work with a focus on stigma, PrEP skepticism, and medical mistrust among Black cisgender women residing in rural and urban areas of Alabama, an *EHE* priority state, and identifies social and structural factors that influence their decision and ability to engage in PrEP care.

Method

Participants and Procedure

The community-based organization Five Horizons Montgomery, formerly Medical Advocacy and Outreach (MAO), located in Montgomery, collaborated with the University of Alabama research team on study design, procedures, recruitment materials, and interview guide piloting of this qualitative study. MAO has expertise in providing HIV care and prevention services to rural counties throughout Alabama. In partnership with MAO, we recruited Black cis-gender women from two urban counties (Montgomery and Jefferson, which include the cities Montgomery and Birmingham, respectively) and four rural counties located in the Black Belt (Wilcox, Dallas, Macon, and Lowndes), a region in South Alabama so named because of the rich soil in the region tied to agricultural roots. Rurality was determined based on Rural–Urban Community Area codes, which are utilized by the Alabama Department of Public Health to define rural counties. The counties selected had the highest HIV incidence for the state, with case rates ranging from 20.4 to 36.2 per 100,000 population, and are among its most impoverished as well (Crear, 2019).

Self-reported participant inclusion criteria were: (1) HIV-negative status, (2) self-identified as a cisgender Black/African American woman, (3) English speaking, (4) age 18–65 years, and (5) living within a designated prioritized AL county. Participants were recruited through social media ads, flyers placed at sexual health clinics, and a snowball sampling strategy in rural counties that encouraged direct referrals from Black cis-gender opinion leaders as well as from MAO providers and staff. The principal investigator and study team consulted with key community leaders from each county to inform the study design and it was decided to conduct focus groups. According to Krueger and Casey (2014), focus groups are known to create a comfortable environment for participants, helping to alleviate their anxiety during discussions. This allows participants to establish a sense of familiarity with the setting and form connections with other group members. The focus group interview guide was prepared by the principal investigator in collaboration with community partners from various counties. There were 6 focus groups conducted, one in each county. The focus groups were moderated by an experienced qualitative interviewer who was a Black woman. The moderator conducted 60–90 min focus group sessions in a private room. The moderator ensured the focus groups established group agreements, encouraged truthfulness and a non-judgmental space, emphasized the importance of confidentiality among participants, and assured the participants that their identities would not be revealed as outlined in the informed consent forms. The interviews were conducted from May to December 2018. All focus group participants completed a brief, self-reported sociodemographic survey after the interview and received a gift card as an incentive.

Measures

The focus group guide was grounded in the constructs of Anderson and Newman's (2005) Behavioral Healthcare Utilization Model, including predisposing characteristics (e.g., demographics, social structure, and health beliefs), enabling resources (e.g., community and personal resources, insurance, social support), needs (e.g., perceived need to take PrEP), and health behaviors (e.g., personal health practices, use of health services). In addition, the focus group guide included questions that explored the participants' preferences in the delivery of PrEP services (e.g., location, type of PrEP provider, and visit frequency). See the Appendix for the questions posed to the focus groups. The focus group guide can be seen in the Supplemental material.

Data Analysis

Deidentified transcripts of the focus groups were entered into NVivo software version 12 (QSR International Pty Ltd,

Melbourne, Australia) for data management and analysis. A team of two qualitative researchers analyzed the data (WI, LE) The team independently reviewed the transcripts and together created a preliminary codebook used to concurrently code the transcripts. The first round of concurrent coding was open, where both coders analyzed the transcripts based on the preliminary codebook. The team refined the codebook based on the initial round of analysis. The next round of concurrent coding was axial coding, where both coders used the codebook to analyze the transcripts and identify relationships between existing codes and new codes creating defined categories and subcategories. The codebook was updated to reflect the changes and agreements among the research team during each round of coding. Coding disagreements and inconsistencies between the team were discussed in detail to achieve consensus and finalize the codebook. To address the current research question transcripts were analyzed with the final version of the codebook to examine codes, categories, and quotations for meaning related to social determinants of PrEP interest and uptake.

Results

The final sample included 63 Black women (Table 1). Black women who resided in rural counties of Alabama comprised 65% of the sample with a median age of 50, 66% had an annual household income < $30,000, and 73% were not in a committed relationship (single, dating, divorced, widowed. or separated). The median age of Black women who resided in urban counties was 35, 30% had an annual income < $30,000, and 50% were not in a committed relationship. Most participants lived in rural settings; the themes presented were convergent across settings, with no distinctions in theme prevalence (Robinson, 2022) between the urban and

Table 1 Characteristics of study population ($N = 63$)

Characteristics	*N* (%)	
Counties	Rural 41 (65)	Urban 22 (35)
Dallas	15 (37)	–
Macon	10 (24)	–
Wilcox	9 (22)	–
Lowndes	7 (17)	–
Montgomery	–	14 (64)
Jefferson	–	8 (36)
Age *Median (range min–max)*	50 (20–65)	35 (23–54)
Health Insurance		
Private, Market Place	28 (68)	17 (77)
Medicaid or University of Alabama Charity	8 (20)	3 (14)
None reported/refused to answer	5 (12)	2 (9)
Household Income		
Less than $9999	9 (24)	1 (5)
$10,000–$29,999	16 (42)	5 (25)
$30,000–$49,9999	8 (21)	10 (50)
$50,000 or more	5 (13)	4 (20)
Education		
High school or GED	14 (34)	2 (9)
Some College, Associates, or technical degree	15 ((44)	8 (38)
Bachelor's degree	9 (22)	5 (24)
Any post graduate studies	3 (7)	6 (29)
Employed		
Unemployed or unable to work	13 (33)	2 (10)
Part-time or student	3 (7)	4 (19)
Full-time or retired	24 (60)	15 (71)
Relationship status		
Single or dating	23 (56)	9 (41)
Married/domestic partnership	8 (20)	7 (32)
In a monogamous relationship	3 (7)	4 (18)
Divorced, widowed, separated	7 (17)	2 (9)

rural participants. Qualitative results are presented below as themes with corresponding quotes to support the findings.

Theme 1: "It's Just Like HIV": PrEP Shares the Gravity of HIV-Related Stigma

For some Black women, stigma was a dominant concern and barrier to PrEP use. Many women stated that a barrier to PrEP use would be the concern that if revealed to be taking PrEP, or if seen taking a pill for anything HIV related, people in their community would question their HIV status, the HIV status of their sexual partners, or even their sexual behaviors. This is a form of HIV-related stigma that impedes PrEP's potential to help end the HIV epidemic in Black communities.

> I think some people may not want to take it because they may feel like they're then associated as either someone that has HIV or is sleeping with someone who is [living with HIV]. [Urban County]
> [If you take PrEP] they might think you're already HIV infected as opposed to tryin' to prevent being infected, so I think that would be an issue… [Rural County]

Several participants believed that HIV-related stigma would make it particularly difficult for Black women to access PrEP. They suggested that accessing PrEP would lead to feeling judged, ashamed, and socially isolated, a risk that Black women may not be willing to take for PrEP. For many Black women, HIV-related stigma was such a pronounced barrier that it was expressed that the stigma of using PrEP would be just as stigmatizing as living with HIV:

> Just the stigma that's associated with it, makes you feel like it's just HIV just itself. [Urban County]
> I think [PrEP is] great thing if they have it, but the stigma of it is, will you be able to get people to take it? See, so many times, people don't take medication, don't take pills, and…Some people would rather run the risk of getting AIDS than to take pills, and if they're not really familiar with it, they're not gonna really take it. [Rural County]

Black women shared a communal perspective and identified the repercussions of HIV-related stigma in the Black community. Participants shared that the lack of communication about HIV and sexual health has an influence not only on PrEP uptake but also on the historical and current perceptions of HIV prevention and treatment in Black communities.

> These are my topics where it's one of those things where people will tiptoe around because it's such a touchy thing, especially, I feel, in the African-American community. They act like it's such one of them things, oh, we can't talk about it. [Urban County]

Theme 2: Comprehensive PrEP and HIV Education as the Key to Stigma Reduction

Education and access to comprehensive resources about HIV and PrEP were identified as critical to reducing the stigma among Black Americans surrounding PrEP for HIV prevention. Black women stated that HIV-related stigma is able to persist due to the lack of information about PrEP in Black communities. In addition, women shared that if people in their community knew more about the rates of HIV infection among Black women that would help them improve attitudes toward PrEP and HIV prevention:

> With this virus, it is very important to educate the African-American community. One, because of the stigma associated with the disease. PrEP is good, condoms is good, but it's changing it in people's mind state of, yes, I know this is out there, and, yes, I not only want to protect myself, but I want to protect others. Education and prevention is very important. [Urban County]
> I think the stigma behind there not being a lot of information out about PrEP, so when there are advertisements about what PrEP is for and someone now knows that you take PrEP, I think some people may not want to take it because they may feel like they're then associated as either someone that has HIV or is sleeping with someone who—so I think that could be a reason why someone would decide, I'm just gonna use condoms, or I'm just not going to take PrEP. [Rural County]

Theme 3: "I Just Feel Like It's Not Necessary": The Lack of Accessible Information About PrEP Efficacy and Side Effects that Leads to PrEP Skepticism

Specific concerns around the length of use and side effects were expressed as points of concern and potential barriers to PrEP use. Multiple Black women expressed that limited information about PrEP's side effects would make them hesitant or disinterested in the medication. This was pervasive across focus groups as a common barrier among women, with Black women reporting they would need to weigh whether using PrEP is worth enduring potential side effects:

> I just feel like it's not necessary—when I say necessary, I guess it's gonna prevent something—I don't want to introduce myself to a new medication, knowing that it's more side effects, what side effects. [Rural County]

In addition to side effects, women expressed concerns about the duration of use and whether PrEP would require long-term use, and the specific consequences of long-term PrEP use on their bodies or lifestyles. Again, women wanted to be assured of the safety of daily PrEP use:

> I don't think that PrEP would actually be something that I would consider because of long-term use of any medication and just different side effects—not to say there would be a side effect right then. [Urban County]
> My concern is just long-term use of that medication I would want—I guess the only shaky part that I have with PrEP. [Urban County]

Theme 4: Medical Mistrust and Engagement in Health Care Were Notable Factors Influencing Black Women's Interest in PrEP

Women expressed skepticism about the medical community's ability to anticipate the long-term side effects of PrEP.

> Just like you said, it's still new even though it's a couple of years out. They didn't think cigarettes was gonna give you lung cancer. Just thinking about medications in general, you never know what's gonna come down five or six years from now. That's the only thing that would make me hesitant, what it could be later on. [Urban County]

Women expressed added mistrust of the medical community by identifying conspiracies related to denying people access to a cure for HIV.

> I feel like, if they've got a pill to prevent you from getting it [PrEP], I believe they got a pill that cures you. They just don't wanna give it to you to cure it I think. That's what I think. [Rural County]

A few women brought attention to the prevalence of home remedies to treat or prevent HIV in lieu of seeking health care. It was felt these health behaviors would be preferred due to the fear and the mistrust associated with the medical community.

> I know a lot of cultural African-centered holistic vegan people who don't trust medicine and the medical system. There are people who are uplifted in that community who say that they can cure AIDS and HIV who would rather go with the natural holistic remedies as opposed to a pharmaceutical drug. [Urban County]

Some women stated that they have observed an overall disengagement in healthcare among other Black women, particularly younger Black women. This perceived and actual disengagement is a critical determinant of PrEP use.

> A lot of women don't go to the doctor. They don't believe in gynecologists and regular checkups. They'll go sometime if they are sick, but a lot of younger black women don't just make a doctor's appointment to go to the doctor. [Rural County]

Discussion

This study is one of the first to concurrently characterize perceptions of HIV prevention and the role of PrEP among cisgender Black women in both rural and urban counties in an EHE designated high priority state in the Deep South. Our findings add to the growing literature by exploring factors beyond the individual level, highlighting the social and cultural perceptions of PrEP engagement. As supported with robust HIV prevention literature among other populations, we found that interpersonal and community-level HIV-related stigma had an important role in the perception of HIV prevention and PrEP attitudes among Alabaman Black women. In addition, the women emphasized the need for HIV and PrEP education to not only promote PrEP but aid PrEP deliberation processes and address PrEP skepticism. PrEP skepticism was a salient theme among Black women who expressed concerns about the side effects and potential risks associated with using PrEP. And finally, medical mistrust was identified as an important determinant of engagement in PrEP among Black women and people in their community (Table 2).

Although more than half of the participants lived in rural settings, the themes presented were shared across settings, with no significant differences in theme prevalence based on locality. Our study contributes to a growing body of research establishing social and cultural factors as critical in shaping attitudes toward PrEP and its usage among Black women in the Deep South. Considering these findings, our study introduces a need for further exploration into strategies specific to the needs of Black women in the rural South. Current HIV research suggests geography is a key consideration, including understanding of community norms, social and sexual networking (Ransome et al., 2020). With this knowledge, although women in both areas share similar sentiments about PrEP, our findings suggest concerted focus on possible mezzo-level facilitators and barriers is imperative to HIV preventative care engagement in the rural South and interventions that are reflective of the characteristics and norms of these environments.

We found that the salience of HIV-related stigma was a barrier to PrEP use for Black women in our sample. For some, PrEP use was considered as stigmatizing as acquiring HIV. Our findings are consistent with emergent themes in previous studies that explore Black women's PrEP attitudes and experiences in urban, Southern cities. Education was also a key component of PrEP information. Previous studies have shown that women believed PrEP was an intervention specific to gay men resulting in pervasive misconceptions about PrEP use, increased stigma, and lack of engagement (Chandler et al., 2022). Consistent with our findings, in Mississippi, PrEP use was a reminder of their HIV/AIDS

Table 2 Major themes and exemplar quotes

Theme	Quotes
PrEP shares the gravity of HIV related stigma	[Black women that you know would not use PrEP due to…] Stigma. Knowing that you've got to be taking this pill to prevent something that's out there. If I have to go into a certain clinic, will someone see me? [Urban County] In the African-American community, they're quiet [about HIV] because I've heard people say, "Oh, we don't air our dirty laundry." Instead, you'll walk around with this going on, you won't get treatment, and then it's a vicious cycle." [Urban County]
Comprehensive PrEP and HIV education as the key to stigma reduction	I think if they had more information about the disease itself as well because I know a lot of people who still have a stigma of HIV as being a gay man's disease. If a lot of black women knew it was affecting them and, if I knew that, then I probably would take it more serious like that. [Urban County] That being said, we all need to be educated on PrEP. That is an excellent medicine that science has brought out because we just find out about it. It need to be exposed to let the young generation know about this. [Rural County]
The lack of accessible information about PrEP efficacy and side effects that leads to PrEP skepticism	When they do advertise drugs and people start to take 'em. Then over a period of time, you start hearing about a whole lot of side effects. Myself, I'm very leery of medicines nowadays. Like you said, all of 'em does have side effects. [Rural County] My concern is just long term use of that medication I would want—I guess the only shaky part that I have with PrEP. [Urban County]
Medical mistrust and engagement in health care were notable factors influencing Black women's interest in PrEP	I have about it is—with this medicine [PrEP], is it just, for lack of a better word, is it geared toward just African Americans? Is it just like they're like the only ones? You're a guinea pig. I mean—you know. [Rural County] I think that people sometimes don't know anything about [HIV] because some people are afraid—still afraid to go to the doctor. They think their home remedies will help them, prevent them from catching it. [Urban County]

risk, which some participants found difficult to accept due to HIV-related stigma (Willie et al., 2022). Black women emphasized the importance of HIV and PrEP-related education and transparency in information provision as viable HIV-related stigma reduction strategies that could improve attitudes toward PrEP for them and members of their community. Improved attitudes and positive social norms regarding PrEP may be key to relieving Black women's concerns about judgment from family, peers, and partners about PrEP use.

Further, community-engaged learning can identify best practices in disseminating educational information. Opportunities also emerge for prevention strategies specific to the needs of the diverse, intersecting identities within Black communities. Black women in previous PrEP studies shared similar sentiments.

In our sample, PrEP skepticism was related to a lack of information about the side effects of PrEP use, the safety of long-term PrEP use, and the efficacy of PrEP for cisgender women. This finding highlights the need for accessible PrEP education and messaging that addresses its side effects, safety, and efficacy. Black women in Birmingham, Alabama, though aware of PrEP, had unanswered questions about affordability and side effects and were uncertain about PrEP's role in HIV/AIDS prevention (Willie et al., 2022). This highlights the distinction between increasing PrEP awareness (e.g., I know about PrEP as an HIV prevention option) and PrEP education (e.g., I understand the cost, side effects, safety, efficacy, and requirements of PrEP care and adherence). Increased awareness of PrEP does not mean that Black women are fully educated about PrEP. However, even PrEP awareness campaigns have fallen short for Black women in our sample. Our findings are consistent with previous studies showing that the scarce representation of Black women in PrEP marketing, increased inquiries about whether PrEP is a good fit for them and their sexual health, as well as PrEP medication outcomes and side effects for Black women (Goparaju et al., 2017; Willie et al., 2022). Black women considering PrEP have the right to have questions and concerns about PrEP, its side effects, and long-term use. Their inquiries and skepticism should be met with information that is clear, consistent, and accessible. In addition, more work is needed to identify who should be delivering the PrEP education and messaging (i.e., providers, peers, or leaders in the community). Appropriate PrEP influencers have the potential to facilitate improved

PrEP knowledge and bridge the chasm of mistrust between Black women and the medical community.

In our sample, medical mistrust of the medical community was a barrier to PrEP use. Black women reported turning to homeopathic or home remedies before trusting the healthcare system for HIV prevention, and some observed an overall disengagement in healthcare among younger Black women. These findings are consistent with previous studies where Black women expressed their mistrust of healthcare institutions and believed they received misinformation about their sexually transmitted infection status and experienced a lack of communication from providers (Randolph et al., 2020). Experiences with providers who are disengaged or provide limited information can perpetuate barriers to care while trusting relationships with providers create pathways to PrEP use (Irie et al., 2023a; Willie et al., 2021). As mistrust and fear of the medical community continue to persist, it is imperative to implement strategies to reduce stigma, implicit bias, and racism in medical settings to heal and transform the relationships between the medical community and Black communities.

The Black women in our sample responses to PrEP are a response to multiple forms of systemic oppression and exclusion, particularly in sexual and reproductive healthcare and education. No singular institution is the root of the barriers to PrEP among Black women, which is why intersectionality as a theory and praxis is important when understanding Black women's responses to and perceptions of PrEP (Dale et al., 2022). Intersectionality is key in affirming diverse, lived experiences through acknowledgment of the multiplicative effects of interlocking oppressive systems and, in this context, the subsequent impact on optimal sexual health outcomes (Collins, 2019; Crenshaw, 1989, 2013; The Combahee River Collective, 1977). When using the intersectionality framework to apply socio-structural considerations to Black women's experiences with PrEP, our findings support Black women's report that gendered racism, negative connotations, and discrimination inform their medical mistrust (Dale et al., 2022). Although understudied, these experiences may increase Black women's vulnerability within their communities (Willie et al., 2021). As voiced by women in our sample, PrEP use jeopardizes their community ties, which, if lost, can lead to social isolation. Intersectionality requires that the pathway toward improved PrEP implementation for communities of Black women be through (1) multi-system interventions including healthcare systems to improve the quality and reach of HIV prevention and PrEP delivery; and public education systems to improve sexual health knowledge, reduce HIV-related stigma and misinformation; and (2) multi-level interventions including community-level interventions and partner-level interventions to reduce stigma, increase positive social norms and communication about PrEP (Irie et al., 2023b).

The study included several limitations including the modest sample size; our study used qualitative and cross-sectional data; therefore our findings are not generalizable to Black women in the rural and urban Deep South. During our study, we did not explore other PrEP modalities currently available to US women, like long-acting injectable PrEP. The study team worked closely with community partners and elected to use the focus group data collection method instead of individual interviews; however, for sensitive topics such as sexual health and HIV, individual interviews may have allowed for more in-depth exploration of the topics due to increased privacy and time with each participant. Despite these limitations, we included focus group data from various counties in the Deep South and were able to share the experiences of Black women who represent both urban and rural communities.

Our findings highlight the need to design and implement PrEP interventions that fully encompass the complexity of HIV-related stigma in the Black community. Due to the lack of universal, comprehensive sexual education, it is critical that we identify modes of HIV and PrEP knowledge diffusion, particularly for rural communities disproportionately impacted by HIV. Critical next steps involve an examination of the prevalence of HIV stigma and medical mistrust among Black women in the US and identifying the mechanisms that uphold these attitudes, beliefs, and experiences. Upon identification, there are opportunities to design interventions that are responsive to these realities and can reduce the prevalence of these salient barriers to HIV prevention and PrEP engagement among Black women.

Appendix

Focus Group Questions

Let's talk about…

- **How important is it to prevent contracting HIV?**
  (Probe: Do you feel that you are at risk of for getting HIV?)
- **Do you feel that you have control over preventing HIV?**
  (Probe: Why or why not?)
- **Do you feel that you are able to control if you use condoms with sexual partners?)**
  (Probe: Why or why not?)
- **Do you feel it is important to get tested for HIV and other STIs?**
  (Probe: Why or why not?)
  I'd like to spend the rest of our time talking about a specific type of HIV prevention, called "PrEP" or Pre-exposure Prophylaxis.

- **Have you heard of PrEP before?**
  [If participants knows nothing about PrEP, give the following description. **PrEP is**
  Pre-Exposure Prophylaxis which is an oral pill taken once a day to prevent infection with HIV after potential exposures to the virus]

- **How do you feel about PrEP?**
  (Probe: Who would you think PrEP is for?)
  (Probe: What concerns would you have about taking PrEP?)
- **Do you think black women would be interested in taking PrEP or consider recommending it to a friend?**
  (Probe: Why or why not?)
  (Probe: What would make you consider using PrEP or recommending it to a friend?)
- **If you thought taking PrEP was a good idea, where would you feel comfortable receiving it?**

  - **Who would you feel comfortable getting PrEP from? Would you feel comfortable getting care through Telemedicine?**
  - **Where would you feel comfortable getting STD testing?**
  - **What frequency of clinic visits do you feel would be reasonable to get PrEP? 3 months? 6 months?**

- **Could you talk to me about what could make it hard for black women to access PrEP?**
- **What do you feel is the best way to get black women hearing about and considering taking PrEP?**
  (Probe: Is messaging for PrEP important in getting people to consider it?)
  (Probe: What type of messaging would make you more inclined to take PrEP?)
  (Probe: Where should messaging come from? Radio, TV, church, etc.?)
  (Probe: Should messaging be about risk of HIV, safe sex, healthy living, etc.)

Closing

That's it for my questions. Would you be interested in adding additional thoughts to any of today's topics? Are there topics that we might have missed? Do you have questions for me?

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Data Availability Data are not currently publicly available.

Declarations

Conflict of interest Irie has received unrestricted medical education funds from ViiV. Healthcare Elopre has received grant support from Merck pharmaceuticals, Marrazzo has participated in advisory meetings for Merck and Gilead, Van Der Pol has received grant support from Abbott, BD Diagnostics, BioFire, Cepheid, Hologic, Roche and SpeeDx.

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

Consent to Participate All study participants provided informed consent before engaging in study activities.

References

Aholou, T. M., Cooks, E., Murray, A., Sutton, M. Y., Gaul, Z., Gaskins, S., & Payne-Foster, P. (2016). "Wake up! HIV is at your door": African American faith leaders in the rural south and HIV perceptions: A qualitative analysis. *Journal of Religion and Health, 55*(6), 1968–1979. https://doi.org/10.1007/s10943-016-0193-z

Ahrens, K., Burgess, A., Munk, L., & Ziller, E. (2021). *Rural HIV prevalence and service availability in the United States: A chartbook*. University of Southern Maine, Muskie School, Maine Rural Health Research Center. https://digitalcommons.usm.maine.edu/population_health/16

Alabama Department of Public Health. (2019). *Brief facts on African-Americans and HIV in Alabama*. https://www.alabamapublichealth.gov/hiv/assets/brieffactsonafricanamericansandhiv.pdf

Anderson, R., & Newman, J. F. (2005). Societal and individual determinants of medical care utilization in the United States. *The Milbank Quarterly*, *83*(4). https://doi.org/10.1111/j.1468-0009.2005.00428.x

Brown, E. J., & Van Hook, M. (2006). Risk behavior, perceptions of HIV Risk, and risk-reduction behavior among a small group of rural African American women who use drugs. *Journal of the Association of Nurses in AIDS Care, 17*(5), 42–50. https://doi.org/10.1016/j.jana.2006.07.004

CDC. (2019). HIV in the southern United States. *CDC Issue Brief, 29*(September), 1–4.

Chandler, R., Guillaume, D., Wells, J., & Hernandez, N. (2022). Let me prep you to prep me: Amplifying the voices of black women and their providers to consider PrEP as an HIV prevention option. *International Journal of Environmental Research and Public Health, 19*(3), 1414. https://doi.org/10.3390/ijerph19031414

Collins, P. H. (2019). *Intersectionality as critical social theory*. Duke University Press.

Crear, D. (2019). *2019 State of Alabama HIV Surveillance Annual Report* (p. 32). Alabama Department of Public Health. https://www.alabamapublichealth.gov/hiv/assets/hivsurveillanceannualreport_2019.pdf

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. *The University of Chicago Legal Forum, 1989*(1), 139–167.

Crenshaw, K. W. (2013). Mapping the margins: Intersectionality, identity politics, and violence against women of color. In *The public nature of private violence* (pp. 93–118). Routledge.

Dale, S. K., Ayala, G., Logie, C. H., & Bowleg, L. (2022). Addressing HIV-related intersectional stigma and discrimination to improve public health outcomes: An AJPH supplement. *American Journal of Public Health, 112*(S4), S335–S337. https://doi.org/10.2105/AJPH.2022.306738

Elopre, L., Kudroff, K., Westfall, A. O., Overton, E. T., & Mugavero, M. J. (2017). Brief report: the right people, right places, and right practices: Disparities in PrEP access among African American men, women, and MSM in the deep south. *JAIDS Journal of Acquired Immune Deficiency Syndromes, 74*(1), 56–59. https://doi.org/10.1097/QAI.0000000000001165

Fauci, A. S., Redfield, R. R., Sigounas, G., Weahkee, M. D., & Giroir, B. P. (2019). Ending the HIV epidemic: A plan for the United States. *Journal of the American Medical Association, 321*(9), 844. https://doi.org/10.1001/jama.2019.1343

Gant, L. M., & Gant, Z. C. (2008). Impact of poverty, sex ratios, and marital status on HIV infection rates among African American women in Mississippi. *Journal of Public Management & Social Policy*, *14*(2), 7–19.

Goparaju, L., Praschan, N. C., Jeanpiere, L. W., Experton, L. S., Young, M. A., & Kassaye, S. (2017). Stigma, partners, providers and costs: Potential barriers to PrEP uptake among US women. *Journal of AIDS Clinical Research*, *8*. https://doi.org/10.4172/2155-6113.1000730

Hill, S. V., Pratt, M. C., Elopre, L., Smith, T. V., Simpson, T., Lanzi, R., & Matthews, L. T. (2022). "Let's take that [stop sign] down" Provider perspectives on barriers to and opportunities for PrEP prescription to African American girls and young women in Alabama. *AIDS Care*, *34*, 1473–1480. https://doi.org/10.1080/09540121.2022.2105799

Irie, W. C., Mahone, A., Nakka, R., & Ghebremichael, M. (2023a). Factors associated with comfort discussing PrEP with healthcare providers among black cisgender women. *Tropical Medicine and Infectious Disease, 8*(9), 436. https://doi.org/10.3390/tropicalmed8090436

Irie, W., Mahone, A., Nakka, R., & Ghebremichael, M. (2023b). Confidence in ability to communicate with sexual partners about PrEP among black cisgender women. *AIDS Education and Prevention, 35*(5), 333–346. https://doi.org/10.1521/aeap.2023.35.5.333

Krueger, R. A., & Casey, M. A. (2014). *Focus groups: A practical guide for applied research*. (Fifth ed.). Sage Publications.

Patel, A. S., Goparaju, L., Sales, J. M., Mehta, C. C., Blackstock, O. J., Seidman, D., Ofotokun, I., Kempf, M.-C., Fischl, M. A., Golub, E. T., Adimora, A. A., French, A. L., DeHovitz, J., Wingood, G., Kassaye, S., & Sheth, A. N. (2019). PrEP eligibility among at-risk women in the Southern United States: Associated factors, awareness, and acceptability. *Journal of Acquired Immune Deficiency Syndromes, 80*(5), 527–532.

Randolph, S. D., Golin, C., Welgus, H., Lightfoot, A. F., Harding, C. J., & Riggins, L. F. (2020). How perceived structural racism and discrimination and medical mistrust in the health system influences participation in HIV health services for black women living in the United States south: A qualitative, descriptive study. *Journal of the Association of Nurses in AIDS Care, 31*(5), 598–605. https://doi.org/10.1097/JNC.0000000000000189

Ransome, Y., Bogart, L. M., Kawachi, I., Kaplan, A., Mayer, K. H., & Ojikutu, B. (2020). Area-level HIV risk and socioeconomic factors associated with willingness to use PrEP among Black people in the U.S. South. *Annals of Epidemiology, 42*, 33–41. https://doi.org/10.1016/j.annepidem.2019.11.002

Reif, S., Safley, D., McAllaster, C., Wilson, E., & Whetten, K. (2017). State of HIV in the US deep south. *Journal of Community Health, 42*(5), 844–853. https://doi.org/10.1007/s10900-017-0325-8

Robinson, O. C. (2022). Conducting thematic analysis on brief texts: The structured tabular approach. *Qualitative Psychology, 9*(2), 194–208. https://doi.org/10.1037/qup0000189

Siegler, A. J., Mouhanna, F., Giler, R. M., Weiss, K., Pembleton, E., Guest, J., Jones, J., Castel, A., Yeung, H., Kramer, M., McCallister, S., & Sullivan, P. S. (2018). The prevalence of pre-exposure prophylaxis use and the pre-exposure prophylaxis–to-need ratio in the fourth quarter of 2017, United States. *Annals of Epidemiology, 28*(12), 841–849. https://doi.org/10.1016/j.annepidem.2018.06.005

The Combahee River Collective Collective. (1977). The Combahee River Collective Statement. In B. Smith (Ed.), *Home girls: A black feminist anthology* (pp. 272–282). Kitchen Press: Women of Color Press.

Willie, T. C., Knight, D., Baral, S. D., Chan, P. A., Kershaw, T., Mayer, K. H., Stockman, J. K., Adimora, A. A., Monger, M., Mena, L. A., Phillips, K. A., & Nunn, A. (2022). Where's the "Everyday Black Woman"? An intersectional qualitative analysis of Black women's decision-making regarding HIV pre-exposure prophylaxis (PrEP) in Mississippi. *BMC Public Health, 22*(1), 1604. https://doi.org/10.1186/s12889-022-13999-9

Willie, T. C., Monger, M., Nunn, A., Kershaw, T., Stockman, J. K., Mayer, K. H., Chan, P. A., Adimora, A. A., Mena, L. A., Knight, D., Phillips, K. A., & Baral, S. D. (2021). "PrEP's just to secure you like insurance": A qualitative study on HIV pre-exposure prophylaxis (PrEP) adherence and retention among black cisgender women in Mississippi. *BMC Infectious Diseases, 21*(1), 1102. https://doi.org/10.1186/s12879-021-06786-1