

# HIV-Uninfected Kenyan Adolescent and Young Women Share Perspectives on Using Pre-Exposure Prophylaxis During Pregnancy

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## Abstract

To optimize scale-up of pre-exposure prophylaxis (PrEP) for pregnant women at risk of HIV in high HIV burden settings, implementation strategies must be developed that account for perceptions of PrEP in this unique population. Semistructured focus group discussions were conducted with 68 HIV-uninfected Kenyan pregnant and postpartum women without prior PrEP knowledge or experience. A qualitative descriptive analysis was performed, using a constant comparison approach, to identify key themes related to the values and rationale impacting potential PrEP use in pregnancy. Median age was 19.5 years and participants were either pregnant or had 1–2 children. Almost all (96%) were married or had a steady partner. Women felt pregnancy was a time of high HIV risk because they desired sex less frequently, which may lead their partners to have outside partnerships. This made PrEP an attractive HIV prevention option for themselves and their infants. Although women believed male partner behaviors influenced their HIV risk, many women perceived that male partners would react negatively, including becoming physically violent, if they discovered that women used PrEP. Clinicians were identified as potential facilitators of PrEP use who could explain PrEP to male partners on behalf of pregnant women. Women said that community-level stigma against HIV and potential for conflating PrEP with antiretroviral therapy (ART) would necessitate that PrEP use be discreet. Our results indicate the importance of addressing risk perception of women, concerns of male partners, HIV stigma, and benefits of PrEP for HIV prevention as programs are developed for pregnant women.

**Keywords:** obstetrics/gynecology, PrEP, women, Africa, qualitative data, prevention of mother to child transmission/vertical transmission, prevention of sexual transmission

## Introduction

WOMEN IN HIGH HIV prevalence regions have substantial risk of acquiring HIV during pregnancy and after delivery.<sup>1–3</sup> An estimated one-third of all mother-to-child transmission of HIV (MTCT) is due to acute maternal HIV infection during pregnancy and breastfeeding.<sup>4–6</sup> To achieve global targets for elimination of MTCT and HIV prevention for mothers, it is critical to deliver HIV prevention strategies

to pregnant and postpartum women at risk for HIV. The World Health Organization (WHO) recommends offering pre-exposure prophylaxis (PrEP) to HIV-uninfected pregnant and breastfeeding women in settings with high HIV burden, as part of a comprehensive prevention of MTCT package.<sup>7–9</sup> Programmatic delivery of PrEP for pregnant and postpartum women is currently being considered in countries where HIV prevalence is high. Yet, data on PrEP use among pregnant/postpartum women are limited and almost exclusively from

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women enrolled in PrEP studies among mutually disclosed HIV serodiscordant couples, who may not be representative of general populations of pregnant women.<sup>10,11</sup>

Before scale-up of PrEP programs for pregnant and postpartum women, it is important to understand what may encourage or discourage PrEP use in this population. Perspectives on PrEP use from pregnant and postpartum women who perceive themselves at risk of HIV may offer valuable insights for informing development of PrEP demand creation and implementation strategies. HIV-negative pregnant women may not perceive themselves to be at risk for HIV and therefore may not be interested in PrEP; conversely women may be aware of or concerned about HIV risk and desire access to PrEP during pregnancy. To date, there have been no evaluations regarding PrEP use during pregnancy from the perspective of PrEP-naïve women who are currently pregnant or postpartum in high HIV burden settings. We report on a qualitative study designed to elicit women's perspectives on PrEP use to inform the development of PrEP implementation strategies for pregnant and breastfeeding women at risk of HIV and to provide guidance on considerations for PrEP delivery for pregnant and postpartum clients.

## Methods

### *Study design and population*

From July to August 2015, we conducted focus group discussions (FGDs) with HIV-uninfected pregnant and breastfeeding women seeking care at Mathare North Health Center and Ahero County Hospital, Kenya who had no prior experience with PrEP. Mathare is an urban site within Nairobi, and Ahero is a peri-urban site near Lake Victoria. Both sites are within settings that have high ( $\geq 10\%$ ) antenatal HIV prevalence<sup>12</sup> and high rates of pregnancy. We purposively sampled adolescent (14–18 years) and nonadolescent women ( $>18$  years) at both sites to capture viewpoints that are representative of these populations.

### *Recruitment*

HIV-negative pregnant and postpartum women were recruited from maternal child health and antenatal care (ANC) clinics at Ahero County Hospital ( $n=31$ ) and Mathare North Health Center ( $n=37$ ). All adolescent and nonadolescent women who had documented HIV-negative status and attended a routine clinic visit during the recruitment weeks were eligible to participate. PrEP was not used in national programs in Kenya at the time the study was conducted. Thus, women enrolled in this qualitative study had no personal experience taking PrEP, and PrEP knowledge in these regions was limited. Study staff spent  $\sim 1$  month per site recruiting and conducting FGDs. Recruitment was discontinued when 8–12 women were identified for each focus group.

This study was approved by the Kenyatta National Hospital–University of Nairobi Ethical Review Committee and the University of Washington Institutional Review Board. All participants provided written informed consent.

### *Data collection*

Semistructured FGD guides containing open-ended questions were developed collaboratively between study team members (K.B.S., S.B.T., M.K.) based on literature reviews

and experiences in HIV prevention research. Facilitators piloted guides with Kenyan investigators and staff, including female staff who were currently pregnant, to ensure cultural appropriateness and clarity of questions. Guides were revised following the pilot to help improve question clarity. Final guides were translated into Kiswahili and Dholuo and translations verified by a second staff member. FGD guides captured beliefs and experiences related to the main topic areas of: (1) research participation, (2) decision making on medication use during pregnancy and breastfeeding, (3) HIV risk and prevention, (4) decision making on whether or when to become pregnant, and (5) PrEP use during pregnancy. This analysis focuses primarily on topic areas 3 and 5. Before PrEP-specific questions, the FGD facilitator posed a hypothetical scenario in which medication used for HIV treatment by HIV-infected individuals is introduced to HIV-negative pregnant women for HIV prevention. The FGD guide, which includes this item, is provided as supplemental material.

FGDs were conducted by a female Kenyan social scientist with experience conducting FGDs in these regions and two female Kenyan notetakers. The facilitator and notetakers were not involved in providing clinical or counseling services for any of the participants at either site. Before FGDs, the facilitator and notetakers were trained on how PrEP works and the studies, which established efficacy of PrEP, and the objectives of the current study. The facilitator was instructed to remain fully neutral throughout the FGDs. The facilitator informed FGD participants that information from the interviews would not be shared with staff from the clinic and their participation would not affect their clinical care.

A total of eight FGDs were conducted, four per study site among adolescents (two FGDs) and nonadolescents (two FGDs). FGDs were conducted in Kiswahili or Dholuo based on participants' preference and audiorecorded. The facilitator probed participants with prespecified and response-driven probes to provide the richest data possible. FGDs were conducted with 5–12 participants and lasted 75–116 min. FGDs were conducted in a quiet, private area of the clinics where participants received clinical services with only the participants, facilitator, and notetakers present. Notetakers took detailed notes during each FGD and the facilitator wrote memos following the FGD; FGDs were transcribed and translated to English by the facilitator continuously throughout the data collection process. All documents were reviewed by the data analysis team.

### *Data analysis*

We performed a conventional content analysis<sup>13</sup> using a modified version of the constant comparison method<sup>14</sup> to produce a description of key concepts and themes arising within and between the individual primary categories represented in the FGD guides. An initial codebook was developed both deductively from the interview guide and inductively from the transcripts. The codebook was iteratively refined through preliminary coding applications and group discussions. Transcripts were imported into ATLAS.ti v.7 (Scientific Software Development GmbH, Berlin, Germany) for data management and analysis. All transcripts were coded independently by one member of the study team (S.B.T., A.N., K.B.S.) using the final version of the codebook. Coding was then reviewed by another team member

(S.B.T., A.N., K.B.S., J.P.). Disagreements in code application were resolved through discussion until consensus was reached. After all data were coded, investigators performed a second level of analysis to identify convergent and divergent themes within and between codes.

## Results

Overall, 68 women participated in 8 FGDs. The median age for all participants was 19.5 years. The median age of first pregnancy was 16 years among adolescents and 20.5 years among nonadolescents. All participants were either currently pregnant or had one to two children. Almost all (94%) non-adolescents were married, whereas 69% of adolescents were married with the remainder reporting having a steady boyfriend (Table 1). Over half (53%) of nonadolescents reported having had secondary school education, whereas most adolescents reported having only primary education (75%). Three major themes emerged from the FGDs related to PrEP use during pregnancy: (1) women's need to mitigate HIV risk due to partners' behavior during pregnancy, (2) implications of confusion over using drugs for HIV treatment as prevention, and (3) potential strategies for avoiding social harm while using PrEP.

### *PrEP provides protection from straying partners*

Almost all participants perceived pregnancy as a time of potentially high HIV risk primarily due to changes in sexual behavior within relationships. Several participants reported feeling "less intimate" or "less free" to have sexual intercourse with their male partners while pregnant. Partici-

pants felt that having less frequent sexual intercourse within their primary partnership led male partners to have outside sexual partners who may be HIV-infected. Participants perceived that this phenomenon commonly occurred within their communities and placed both pregnant women and their infants at risk for HIV.

When I am pregnant, I don't feel like being intimate with my husband. He will say that I have changed and he will go and sleep with another woman. Once he has done that, he will come back with the virus [HIV]. It will not be good for the child and I (Nonadolescent, Mathare).

When presented with PrEP as an HIV prevention strategy, most participants expressed that PrEP would benefit pregnant women, given their high risk for HIV acquisition. Participants perceived PrEP as a means of preventing HIV from spreading within families if male partners "brought HIV into the home" while their primary partners were pregnant. PrEP was seen as a potential strategy for mitigating risk brought upon pregnant women by their male partners' behavior.

I think [PrEP] is a good idea because you can never trust a man. If I can be given [PrEP], I will sacrifice to take it so that I don't get [HIV] infection when I am in that state [pregnant] (Nonadolescent, Ahero).

If it is [HIV] prevention, then I can use it because the men we live with have many eyes [admire other women]. So, I can use the drugs when I am pregnant (Nonadolescent, Ahero).

Protecting infants from contracting HIV also made PrEP an attractive option. Understanding PrEP as a prevention strategy with benefits for both mothers and infants was a motivating factor for PrEP use during pregnancy.

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF FOCUS GROUP DISCUSSION PARTICIPANTS

Characteristic	Adolescent		Nonadolescent		Overall	
	N	N (%) or median (IQR)	N	N (%) or median (IQR)	N	N (%) or median (IQR)
Age (years)	32	17 (16.5–18)	36	25 (22–29.5)	68	19.5 (17–25)
Age at first pregnancy (years)	32	16 (15–17)	36	20.5 (19–22.5)	68	18 (16–21)
No. of pregnancies	32	1 (1–1.5)	36	2 (1–3)	68	1 (1–2)
No. of children	32	0.5 (0–1)	36	1 (0–2)	68	1 (0–2)
Pregnancy status	32		36		68	
Currently pregnant		19 (59)		26 (72)		45 (66)
Currently postpartum		13 (41)		10 (28)		23 (34)
Marital status	32		36		68	
Married (monogamous)		22 (69)		24 (94)		56 (82)
Married (polygamous)		0 (0)		1 (3)		1 (1.5)
Steady boyfriend		8 (25)		0 (0)		8 (12)
Single		2 (6)		1 (3)		3 (4)
Relationship length (years)*	24	2 (1–2)	36	3 (1–8.5)	60	2 (1–5)
Employment	32		36		68	
Housewife		12 (38)		7 (19)		19 (28)
Salaried		2 (6)		9 (25)		11 (16)
Self-employed		2 (6)		16 (44)		18 (27)
Unemployed		16 (50)		4 (11)		20 (29)
Number living in household	32	3 (2–4)	36	3 (2–5)	68	3 (2–4)
Monthly rent (Kenyan shillings)	21	3000 (2500–3700)	29	3500 (2500–4000)	50	3450 (2500–4000)
Highest level of education	32		36		68	
Primary		24 (75)		17 (47)		41 (60)
Secondary		7 (22)		18 (50)		25 (37)
College		1 (3)		1 (3)		2 (3)

I can say that [PrEP] is a good idea. At times you may be tested in the clinic and be found to be HIV negative, but you have a man who loves many women. He left you while pregnant and then he will come back after you have given birth. At that time, you don't know what he has carried in his body. When you go for the test again, you are HIV positive as well as your child. If there is any drug that can prevent my child from contracting the virus, I would go for it (Nonadolescent, Ahero).

#### *Confusion over using HIV treatment drugs for prevention*

Some participants struggled to understand how the same drugs could be used for both HIV prevention and treatment. The FGD facilitator clarified that PrEP is a new HIV prevention tool and is analogous to other medications used for both treatment and prevention, such as malaria prophylaxis. After this explanation, participants expressed that understanding the concept of using HIV drugs for prevention would not be a personal barrier to PrEP use.

There is no problem because using [PrEP] does not mean that I am HIV positive. It is just a preventive measure that will help, so there is no problem (Adolescent, Ahero).

Despite the widespread perception that male partners' behaviors drive pregnant women's HIV risk, many participants felt that male partners would react negatively if they discovered that their pregnant partners were using PrEP. They feared that male partners unfamiliar with PrEP would confuse PrEP for HIV treatment since the "same drugs" are used for both prevention and treatment. If male partners suspect their pregnant partners are HIV-infected, this could create problems within the relationship and family.

Some women will not agree to take [PrEP pills] because if they go home with them, their husbands may start questioning them and this may cause lack of peace in their homes. This is because their husbands will think that their wives are HIV-positive, yet they are not (Adolescent, Ahero).

Women's fear of negative reactions from male partners, even violence, was reported as a reason why women may decline PrEP use. Some participants worried that verbal and physical violence could result if male partners did not understand or accept that PrEP drugs were for HIV prevention instead of treatment. Participants also expressed concern that male partners could react violently if they believed that HIV was "brought into the family" by their female partners.

The moment you start using this drug [PrEP], your husband will start questioning where you came from with the virus and say you have brought death to his house. He will think you have infected him with the virus (Nonadolescent, Ahero). There are arrogant men who will look for machetes. He will think that you are HIV positive and that is why you are using the drug. They can go to the extent of violating you with a sharp panga [machete] because he did not bring the virus home, but you have. It can lead to death and that is a challenge (Nonadolescent, Ahero).

Participants also reported that lack of PrEP awareness among the community at large would have implications for whether pregnant women decide to openly use PrEP. Participants felt that community-level stigma against people living with HIV would lead women to avoid PrEP access

points, if offered within traditional HIV service facilities, since collecting drugs can be associated with being HIV infected.

When the villagers see me getting inside here [the clinic], they will say that I am having the virus [HIV]. You will have that stigma because they will be gossiping that you normally go to the VCT [voluntary HIV counseling and testing center] for drugs. As for you, you know that you are preventing yourself [from getting HIV], but from their gossips, you will feel uncomfortable. When you are walking, you will wish people could not see you (Adolescent, Mathare).

#### *Strategies for avoiding potential social harm associated with PrEP use*

Participants believed that if PrEP could be accessed discreetly and PrEP use could be "hidden" or "secret," it would prevent community stigma among users. Some participants expressed that they would only be able to use PrEP if it could be hidden from others.

If it was me, I could use them secretly because if I do it in the open people will start gossiping about me that I am HIV positive. For me to take it, I have to hide (Nonadolescent, Mathare).

Participants thought that concealing PrEP drugs from male partners would be especially challenging during pregnancy as women often receive drugs, such as antimalarials, hematinics, vitamin supplements, known to male partners during ANC. In this scenario, hiding PrEP use from male partners would require additional measures, as described by one participant:

I would hide them [PrEP pills] under the mattress so that he could not find out. Whenever he could come back from work, the first thing he would ask for were the drugs I was given in hospital and I would pretend not to have heard him (Adolescent, Ahero).

Another solution raised by participants to facilitate PrEP use was to attend ANC as a couple so that clinicians could explain PrEP to male partners. Some participants described clinicians as a "second God," someone you could "listen to" and "trust." Therefore, having clinicians available to provide clear messaging about PrEP use could encourage male partners to accept their pregnant partner's PrEP use and clarify its indication for HIV prevention. Participants perceived that clinician-initiated PrEP counseling would be more effective than women discussing PrEP with male partners alone.

You will have to tell your husband because it [taking PrEP] may cause problems. He will ask you why you are using drugs, yet you are not sick [HIV-infected]. You will have to explain yourself or go to the doctor together...He will agree [after discussing with doctor], but will have a lot of questions (Adolescent, Mathare).

## **Discussion**

This qualitative study identifies factors that may influence PrEP use among HIV-uninfected pregnant women in high HIV burden settings in Africa, including potentially significant barriers to PrEP use, such as partner violence and stigma. While women clearly felt that PrEP could be a helpful tool for protecting themselves and their infants against HIV during

pregnancy, a time of perceived high HIV risk, they worried about the repercussions with partners. Despite feeling that male partners' behaviors drive pregnant women's HIV risk, many participants feared male partners' reactions to PrEP use. Participants believed that confusion over PrEP and antiretroviral therapy (ART) may necessitate discreet PrEP use to avoid stigma and negative reactions. Clinicians were identified as potential advocates who could explain PrEP to male partners and broker its use on behalf of women. Results from this study demonstrate the importance of acknowledging concerns related to male partners and stigma and developing strategies to safely disclose PrEP use to male partners or facilitate discreet PrEP use when necessary. As programs consider scaling-up PrEP to general populations of pregnant women in high HIV burden settings, implementation science studies that further explore strategies for engaging male partners and PrEP messaging that is not framed within the context of ART will be critical.

We previously reported that having an HIV-free infant was the primary motivation for using PrEP among women in mutually disclosed Kenyan and Ugandan HIV serodiscordant couples enrolled in the Partners Demonstration Project who continued using PrEP throughout their pregnancy.<sup>10</sup> In our current study, we similarly found that when PrEP was explained to women without any prior knowledge or experience with PrEP, they found it to be an attractive option for pregnant women to protect themselves and their infants from HIV. Our participants perceived pregnancy as a time of high risk for HIV, primarily due to the behavior of male partners. Previous studies from men who have sex with men and HIV serodiscordant couples have shown that HIV risk perception influences PrEP acceptance and uptake, although risk perception does not consistently reflect actual risk.<sup>15,16</sup> Assessing male partner HIV status and whether women believe that their partner may have outside partners could be an important entry for discussing PrEP. Additional data on behavioral risk factors and HIV risk perception, including beliefs about partners' sexual behaviors, among pregnant/postpartum women and how they may influence PrEP uptake and longitudinal adherence are warranted.

We did not ascertain information on the HIV status of participants' male partners in our study. However, women did not report fear of infection from partners with unknown HIV status who may be HIV infected and put women at risk in pregnancy even without external partnerships. Recent data have underscored biological risk during pregnancy and postpartum that may specifically increase HIV acquisition during this period.<sup>17</sup> Messages to encourage partner HIV testing and underscore the need for prevention among women whose partner HIV status is unknown may be useful to appropriately target women who could gain the most benefit from PrEP in HIV high-burden settings.

In our current study, most participants were married or had stable partners. Even within the context of stable partnerships, participants felt that fear of violence from male partners would discourage pregnant women from using PrEP. Previous studies have shown that pregnant women who experience intimate partner violence (IPV) are at increased risk of HIV acquisition<sup>18</sup> and that IPV influences patterns of PrEP uptake and adherence.<sup>19–23</sup> Confusion over HIV drugs being used for prevention and mistaking female partners as HIV infected were believed to be the primary source of potential violence from male partners in our study. Our participants

perceived that clinician-initiated PrEP counseling with male partners would be more effective than women discussing PrEP with male partners themselves. Integrating PrEP counseling into routine ANC service provision may provide an effective introduction to PrEP for male partners, where clarifications could be addressed with clinicians as neutral mediators or advocates. However, male partner attendance and HIV testing during ANC remains very low in sub-Saharan African settings.<sup>24,25</sup> When male partner involvement is not feasible, PrEP counseling during ANC should also address other strategies for facilitating safe PrEP use and mitigating potential harm.

Our participants felt that PrEP users could be mistaken as HIV infected within communities when collecting drugs on a regular basis from clinics that also provide HIV services and that discreet use would be important. Previous studies from community stakeholders in Kenya have reported that community-level stigma against people living with HIV makes it difficult to provide HIV-related services, including HIV testing and PrEP.<sup>26</sup> Community sensitization that frames PrEP as a new medication-based HIV prevention tool, rather than linking it to ART, is needed to encourage broad acceptance of PrEP. Future research on the provision of HIV testing and PrEP drug pick up outside of clinical settings or integrated within non-HIV care clinics, such as antenatal and postnatal clinics, are needed where community stigma persists as a barrier. PrEP agents in development that can be used more discreetly than a daily oral pill, such as long-acting injectables, are another important area of emerging research.<sup>27</sup>

Our study has limitations. FGDs were with women who had no prior knowledge or experience of PrEP and participants only became aware of PrEP during the FGDs. Our FGDs were also conducted before Kenya Ministry of Health guidelines on PrEP were released and therefore PrEP awareness was generally low. As PrEP sensitization campaigns roll out and information about PrEP is spread, it is likely that increased PrEP awareness will shift perceptions. Future studies should evaluate perceptions of PrEP use among pregnant and postpartum women who have heard of or have been offered PrEP within real-world settings to understand barriers and facilitators of PrEP use. Most of our participants were married or had stable partnerships, which may not be generalizable to all pregnant Kenyan women at risk for HIV. Future work should include larger samples of pregnant women, including those who may have less stable partnerships, to understand perceptions of PrEP use in other populations of pregnant women.

In our study, HIV-uninfected PrEP-naïve women perceived that pregnancy was a time of high HIV risk and that PrEP was an attractive option for preventing HIV. As programmatic PrEP delivery scales up for pregnant and postpartum women, community education about HIV risk to infants if women acquire HIV during pregnancy and sensitization that frames PrEP as a new prevention tool will be important. Approaches for safe, discreet PrEP use, including development of longer-acting biomedical HIV prevention methods are also needed.

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### Authors' Contributions

J.P. and K.B.S. wrote the article. G.J.S. and J.M.B. were the principal investigators of this study and parent study, respectively, and oversaw article preparation. G.J.S. and M.K. conceived of and designed the substudy. K.B.S., M.K., P.A., and S.B.T. designed the interview guides. P.A. conducted interviews. J.P., K.B.S., A.N., and S.B.T. analyzed data. All authors reviewed and provided comments on the results and final article.

### Author Disclosure Statement

No competing financial interests exist.

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