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Preexposure Prophylaxis Acceptability Among Pregnant Individuals and Implications for Human Immunodeficiency Virus Prevention

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Abstract

OBJECTIVE: To understand perspectives on and preferences for preexposure prophylaxis (PrEP) for pregnant individuals who are at risk for human immunodeficiency virus (HIV) infection.

METHODS: In this qualitative study, we purposively sampled and conducted in-depth interviews with pregnant participants at risk of HIV infection (indicated by a recent sexually transmitted infection [STI]) from a U.S. urban obstetrics clinic. Interview questions focused on perceived HIV risk, knowledge and perceptions of PrEP, and preferences for different PrEP formulations. We coded data using deductive and inductive codes, created matrices to explore patterns in findings, and wrote memos to interpret emergent themes.

RESULTS: Twenty patients were enrolled. Median age of the participants was 24 years (interquartile range 19–26 years), 95.0% were African American, 65.0% were high school graduates, and 70.0% had unplanned pregnancies. Participants had low knowledge of PrEP and most saw themselves at low to no risk of HIV acquisition, despite their recent STI. Further, participants' low HIV risk perception and medication safety concerns reduced PrEP acceptability. Moreover, very few had discussed PrEP with their obstetrician–gynecologists (ob-gyns) during antenatal care, which further affected perceived acceptability. However, participants who did discuss PrEP with their ob-gyns had favorable perceptions of it. These participants indicated that they would choose a formulation based on individual preferences, which were largely shaped by perceived ease of use, acceptability, and prior experience with other medication regimens.

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CONCLUSION: Obstetrician–gynecologists may play an important role in increasing pregnant individuals' knowledge of and access to PrEP during pregnancy among those who are at risk of HIV acquisition. To maximize uptake and adherence during this time, PrEP formulations should be tailored to individual preferences. Prevention of HIV during this critical life transition is important not only for the long-term health and well-being of pregnant individuals and their infants, but to the plan to end the HIV epidemic in the United States by 2030.

Of the 1.2 million people in the United States who have been diagnosed with human immunodeficiency virus (HIV) infection, more than 22% are women.[1] In 2018 alone, 7,190 women were diagnosed with HIV infection, and there continue to be racial disparities in HIV infection, such that nearly 80% of these diagnoses occurred among women of color. The most common mode of transmission among women is through heterosexual contact.[2] Furthermore, females of reproductive age are significantly affected by HIV infection; approximately two thirds of new HIV infections that occurred in females in 2018 occurred among those between the ages of 13–44 years.[1] Moreover, pregnancy and the postpartum period are a particularly unique time of HIV risk for women, given the biological changes that accompany pregnancy[3–5] and given that the relative risk of HIV infection per sex act is twice as high for pregnant individuals compared with nonpregnant individuals.[6]

Preexposure prophylaxis (PrEP) is one of the only HIV-prevention methods available that can be controlled by women without having to involve their partner.[7,8] Currently, tenofovir disoproxil fumarate and emtricitabine is the only U.S. Food and Drug Administration–approved PrEP formulation for use in women. Tenofovir disoproxil fumarate and emtricitabine is not associated with increased adverse events during pregnancy,[9] and World Health Organization guidelines state that PrEP can, "be considered as an additional prevention choice for HIV-negative pregnant women who are at substantial [risk] of HIV infection…" to avoid mother-to-child transmission.[10] Tenofovir disoproxil fumarate and emtricitabine is taken orally; however, given the well-known challenges with adherence for daily oral medication regimens,[11–14] research on alternative formulations of PrEP —including, but not limited to, long-acting injectable PrEP formulations—is ongoing. Scientific studies have established that the long-acting injectable PrEP formulation (cabotegravir) is superior to oral PrEP (tenofovir disoproxil fumarate and emtricitabine) for women,[15,16] and the U.S. Food and Drug Administration approved one long-acting injectable PrEP formulation, Apretude (cabotegravir extended-release injectable suspension), on December 20, 2021.[17] However, Apretude was approved only for women who are not pregnant or breastfeeding, given that safety data on long-acting injectable PrEP formulations are not yet available for women who are pregnant or breastfeeding.

Despite global guidance that oral PrEP is safe for women, PrEP uptake among women in the United States remains low,[18] and only a handful of studies to date have examined the barriers and facilitators to PrEP uptake among women.[18,19] This gap in research is particularly striking for women who are at risk of HIV infection during pregnancy and the postpartum period. Additionally, to our knowledge, there are no studies that examine women's willingness to consider long-acting injectable PrEP formulations in the post-partum period.

Understanding whether women at risk of HIV infection feel that PrEP is acceptable during and after pregnancy and their preferences regarding their PrEP formulation during this time is important to reduce HIV transmission among women and their children in the United States. Therefore, the purpose of this qualitative research study is to understand perspectives on and preferences for PrEP among pregnant individuals who are at high risk of HIV infection.

METHODS

Patients who were receiving antenatal care at an inner-city university hospital were eligible to participate in the study if they were currently pregnant, older than 14 years of age, spoke English, and had screened positive for a sexually transmitted infection (STI) during pregnancy or in the year preceding pregnancy. Although we did not sample by race, we anticipated that a substantial proportion of our participants would identify as Black, based on the broader demographics of the population seeking care at the antenatal clinic. The inclusion of Black participants in our sample was appropriate given their disproportionate risk of HIV acquisition.[3] We identified patients who fit such criteria by doing chart reviews; 109 patients were eligible based on chart reviews. We attempted to contact all eligible patients by phone. Reasons for no interview included did not pick up (n=30), scheduled a time for the interview but did not pick up at the scheduled time (n=27), refused, no reason given (n=23), or gave birth by the time we reached out to them (n=8). All patients who agreed to participate in the study provided informed consent. The study was approved by the University of Pennsylvania's institutional review board.

Participants first completed a short Redcap survey that included questions relating to sociodemographic information and obstetric health history. The second author (J.V.) started the virtual, in-depth, semi-structured interviews using video conference software with 21 pregnant participants; interviews typically took about 30 minutes (see Appendix 1, available online at http://links.lww.com/AOG/C606, for interview guide). One interview was removed because the participant was not alone for the remote interview (there were other people present in the background).

We started the interview by asking participants questions about their experiences taking any medication during pregnancy, their perceived HIV risk, and their experiences with HIV and STI testing during pregnancy. Next, we asked participants to describe what they knew about PrEP (or if they knew of PrEP at all). The interviewer then provided a short summary of what PrEP was before asking participants how they felt about taking PrEP during pregnancy. Finally, the interviewer asked participants if they had a preferred PrEP formulation (oral PrEP vs long-acting injectable PrEP) and why they preferred such a formulation. Participants received $50 through a ClinCard to compensate them for their time.

We used a direct content analytic approach to analyze the qualitative data.[20] After transcribing and reading all interviews, we used deductive and inductive codes to code the data using Dedoose 8.0. Next, we created matrices to explore patterns in findings across different participants (eg, those who perceived themselves to be at risk of HIV infection

and those who did not perceive themselves to be at risk of HIV infection).[21] We wrote memos to interpret emergent themes and discussed findings and interpretations across our team in regular meetings. In the rare instance where consensus was lacking around a particular theme, we revisited the coded data in team meetings and discussed the findings until we reached agreement. To increase the trustworthiness of the findings,[22] we conducted member-checks (ie, solicited feedback) on our interpretation of the qualitative results from HIV health care professionals and obstetrician–gynecologists (ob-gyns).

A priori we planned to purposively sample 20 participants based on their HIV risk, with the goal of achieving depth of understanding of our research question (ie, “saturation”) with this sample size.[21,23]

RESULTS

We completed interviews with 20 participants between July 2020 and June 2021 (Table 1). We identified several barriers to PrEP acceptability during pregnancy. First, participants did not perceive that they were at risk of HIV infection; second, they had little to no knowledge of PrEP; third, they were concerned about side effects of PrEP for their unborn child; and fourth, very few of their ob-gyns discussed PrEP as an HIV prevention tool with them. Finally, participants’ preferences for oral PrEP formulations as compared with long-acting injectable PrEP formulations varied based on individual characteristics. We elaborate on these four themes below.

Participants who were clinically at high risk of HIV infection saw themselves at low or no risk. Despite being diagnosed with an STI in the prior year, more than three quarters of the participants interviewed felt that they were at low or no risk of HIV acquisition. Participants’ perception of their low-risk status was based on their current sexual behavior and their beliefs about their partners’ sexual fidelity. A few participants shared that they were not sexually active during their pregnancy. Sexually active participants identified themselves as monogamous and equated their sexual exclusivity or belief that their partner was not being sexually concurrent with anyone else with being low risk. Consequently, few used condoms consistently during sex or engaged in couples’ HIV testing. The remaining quarter of participants were unsure of their HIV risk. Finally, only one participant felt that she was at risk of HIV infection. She felt vulnerable to HIV infection because she knew her sexual partner had other sexual partners.

Participants’ knowledge of PrEP was low. Approximately two thirds of participants had never heard of PrEP before discussing it during the in-depth interview. The remainder had heard of PrEP and knew that it would prevent HIV acquisition. Almost all participants who knew about PrEP had learned about it through marketing campaigns (ie, commercials), and some voiced skepticism about the efficacy of PrEP based on learning about it through television: “…cause you know TV commercials could be just trying to promote the product. I don’t believe it works 100%. I probably think it’s like 50%.” Just two participants noted that their ob-gyns had talked with them about the benefits of PrEP in reducing HIV risk during pregnancy.

Participants' concerns about safety decreased their interest in PrEP. Most participants had concerns about taking any medication while pregnant, including PrEP, unless their clinician indicated that it was necessary and safe. Participants' aversion to medication broadly and to PrEP specifically during pregnancy stemmed from a desire to protect themselves and their babies from potentially harmful side effects of medication. Further, their low perceived susceptibility to HIV infection combined with their low knowledge of PrEP meant that, for most participants, these perceived risks of PrEP outweighed the perceived benefits. One quarter of participants did not have any opinions regarding PrEP use in pregnancy, which may be partially due to the fact that all of these participants learned about PrEP for the first time during the in-depth interview.

Conversations about PrEP for HIV prevention were largely absent from antenatal encounters. Although an overwhelming majority of participants did not discuss PrEP for HIV prevention with their ob-gyns, they were unanimously open to such conversations: "I think if you found out you're pregnant and they do your blood work and feel like you're at high risk of getting HIV. I feel like you should, they should give you PrEP as a medication, or tell you about it and give you options." Moreover, they indicated a strong preference for hearing about PrEP from their ob-gyns as opposed to a pharmacist or through commercials. Their preferences were based on the perception that their ob-gyn is a credible source of information: "The information they tell me, I feel confident in talking to them about certain stuff because they're gonna tell me the truth and they're gonna give me the information about it."

In the rare instances when ob-gyns discussed PrEP with participants during antenatal care, participants' awareness of their HIV risk increased, and their perceptions of PrEP were largely favorable. Only two participants recalled such conversations. The first participant was uncomfortable when her ob-gyn first introduced the topic, because she had originally perceived she was at low risk of HIV infection: "Hearing it from my doctor was kind of scary in a sense because it was just like, 'why are you bringing this up if I don't have HIV?'" However, after their discussion, she felt comfortable asking more about PrEP in future health visits out of interest in taking care of her health. Although the conversation about her HIV risk was a surprise, she appreciated how her ob-gyn engaged her in the conversation: "It was informative, in a sense, where I could ask the questions that I need to ask on the things that I had questions about." Despite the positive patient–physician communication, the participant still considered herself low risk for HIV infection and declined PrEP use during pregnancy.

The only other participant who discussed PrEP with her ob-gyn said that the ob-gyn initiated the conversation with her based on her STI history: "She talked to me when we had a conversation of any STDs I had in the past and stuff like that. And she just said it'll probably be a good idea like for me to take it [PrEP] for any risk." Although the participant appreciated the conversation with her doctor and felt favorably toward oral PrEP, she was still deliberating whether she would take it during her pregnancy.

Few participants were interested in using PrEP during the perinatal period; however, when prompted to choose a hypothetical regimen, participants' preferences varied

considerably and were driven by multiple factors. Participants who indicated that they would (hypothetically) prefer an oral PrEP formulation over a long-acting injectable PrEP formulation did so out of a desire to avoid needles. Some were also hesitant to start a long-acting injectable PrEP regimen because they had received injections in the past and had not understood what they were for. These experiences contributed to mistrust of injections: “People [providers] inject me with stuff.I don’t really know what it is, so I don’t prefer any injections.”

On the other hand, participants who preferred a long-acting injectable PrEP formulation either disliked taking pills or had inconsistent pill-taking behaviors, as recounted by this participant: “With the pill, I might forget to take it every day. So, that’s just like when I was on birth control. The pill wasn’t good for me because I would forget to take it every day.” Although most of these participants indicated that the primary perceived benefit of a long-acting injectable PrEP formulation was that it was not a daily obligation, several also voiced concerns about side effects or the composition of the injection itself. A few participants did not have strong opinions regarding either formulation and were open to learning more about PrEP options.

DISCUSSION

Both the World Health Organization and the American College of Obstetricians and Gynecologists recommend that PrEP be offered as part of combination HIV prevention for individuals at risk of HIV infection during and immediately after pregnancy.[24–26] Yet, there has been limited research on the acceptability of PrEP among pregnant individuals at risk of HIV infection in the United States. In this qualitative study, we explored at-risk pregnant individuals’ perspectives on and preferences for PrEP in an urban antenatal context.

Two key barriers to PrEP acceptability for pregnant participants in our sample were low HIV risk perception and low knowledge of PrEP. Low HIV risk perception and low knowledge of PrEP are also reported barriers to PrEP acceptability among other pregnant individuals in the United States[27] and Africa,[28,29] as well as with other populations of women at risk of HIV infection in the United States.[30,31] Although these findings highlight consistent barriers to acceptability across populations and contexts, more research is needed to understand barriers to acceptability (and uptake) specifically for individuals in the United States who are offered PrEP or referred for PrEP during pregnancy, particularly across different geographic settings. Because we spoke with only two pregnant participants in our sample who had actually discussed PrEP with their ob-gyns, we are unable to identify meaningful patterns in barriers to PrEP acceptability (or uptake) during pregnancy among those actually offered PrEP. In one quantitative study in Washington, DC, that examined pregnant women’s intention to take PrEP, only 10% of participants (n=21) intended to initiate PrEP during pregnancy. In bivariate analyses, women who had a favorable attitude toward PrEP were significantly more likely to intend to take PrEP in pregnancy than women with less favorable attitudes.[27] However, the small number of women who intended to initiate PrEP suggests that women may not perceive PrEP to be acceptable during pregnancy, and the study is also limited in that it assessed intention but not uptake. Additional research is needed among pregnant women at risk of HIV infection in the United States to understand PrEP uptake,

PrEP adherence, and retention in PrEP care during pregnancy to fully characterize women's engagement in the PrEP care continuum during this time.

An unanticipated study finding was how few ob-gyns had discussed PrEP with pregnant participants who had recently been diagnosed with an STI. Our participants indicated that they were open to learning more about PrEP in the context of antenatal care. Other research has shown PrEP acceptability to increase after receiving a strong recommendation from a trusted health care professional.[32–34] Such conversations may help diminish patients' fear of harmful side effects of medication (including PrEP) during pregnancy and increase acceptability during pregnancy. There is some evidence that non–HIV-focused health care professionals, particularly those who provide care for women and children, may be unfamiliar or uncomfortable in providing counseling or referrals for PrEP.[35,36] However, a search of PubMed and Google Scholar on December 16, 2021, using the search terms (ob-gyn OR provid* AND (pre-exposure prophylaxis) OR PrEP AND pregnancy AND (United States) OR USA OR US) with no date restriction, yielded no articles that specifically examined knowledge of PrEP among ob-gyns or assessed the perspectives of ob-gyns on prescribing PrEP to their patients during and after pregnancy. It is possible that ob-gyns might discuss other issues that they consider more important than PrEP during prenatal visits. Moreover, ob-gyns' biases toward women of color could negatively affect patient–physician communication and contribute to lack of patient education on need for PrEP.[37] Research with ob-gyns is sorely needed to optimize PrEP acceptability and to identify strategies for screening and referring women who would be eligible for PrEP in pregnancy.

Finally, pregnant participants' preferred PrEP formulation varied considerably, which is consistent with the broader literature on hypothetical PrEP preferences among nonpregnant women in the United States[19,38] and nonpregnant women in sub-Saharan Africa.[39,40] Participants in our study based their decisions on multiple attributes, including perceived convenience, beliefs based on prior experience with birth control, perceived safety, and side effects. Understanding whether PrEP formulation preference is associated with initiation and ultimately adherence is needed once products are available for use, because pregnant individuals' perspectives may change when they are offered PrEP.

There are several study limitations. One limitation is that we did not include Spanish-speaking patients in our sample. Although there is no literature to suggest that there are differences between racial and ethnic minority individuals in terms of PrEP knowledge or PrEP acceptability, it is possible that racial and ethnic identities might influence preferred PrEP formulation. For example, medical mistrust (stemming from historical and current discrimination and abuse) has been shown to affect birth control decision making among Black and Latina women[41] and may also affect PrEP formulation preferences. A second limitation is that barriers to PrEP acceptability may differ for women who have actually been offered PrEP during pregnancy as compared with those who are learning about it for the first time in the context of an interview. Although all participants in our sample were clinically eligible for PrEP based on their HIV risk, most were unaware that they were at risk of HIV infection and had not considered PrEP before the interview itself. A final limitation of our study is that our findings are specific to pregnant individuals seeking care in a large urban context. Given such, our participants' perspectives on and preferences for PrEP may not be

transferable to pregnant individuals in other geographies (eg, rural areas, smaller cities) in the United States.

Despite these limitations, our study also has several strengths. Our study highlights that patient–physician communication (or lack thereof) is a barrier to PrEP knowledge and potentially to PrEP uptake among individuals at risk of HIV infection during pregnancy. Second, participants in our study had different preferences for PrEP formulations during pregnancy and breastfeeding. This finding serves as an important reminder that offering pregnant and breastfeeding individuals an array of PrEP modalities may be key to maximizing their effectiveness. Although it is perhaps unsurprising that pregnant individuals are similar to nonpregnant individuals in desiring choice in medication formulation, delays in research specifically with pregnant individuals and the exclusion of pregnant individuals from large-scale PrEP safety and efficacy trials may delay their access to lifesaving HIV-prevention tools.[42]

There are several potential intervention implications from our study. First, interventions to address barriers to PrEP initiation (ie, providing patient-centered counseling on HIV risk perception, increasing knowledge of available HIV-prevention tools, using decision aids to facilitate communication, providing adherence support) may increase PrEP acceptability and initiation,[43–46] though to our knowledge, these interventions are in early stages of implementation and none have been evaluated for use with pregnant individuals in the United States. Second, health care professional or clinic-level interventions may also increase PrEP acceptability and subsequently affect demand. One promising intervention study in Kenya demonstrated that health care professional training using standardized patient actors improved patient–physician interactions and positively affected the quality of PrEP counseling for young women.[47] Similar strategies may be transferrable to the U.S. context and warrant further exploration.

In conclusion, individuals who are of childbearing age continue to compose a significant portion of new HIV infections among women in the United States, and racial and ethnic disparities persist such that most new HIV infections occur among Black women. Obstetrician–gynecologists may play a critical role in increasing pregnant individuals' awareness of and access to PrEP among those who are at risk of HIV acquisition during pregnancy. Improving women's engagement in the PrEP care continuum among those who are at disproportionate risk of HIV infection during and after pregnancy has important implications for health equity and for ending the HIV epidemic in the United States.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Sociodemographic and Pregnancy Characteristics of the Sample (N=20)

Characteristic	Value
Age (y) (continuous)	24 (19–26)
Younger than 18	3 (15)
18–24	10 (50)
25 and older	7 (35)
Race	
Asian	1 (5)
Black or African American	19 (95)
Ethnicity	
Hispanic	2 (10)
Not Hispanic	18 (90)
Education	
9th through 11th grade	7 (35)
High school graduate or greater	13 (65)
Insurance	
Private or HMO	3 (15)
Medicaid	11 (55)
Medicare	3 (15)
None	1 (5)
Other	2 (10)
Marital status	
Never married	20 (100)
No. of living children	
0	10 (50)
1	3 (15)
2	5 (25)
3 or more	2 (10)
Current pregnancy intention	
Unplanned	14 (70)
Planned	6 (30)
Lifetime pregnancies (including current)	
1	10 (50)
2	4 (20)
3 or more	6 (30)

HMO, health maintenance organization.

Data are median (interquartile range) or n (%).