



“You tell him that ‘baby, I am protecting myself’”: Women’s agency and constraint around willingness to use pre-exposure prophylaxis in the Masibambane Study

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Abstract

Objectives: To explore women’s willingness to consider using pre-exposure prophylaxis for HIV prevention in the context of gendered relationship dynamics, in Durban, South Africa.

Methods: As formative research prior to development of a gender-informed intervention to introduce pre-exposure prophylaxis to young, urban, educated women, we conducted six focus-group discussions and eight in-depth interviews with 46 women ages 18–25 years, who were not current pre-exposure prophylaxis users. Women were recruited from clinic and community settings using a criterion-based snowball sampling technique. Qualitative data were coded and analyzed thematically, with a team-based consensus approach for final coding, analytical decisions, and data interpretation.

Results: Women clearly understood the benefits of pre-exposure prophylaxis for themselves and their partners, focusing on promoting health and their right to protect themselves from HIV infection. At the same time, and in accordance with findings from other studies, women were realistic about the concerns that would arise among male partners, including disapproval, loss of trust, possible loss of the relationship, and in some instances, the potential for violence, if they were to propose pre-exposure prophylaxis use. To resolve this tension, some women advocated for covert use as the best option for themselves and others argued for disclosure, proposing various approaches to working with partners to adopt pre-exposure prophylaxis. The suggestion that both partners use pre-exposure prophylaxis was made repeatedly. Thus, women sought to avoid discussions of trust or lack of trust and a partner’s possible infidelities, choosing instead to focus on preserving or even building a relationship through suggesting pre-exposure prophylaxis use.

Conclusion: Women offered diverse narratives on agency and constraint in relation to choosing pre-exposure prophylaxis as a future prevention strategy, as well as ways to engage with their male partners about pre-exposure prophylaxis. These findings speak to the need for interventions to bolster women’s confidence, sense of empowerment, and their communication and decision-making skills for successful HIV prevention.

Keywords

empowerment, gender, HIV prevention, pre-exposure prophylaxis, relationships, South Africa, women

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Introduction

Oral pre-exposure prophylaxis (PrEP) became available as an HIV prevention method in South Africa in 2017, following trials of oral PrEP and vaginal microbicides.^{1,2} Young South African women have some of the highest rates of HIV infection in the world, an epidemiological reality that has shaped prevention efforts for the past two decades.³ With such high rates of HIV infection, South Africa is an important location to promote PrEP. In KwaZulu-Natal Province, the site for this research, 29% of 15- to 24-year-old women live with HIV.⁴ While HIV treatment is widely available, high HIV incidence signifies the failure of prevention efforts to reduce HIV among young women.⁵ In recent years, South Africa has focused on implementing PrEP more widely² through health services and complementary interventions, such as the DREAMS initiative,⁶ albeit with limited success and still far short of targets.⁷

Studies across sub-Saharan Africa document women's ambivalence about PrEP, focusing on partners' concerns about infidelity,^{8–15} whether to disclose to partners¹⁶ fear of side effects,¹⁷ and stigma associated with daily pill use, including concerns about privacy.¹⁸ Recent prospective studies provide insight into barriers to and facilitators of PrEP use over time.^{19–24} In KwaZulu-Natal specifically,²⁵ Govender et al. (2017) found that increasing agency and women's empowerment regarding PrEP were important potential facilitators. In addition, studies of PrEP uptake show increased women's resilience over time, despite initial hesitation.^{17,26} Other studies have examined women's preferences around how to deliver PrEP, finding that women express strong preferences for injectable and other forms of PrEP, beyond the daily pill associated with oral PrEP use.^{10,14,15} Current interventions thus focus on comprehensive adherence support,²⁷ and note the need to increase women's agency and empowerment in relation to PrEP,^{28,29} as well as expanded access to different PrEP formulations as they become available.^{30,31}

Gender power relations influence women's HIV prevention behaviors in multiple ways.³² Connell's (1987)³³ theory of gender and power described the concept, which was then applied in numerous gender and HIV-focused studies (Jewkes et al., 2008),^{34–37} including the design and evaluation of gender-transformative interventions.³⁵ Throughout sub-Saharan Africa, women's unequal gender power dynamics in intimate relationships, families, and society have provided an important explanation for the disproportionately high rates of HIV infection among younger women.³⁸ Furthermore, the confluence of high rates of violence, HIV, substance use and other forms of disadvantage create syndemic effects, in which individual causal factors act synergistically to worsen health outcomes.³⁹ The question remains: how can women assert agency in relationships and decision-making about sexual health despite the

existence of gender power inequalities, along with other structural constraints on accessing prevention and care services?

This article addresses that research gap, examining how young women in Durban, South Africa described opportunities and challenges for using PrEP to prevent HIV and promote their health through the lens of agency, the right to health, and a desire for empowerment, and despite the gendered dynamics of their relationships with male partners. A notable feature of our study is that we targeted young women who were living, working, and attending school in central Durban and who, as a relatively well-educated population, were thought to potentially have greater ability to take up and use PrEP.

Relatedly, this qualitative study was conducted in 2019, at a time when PrEP was just beginning to be widely available in public sector clinics in South Africa outside of the context of clinical trials and demonstration projects. Prior to that, national policy had focused primarily on PrEP use for key populations, such as men who have sex with men (MSM) and sex workers and more recently for young women through DREAMS. We, therefore, were interested in the views of women who may or may not have been eligible or targeted for earlier trials, but for whom PrEP could be highly relevant, given that HIV incidence in South Africa remains high among young women with varied social and economic backgrounds. Because widespread knowledge and acceptability of PrEP will help to create demand and destigmatize PrEP, our aim was to obtain the perspectives of women who were sexually active with men, regardless of whether they met specific criteria for being "high risk," and in line with current guidelines that seek to broaden access to and demand for PrEP, to develop the most appropriate intervention following this qualitative study.

Methods

Study setting

This study took place in Durban (eThekweni), South Africa, the urban center of KwaZulu-Natal Province, in 2019. Data were collected by local research staff at the South African Medical Research Council (SAMRC), as part of a South Africa–US research collaboration. Durban has a young and diverse population: 38% is under the age of 19, with 51% Black, 25% Asian, 15% White, and 9% mixed-race.⁴⁰ Historical socioeconomic, racial and gender discrimination have adversely affected the health of South Africans⁴⁰ who face a quadruple burden of disease from HIV and other comorbidities^{41,42}. KwaZulu-Natal experiences some of the highest HIV rates globally. Although South Africa has 11 official languages and English is the medium of instruction, *isiZulu* is the dominant language of 82.5% of the population in KwaZulu-Natal.⁴³

Study design and sample selection

This article reports findings from the formative qualitative component of the *Masibambane* project, a gender-focused intervention development study being implemented by and for young black South African women living in a high HIV prevalence setting. The qualitative data reported here were collected prior to the intervention phase of study. Prior to enrollment in the study, most participants were not informed or educated about PrEP, except through participation in the focus-group discussions (FGDs) and in-depth interviews (IDIs) and were not current PrEP-users. The study was informed by the theory of gender and power (Connell, 1987) and the information–motivation–behavior (IMB) model.⁴⁴ FGDs and IDIs were conducted with 46 female participants aged 18–25 years in 2019. Participants were urban women with secondary school education; this population was selected as possibly being good candidates for future PrEP use. A local *isiZulu*-speaking team conducted the research, including transcription and translation of the six FGDs and eight IDIs. The team comprised three female interviewers, who filled the positions of study co-ordinator (BA, studying for a master's), and two BA-level research assistants (RAs) and three additional RAs who assisted with transcription and translations. All were highly trained research staff, with prior qualitative research experience and training. Table 1 provides details of the consolidated criteria for reporting qualitative research (COREQ) guidelines in relation to this study.⁴⁵

Using a criterion-based and snowball sampling technique, potential participants were purposively recruited from a public hospital-based clinic in Durban with a youth-friendly sexual and reproductive health program and from community venues, including residences where some students from nearby universities lived. Participants were recruited primarily in person, using a face-to-face approach, with telephone follow-up if needed. Eligibility criteria included (1) aged 18–25 years, (2) self-reporting HIV-negative or unknown HIV status, (3) reporting heterosexual vaginal or anal intercourse in the past 6 months, (4) being conversant in English or *isiZulu*, and (5) being willing to be audio-recorded. Women with discernible cognitive impairment were excluded.

For the FGDs, pre-set recruitment targets were four community-based FGDs and two family planning clinic-based FGDs, with half of each type of group for women aged 18–21 and half for women 22–25 years of age. The size of the focus groups ranged from four to eight participants. Recognizing that the FGDs would yield a group-level, collective understanding of the topics under investigation, we planned the original study to conduct IDIs to elicit a more in-depth, individual-level perspective, and to follow up on any key topics from the FGDs.⁴⁶ This design also ensured data saturation through discussion of

similar topics using both methods and permitted triangulation of data from the two different methods during data analysis. IDIs were thus conducted with eight participants who attended the FGDs. After the FGDs, participants were invited to attend an interview to discuss the same topics. Interested participants were asked to provide contact information for follow-up. From each of the six FGDs, one woman who had volunteered for an IDI was randomly selected and one additional woman was selected from a younger and older community-recruited focus group, to achieve the desired sample size of $N=8$, with a balance in age groups.

Data collection

FGDs and IDIs explored knowledge of PrEP; young women's life concerns and priorities; HIV risk perception; relevance of HIV prevention for them; and prevention strategies they use or have used. Women's views regarding gender and relationship dynamics were explored in relation to choosing PrEP. Table 2 provides a more detailed description of the FGDs guides and the topics for the IDIs.

Women's FGDs and IDIs lasted approximately 60–90 min and were conducted in a private setting at a tertiary educational facility, student residence buildings, the hospital-based clinic, and the SAMRC Offices. FGDs and IDIs were facilitated by one interviewer and one RA who took notes. FGDs and IDIs were mostly conducted in *isiZulu*, the primary language of the women, and some were conducted using a mixture of English and *isiZulu*. All sessions were audio-recorded. Each participant signed an informed consent prior to taking part in FGDs and IDIs. Participants received a reimbursement of R50 (~US\$3.85) for completing the eligibility screening, as well as R150 (~US\$11.55) for participating in the FGD or IDIs.

Data analysis

FGDs were transcribed and translated into English by interview staff in Durban and stored on a password protected computer. Working across geographic locations, an 8 person research team participated in coding and data analysis. To ensure a rigorous process, transcripts were read by all team members to check clarity of translation and meaning. The transcripts were then uploaded to NVivo 12 for data management and analysis. Working iteratively, the research team developed a codebook based on the major areas of inquiry outlined in the FGD and IDI question guides and on new themes that emerged during research. The codebook included six major topical areas: (1) perceptions and knowledge about PrEP; (2) motivations, uptake, and access to PrEP; (3) young women's lives; (4) women, sexuality, and partnerships; (5) intervention pointers; and (6) additional themes, including personal experiences of HIV prevention and

Table 1. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist.

Number	Item	Guide questions/description	Masibambane study
Domain 1: Research team and reflexivity			
Personal characteristics			
1	Interviewer/facilitator: Which author(s) conducted the interview or focus group?		NB, NT, SK
2	Credentials: What were the researcher's credentials? For example, PhD, MD		2 BA level RAs 1 BA, studying for master's
3	Occupation: What was their occupation at the time of the study?		Research assistants; study co-ordinator
4	Gender: Was the researcher male or female?		3 female interviewers
5	Experience and training: What experience or training did the researcher have?		3–5 years of research experience, including qualitative data
Relationship with participants			
6	Was a relationship established prior to study commencement?		NO
7	Participant knowledge of the interviewer What did the participants know about the researcher (reasons for doing the research)		A detailed explanation of the study was provided
8	Interviewer characteristics What characteristics were reported about the interviewer/facilitator? For example, bias, assumptions, reasons, and interests in the research topic		Personal characteristics of the interviewers were discussed briefly
Domain 2: Study design			
Theoretical framework			
9	Methodological orientation and theory What methodological orientation was stated to underpin the study?		The study is informed by the theory of gender and power, and the information–behavior–motivation model (citations for both are in the manuscript)
Participant selection			
10	Sampling: How were participants selected? For example, purposive, convenience, consecutive, snowball		Focus-group discussions: purposive sampling In-depth interviews: random selection of 1–2 individuals from each focus-group discussion
11	Method of approach: How were participants approached? face-to-face, telephone, mail, email		Face-to-face and phone/WhatsApp
12	Sample size: How many participants in the study?		N=46 participants
13	Non-participation: How many people refused to participate or dropped out? Reasons?		73 individuals were screened to achieve the sample size of N=46
Setting			
14	Setting of data collection: Where was the data collected? For example, home, clinic, workplace		Private research venue
15	Presence of non-participants: Was anyone else present besides the participants and researchers?		NO
16	Description of sample: Important characteristics of the sample? For example, demographic data		YES This is fully described in Table 3

(Continued)

Table 1. (Continued)

Number	Item	Guide questions/description	Masibambane study
Data collection			
17	Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?		YES
18	Repeat interviews: Were repeat interviews carried out? If yes, how many?		NO; but IDIs were follow up to FGDs
19	Audio/visual recording: Did the research use audio or visual recording to collect the data?		YES
20	Field notes: Were field notes made during and/or after the interview or focus group?		YES
21	Duration: What was the duration of the interviews or focus group?		Approximately 1 h for each
22	Data saturation: Was data saturation discussed?		YES
23	Transcripts returned Were transcripts returned to participants for comment and/or correction?		
Domain 3: Analysis and findings			
Data analysis			
24	How many data coders coded the data?		8
25	Coding tree: Did authors provide a description?		YES
26	Themes: Identified in advance or derived from data		Both; mainly a priori
27	Software: What software, if applicable, was used to manage the data?		NVivo
28	Participant checking: Did participants provide feedback on the findings?		Yes (1 participant)
Reporting			
29	Quotations: Were participant quotations presented to illustrate the themes? Was each quotation identified? For example, participant number		YES
30	Data and findings: Consistency between the data presented and the findings?		YES
31	Clarity of major themes: Were major themes clearly presented in the findings?		YES
32	Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes?		YES

Table 2. Focus group discussion and in-depth interview guide questions Masibambane Young Women's PrEP Study Durban, South Africa.**Opening remarks****Notes for facilitator:**

Upon arrival to the focus group discussions, women were thanked for their participation and attendance, and for agreeing to participate in this research. The intent of this portion of the focus group agenda is to welcome participants and make them as comfortable as possible by explaining the purpose of the focus groups and the details of the procedures. Participants are informed that the focus group and other procedures will take approximately 2.5 h

1. Objectives of the focus groups are as follows:

- a. Find out what are the information gaps among women regarding oral PrEP, as well as what they may have heard about the method that might influence their use of it
- b. Explore if and how oral PrEP would be acceptable as a strategy specifically designed for young women in the age group 16–25 years
- c. To understand social norms related to relationships, HIV prevention and reproductive health by exploring women's lives and concerns and to understand how these do—or do not—influence their willingness to use oral PrEP as an HIV prevention strategy
- d. To explore how social and community norms related to gender, power and relationship dynamics, may influence women's willingness to use oral PrEP
- e. What are women's expectations if they were to use oral PrEP, that is, what positive and negative outcomes would women like themselves expect in relationships with partner and community members when they disclose use of oral PrEP

The focus-group discussions (FGDs) explored six specific content areas: (1) women's knowledge of PrEP, (2) factors that would influence PrEP use, (3) individual barriers to using PrEP, (4) messages that would encourage PrEP use, (5) community barriers and facilitators, and (6) community perceptions of HIV. The in-depth interviews (IDIs) explored topics highlighted in FGDs at an individual level, discussing knowledge of, beliefs about, motivators for, and concerns about PrEP in the context of gender, relationships, and PrEP stigma.

Below, we provide exemplar questions for Content Area 1, Women's Knowledge of PrEP.

As most women were not familiar with the use of antiretroviral therapies (ARTs) or PrEP for HIV prevention, the initial questions are accompanied by a statement about PrEP that is read by the facilitator of the FGD.

1. Attitudes toward oral PrEP (community and individual)

Questions	Probes
Q1.1. Have you ever heard of oral PrEP?	<ol style="list-style-type: none"> a. Is this a term you are familiar with? b. What do you know about PrEP?
Q1.2. If you have heard of oral PrEP, where did you hear or learn about it from?	<ol style="list-style-type: none"> a. Are the main sources of information about PrEP? (family/friends/community/media/others)
Q1.3. What are community perceptions about oral PrEP?	<ol style="list-style-type: none"> a. What do people you know say about PrEP, or about oral PrEP specifically? a. Do you want to know more about? b. About terms that you don't understand? What other information about oral PrEP would you like? c. Myths and misconceptions: Are there things that you have heard about PrEP that you wonder whether they are true or not?
Q1.4. What questions do you have about oral PrEP?	
Q1.5. What are some of the things that would influence young women like yourselves to consider using oral PrEP?	<ol style="list-style-type: none"> a. Are motivating or enabling factors—things that would encourage young women to use oral PrEP? b. Are factors that might prevent young women from considering oral PrEP? c. What are other barriers and challenges to oral PrEP?

(Continued)

Table 2. (Continued)

After this discussion, the facilitator gave basic information about oral PrEP, reading from the following script:

PrEP means pre-exposure prophylaxis, and it is the use of anti-HIV medication to keep HIV-negative people from becoming infected. Oral PrEP is a daily pill. If taken every day, PrEP can lower the risk of getting HIV by at least 90%. There are minimal side effects; however, consequences of long-term use are not known. PrEP has been shown to be very safe for women and men, even for women who are trying to get pregnant, are pregnant, or are breastfeeding. PrEP is VERY effective in preventing HIV, but it does not protect against other sexually transmitted diseases, such as chlamydia or gonorrhea. Only condoms can protect against those infections. Prescription of oral PrEP requires a medical examination as well as medical follow-up

2. Facilitators related to choosing to use oral PrEP and outcome expectancies (including partner relationship impact)

This part of the focus group addressed potential barriers and/or facilitators for women to use oral PrEP as an HIV-prevention method. Focus-group participants were asked to write down three or more possible reasons for choosing to use oral PrEP

Then, this section consists of eight detailed questions and sub-questions and follow-up probes on the following topics: challenges in taking daily medication, for example, oral PrEP; concerns about PrEP side effects; confusion of ARTs and PrEP; assumptions that person who takes PrEP is HIV positive; partner concerns and reactions; pros and cons of covert use; how would condoms fit in with PrEP use, for an individual or her partner; what about men using PrEP; what are the factors that will make women think PrEP is a good idea for them; what are the factors that might make them reject the idea?; what are important messages that could help women to accept PrEP?; what are different types of PrEP that women would like; what are different venues (outside of clinics) that would be preferred for PrEP distribution.

3. Community-level barriers and facilitators to HIV and pregnancy

The focus group then moved on to a discussion of community-level barriers and facilitators

Facilitator introduction: Now we would like to speak with you about some of the factors in your life and in your community that can help you to successfully prevent HIV infection—and also things that are challenges to preventing HIV infection. We will also talk about pregnancy prevention.

This section consists of 10 detailed questions and sub-questions and follow-up probes on the following topics: What are the biggest concerns that women face in their lives; where does becoming infected with HIV fit into a person's concerns; what are the HIV prevention methods that women prefer?; what about men and their preferred HIV prevention methods; what about pregnancy prevention; what about HIV testing—how do you or your friends think about HIV testing; how frequently do you test?; what are the stigma and negative reactions to PrEP use that a person might face?; who controls decisions about contraception and/or condom use and other prevention; how is risk for HIV currently in your community?; what about issues like education and a good job—how do these issues influence how much a person is at risk for HIV?

The IDIs were based on a shortened and more focused set of individual questions on the topics outlined in the second and third sections above.

men's attitudes toward PrEP. Coding of the transcripts was conducted in pairs. In this system, each transcript was double-coded, once by a team member in South Africa and once by a US-based team member. To enhance trustworthiness, disparities in coding were discussed by each pair of coders and resolved. Following final agreement on all coding decisions, the data manager systematically merged the NVivo files for each code, creating a centralized database. Working in the coding pairs, the teams then wrote thematic summaries for each code. The analysis of this article draws on codes related to (1) young women's sexuality; (2) notions of PrEP, including ideas about men's perceptions; (3) disclosure to partners, peers, and families; and (4) relationship issues and dynamics to address the topic of gender, sexuality, and relationship norms.

The institutional review board (IRB) approval was obtained from the SAMRC (EC015-9/2018) and from the New York State Psychiatric Institute at Columbia University Irving Medical Center IRB Protocol #7682.

Results

Study participants

The 46 participants ranged from 18 to 28 years old (mean age=21.2). Most women (84.8%) were current students, all had completed secondary education, and 58.7% also reported post-secondary education (Table 3). Most participants had never used PrEP and had little knowledge of PrEP as an HIV-prevention method.

Themes

Women framed their discussions of PrEP, prevention and health through several diverse narratives. First, women's desire for agency and independence in making decisions about their own health was a paramount concern. Second, women understood the health benefits of PrEP, and they framed this in relation to control over HIV prevention and their right to protect themselves. Simultaneously, women face constraints in seeking to enact health protecting behaviors, and they described how these constraints occur in relationships with male partners. Despite asserting their desire for agency related to decisions about prevention, they acknowledged the limitations to achieving this within their own relationships. Finally, in considering PrEP as a potential future prevention strategy, the issue of whether or not to disclose to one's partner was at the crux of women's thoughts regarding decisions related to initiating PrEP. Women's narratives on this topic were complex and varied, reflecting notable differences of opinion, as they sought to balance their rights and desires for prevention with concerns about loss of trust and other negative reactions to discussing PrEP with a partner.

Table 3. Demographic characteristics of 46 women recruited for FGDs on PrEP, Durban, South Africa, 2019.

Characteristics	N (%)
Age	
18–20	20 (43.5%)
21–23	14 (30.4%)
24–25	12 (26.1%)
Student status	
Student	39 (84.8%)
Not student	7 (15.2%)
Employment status	
Employed	3 (6.5%)
Unemployed	43 (93.5%)
Education	
Secondary	19 (41.3%)
Post-secondary	27 (58.7%)
Relationship status	
Has a partner	41 (89.1%)
Does not have a partner	4 (8.7%)
Refused to answer	1 (2.2%)
Number of children	
None	35 (76.1%)
One or more	11 (24.9%)
HIV testing status	
Tested within the past year	42 (91.3%)
Tested more than 1 year ago	3 (6.5%)
Never tested	1 (2.2%)
No. of sex partners, last 3 months	
1 or none	28 (60.9%)
2 or more	7 (15.2%)
Refused to answer	11 (23.9%)
Recruitment location	
Community	30 (65.2%)
Clinic	16 (34.8%)

Women's agency: women have a right to protect themselves from HIV

Most women were not familiar with PrEP prior to participation in the study. After a short explanation of PrEP, however, they understood clearly that PrEP could be beneficial to them and their partners. They expressed positive views of PrEP and how it could make a difference in their lives, referring to PrEP as a “good course” that can help them to navigate the many challenges they experience in their “city life,”

I: . . . Will using PrEP by yourself make a difference in your life?

Honestly, yes. Besides myself, it [PrEP] is generally for a good course to use it. Even though we will forget it but it's a good course because you know that city life is hectic, everything is fast. You can get infected without even noticing and knowing that you are exposed to a lot of diseases and you can get them if you are sexually active. If you know that you are taking

PrEP you know that minus one trouble, you are good with one.
Clinic Focus Group, ages 22–25

In addition to the potential benefits, women acknowledged the potential stigma associated with PrEP. Many women discussed the prevailing idea that a woman using PrEP (or otherwise taking steps to protect herself from HIV) could lead a boyfriend to think she had other partners. Yet even while acknowledging stigma, women rejected the idea that using PrEP would signify being promiscuous or having multiple partners:

Well on my side, regarding PrEP there is nowhere where I heard that we must be promiscuous, what I heard is that we are protecting ourselves from getting infected. **Clinic Focus Group, ages 22–25**

As illustrated by the FGDs below, women asserted agency regarding the decision to protect themselves, stating that ‘we need to teach ourselves to be independent and not be discouraged by your partner about what you need to do or what not to do’:

If it means that the relationship should come to an end between us, let it be, because when someone says you should not use PrEP, then it means that, that person is saying that you should not protect yourself knowing very well that he does not protect himself. **Clinic Focus Group, ages 22–25**

More broadly, women discussed their right to protect themselves and also their right to health.

PrEP as a health benefit

Related to positive notions of PrEP as a woman-controlled prevention method, women recognized that the responsibility for prevention and health rested squarely on them. In thinking about potentially using PrEP, participants expressed concern about how they would enact PrEP use in their relationships. On one hand, they assumed that male partners would be suspicious of a woman’s motivation for using PrEP. On the other hand, they thought that men were not taking steps to protect the relationship on their own, either through condom use or by reducing their number of partners. But women asserted their right to prevention and to remaining free of HIV, as in this discussion:

Participant 1: What are you protecting yourself from?

Participant 2: I am protecting myself from getting HIV, it doesn’t mean I need to be promiscuous and sleep around with different men, no! I am protecting myself from my current partner it doesn’t mean that he is [protecting himself]

Participant 1: You tell him that baby I am protecting myself and I am drinking pills for you. **Clinic Focus Group, ages 18–21**

One participant explained her concern about potential exposure to HIV because she is recently sexually active with a new male partner in a long-distance relationship. In exploring how PrEP could reduce the stress of HIV risk, this participant explained that it could supplement her existing HIV prevention methods of condom use and HIV testing:

I think that using PrEP would reduce stress for me because, if it happens, let’s say, my partner and I, we meet unexpectedly or having not planned, or maybe find that we went out and then we decide that, “Okay, let us go to his house” and then, during that time, find that, maybe he does not have condoms. So, just because I have PrEP, I will not be worried that, what if he is HIV positive, since we have never tested it (HIV) together. **In-depth Interview, P22F, 24 years old**

In one FGD, some women discussed their preferences for not using a pill:

I think that women would be interested in using, but only if it will be in a form of an injection because, as for pills, some of us really do not like them. Others do mention that, even in clinics. Can you imagine having pills that you have to drink every day. **Community Focus Group, ages 22–25**

Women thus viewed PrEP as providing both mental and physical health benefits by addressing their concerns about HIV in long-distance relationships where there might be other partners, or if they did not know their partner’s HIV status. PrEP use was thus viewed as having the potential to allow women greater control over their own health.

Gender dynamics of women’s relationships

In considering whether to use PrEP, women reflected further on their concerns. If they chose to use PrEP, women feared causing stress or discord with their partners, and risking both the loss of the relationship, or for some women, the threat of violence or injury to themselves. Thus, women’s positive attitudes toward PrEP were tempered by recognition of the reality of their relationships and, in particular, by frequently unequal gender dynamics. These dynamics were acknowledged as making it difficult for women to exercise their desired agency or take steps to protect themselves.

Women are at a greater risk of HIV than they would like due to men having multiple partners, or not wanting to use condoms; participants received constant reminders that they do not always control the terms of sexual encounters.

The bad thing is that, sometimes, he insists on us having unprotected sex, which is not a good thing because there are a lot of consequences which are associated with having unprotected sex. **In-depth Interview P11, 18 years old**

Specifically, women feared the potential for a breakup stemming from a perceived loss of trust or disagreement. In the focus groups, women actively engaged with specific details of how their partners might react:

So, it means that, since you are taking pills, it means that you do not trust him. He needs to go and find someone who will trust him and do everything with that person, since you are now taking pills to prevent yourself from getting HIV. **Community Focus Group, ages 18–21**

Responding to an interviewer's question, women reflected concerns that discussing the idea of PrEP use with a partner would lead to mistrust:

Alright. So, do you think your partners would support using oral PrEP?

Participant G: He will say I am cheating

Participant B: I will need two years just two years of explaining to him about PrEP *laughs* He won't understand. **Clinic FGD, ages 22–24**

Women recognized the possibility for relationship difficulties if they were to discuss PrEP, and there was widespread understanding of the risks to one's relationship if a partner were to discover her PrEP use. Across the different focus groups, women discussed their concerns for how their decision to use PrEP would result in a fight:

let's say I have a partner, but I suspect that he is cheating, and I take PrEP and my partner is not taking it and he finds out that I am taking it and maybe that results in a fight. **Clinic Focus Group, ages 22–24**

For many women the prospect of such disagreement led to broader concerns about violence. With many women facing the very real threat of violence in their relationships, addressing these concerns must be part of any PrEP promotion strategy. Women's discussions of mutual protection, or benefit, from PrEP use, along with ideas of both partners using PrEP, were attempts to focus attention on strengthening relationships, not placing women at greater risk. Although fears of violence were often centered on the relationship itself, some women also argued for taking PrEP to mitigate the risks of life in a violent setting: 'he needs to know my reasons why, I am going to tell everything cause it's not like I'm doing anything wrong. I'm just protecting myself from the kind of environment.' (Clinic Focus Group, ages 18–21)

Reflecting these concerns, women discussed various strategies to discuss PrEP use with partners. These included educating partners about PrEP and its benefits, and focusing on PrEP use as a decision to promote the health of both partners.

I: Okay. How do you think women should talk to their partners about this [PrEP]? How should they put it?

Participant L: So, it is easier maybe to first educate them about it, if need be, if you know that there are high chances that they do not know about PrEP . . . So, when you explain to him, make them see it in your view, and how important it is, not only for your relationship with them, but for your health, in future. **Community Focus Group, ages 22–25**

Women emphasized that this could be more easily accomplished in a relationship with good communication:

As, G, to add to that, I feel that, as we all know that relationships are not the same. Some people communicate, some people can't. So, okay, if in your relationship, you can communicate with your partner, you can just sit down with them and let them know. Or, you can just take your partner to one of the programs that are available, so that he can be educated by people who know better. Or, you can do some research and give him that research information that you have. **Community Focus Group, ages 18–21**

In discussing the importance of good communication, women highlighted ways that introducing PrEP could be successful. At the same time, the discussion of "good communication" suggests a relationship where a woman feels safe and respected. In such a relationship, discussing PrEP would not be a problem. However, for women who are uncertain about a partner's reaction to discussing PrEP, the idea of "PrEP as a future benefit" or "PrEP as a benefit to both partners" or "PrEP as something that can protect a woman if she is raped" may provide more feasible avenues for initiating a discussion about PrEP, by taking the emphasis off of the female partner and framing PrEP as a benefit to the relationship. In this way, women sought to avoid discussions of trust or lack of trust and a partner's possible infidelities, choosing instead to focus on how to preserve or even build a relationship through suggesting PrEP use.

Similarly, the suggestion that both partners should use PrEP was made repeatedly. As one woman elaborated, an ideal scenario for PrEP might be one in which both partners would be informed and use PrEP, thus reducing suspicions and lack of trust between partners.

PrEP should be like, vice versa. Men should also take it and women should also take it too, so that there will be a mutual understanding, because my partner can get HIV from me and I can also get HIV from my partner. Which is why, both of us, we need to go to the clinic, in order to be informed about it. **Clinic Focus Group, ages 18–21**

Beyond the issue of trust, women discussed that having their partners use PrEP could be beneficial as a mutual prevention strategy, pursued and discussed by both partners:

I think that, if I am using PrEP ourselves, we also need to be motivated, that it is also important that I also force him to do it (take PrEP), even if my partner does not want to, so that my partner also uses PrEP too, so that both of us can protect ourselves, so that it does not seem like I am using it because I want to test whether he is loyal or not. **In-Depth Interview, age 22**

Besides removing the burden for prevention from women, mutual use of PrEP was viewed as a strategy that could increase acceptance of PrEP and also provide mutual support for the daily regimen of pill-taking:

I think it would be best if one can inform her partner about taking PrEP, maybe, so that he can also be interested. And then, they can make up time, that, “Okay, at this time, we are taking PrEP.” So that they can remind each other. It would be more interesting if you are taking it with your partner. **Community Focus Group, ages 18–21**

Women thus affirmed opportunities to promote shared prevention strategies, and to move forward by building connection to a partner through open discussion of PrEP use. These expressions of a desire for mutuality with using PrEP together, and also discussing other HIV prevention strategies, were juxtaposed against women’s challenging relationship situations.

Disclosure, non-disclosure, and the right to covert use

Women were asked to discuss the idea of covert, or clandestine, use of PrEP; or the idea of using PrEP without informing their partner. Some women advocated this idea, viewing it as their right, and also a strategy to ensure they could protect themselves without interference or a negative reaction from their partner. In the focus groups, women discussed ways to establish their partner’s attitude or level of support for PrEP use and stated that it is their right not to disclose if this attitude was found to be negative. More broadly, women articulated the pros and cons of disclosing PrEP use to their partners, emphasizing the importance of trust and communication, but also highlighting other valid reasons for taking PrEP, such as high levels of rape and other violence in many communities.

Women’s perspectives on whether it was beneficial or desirable to inform a partner of PrEP use differed substantially. Many women viewed PrEP use as a right and a means of protecting themselves. Others believed they would experience negative consequences if their partner did not understand the reasons for using PrEP. These diverse perspectives are captured below; when asked by the facilitator if informing a partner about PrEP use was important, women responded on both sides of the question:

Participant E: Yes, it is important.

Participant H: No, it is not important. **Community Focus Group, ages 18–21**

Later in the discussion, one woman reiterated that it is a woman’s right to use PrEP, and it should not be necessary to hide that from a partner. Yet she noted that not every partner will react well to the idea of using PrEP:

I do not see the reason to lie or to hide it, I really do not see the need to hide because this is for your own good, for both of you. So, I do not see the need for him, not to know about it. But, as I have mentioned that, by him knowing about it, it also depends on his mentality and what type of a person he is. It depends on whether once he is aware, he might then go and talk about you and say, “That girl is like this and that, and she is taking something like this.” Because, men have their own mentality, but they need to know about it. **Community Focus Group, ages 18–21**

In discussing the dilemma of when and how to discuss PrEP with a partner, women asserted both their right to PrEP use and their right to covert use if they choose not to inform their partner. At the same time, they sought strategies that would build relationships, describing PrEP as a long-term health benefit for both partners. This ambivalence reflects the complexity of women’s lives and relationships in a time of evolving gender relations and norms, leading women to express uncertainty about whether or not they would want or be able to disclose PrEP use in their relationships, or even discuss the topic successfully.

Discussion

Women’s diverse narratives about PrEP reflected a strong sense of agency—that women can and should control health-related decisions. Similar to findings from other studies, women emphasized their right to protect themselves from HIV infection, rejecting negative views of women who use PrEP as promiscuous or unfaithful. Yet, women recognized constraints in their own lives and relationships that could make exercising this agency difficult. Women were largely unfamiliar with PrEP as an HIV-prevention method, an important finding that reinforces the still-limited prevention options available to women two decades into South Africa’s severe HIV/AIDS epidemic. Upon explanation of the purpose and benefits of PrEP, women responded positively, emphasizing their right to use PrEP to protect themselves. Women immediately understood the potential health benefits of PrEP, and also viewed PrEP as something that could empower and protect women, referencing ideas of sexual rights. Overall, these narratives pointed to a sense of agency and a person’s right to good health. Similarly, the recent Community Health Clinic Model for Agency in Relationships and Safer Microbicide Adherence (CHARISMA) study found

high acceptability and feasibility for a tailored lay counselor PrEP intervention aimed at building agency and safety in women's relationships.^{28,29}

Women also readily described the challenges posed by male partners and the complexities of disclosing, or even initiating, discussion of PrEP use within a relationship.

Because covert use of PrEP could introduce suspicion or mistrust if a male partner found out, women advocated for other strategies first. PrEP and other prevention products have long been viewed as a way to overcome the constraints of gendered power dynamics in heterosexual women's relationships, as women could use this method privately, without informing partners.⁴⁷⁻⁴⁹ At the same time, covert use of PrEP is not the preference of all women, as reflected in the heated discussions within the focus groups for this study. In those discussions, women voiced concerns about whether to disclose and what would happen if one did or did not do so. In particular, women feared the consequences if a partner were to find out about PrEP use, highlighting that covert methods do not fully address the gendered relationship dilemmas that women face.

Given the community-engaged focus of this research and the need to connect with the realities of on-the-ground health service provision, we focused this inquiry on available prevention methods. Oral PrEP became available to women via the public sector in 2018-2019, as this study was beginning. Nonetheless, women asked about the possibility of not taking a daily pill, and also about ways to access PrEP outside of health services. Going forward, it will be important for HIV prevention interventions informed by this research to address women's sexual and reproductive health needs in a comprehensive manner, and to include information about oral and injectable forms of PrEP, as well as the ring and multipurpose technologies.

As new, potential users of PrEP, women in this study focused heavily on ways to introduce PrEP as a strategy that could benefit their relationship. Repeatedly, women raised the issue of both partners using PrEP, describing how this could foster communication and even improve the success of adherence, for example, if both partners were involved in remembering to take pills. More broadly, women feared that not discussing PrEP use with a partner was a missed opportunity to strengthen, rather than threaten, a relationship. Thus, some women viewed PrEP as a method that could be beneficial for women and for their partners—providing a tangible benefit to a relationship through fostering communication. Other studies have emphasized the need to support young women in making decisions about PrEP and in sustaining use of HIV prevention products over time.^{8,28} Importantly, this study found a diversity of opinions about informing or not informing a partner about PrEP use. Most women expressed concerns about negative reactions of some kind, a reminder that discussing PrEP and initiating HIV prevention is not the reality of every woman. Oral PrEP, in particular, may make

this more difficult as it is a daily pill that might be more easily discovered by a partner or family member. Real concerns were expressed by many about violence and other negative reactions including loss of trust or a breakup caused by a partner's anger.

Implicit in many women's comments about their desire for prevention strategies that were mutually agreed upon was a sense of not wishing to bear sole responsibility for prevention within an established relationship. Correctly or incorrectly, most women viewed themselves as being at risk of HIV from the actions and behaviors of their partners, not themselves. To then suggest that women carry the weight of responsibility for prevention did not sit well with some women. The FGDs were an important locus for rich discussions about women's views of PrEP and the potential challenges and risks posed by the decision to use or not use PrEP. We reflect on the fact that the group format appears to be a positive feature of this research, allowing shared views to emerge, and also a forum for women's discussions and disagreements over the best way to approach partners. In further development of the intervention to follow, we plan to develop a group-based format where women can discuss issues and consider solutions, reflecting women's own stated needs and priorities.

This study has important limitations. As with any research on sensitive behaviors, our data are subject to social desirability bias. Also, women's expressions of interest in PrEP were based on one or two research encounters; the actual transition to using and maintaining PrEP use over time would rely on more specific intervention and motivation. As a small qualitative study, these data are not generalizable, nor are they representative of all African women. However, they do offer important insights into women's current interests and concerns related to PrEP outside the context of clinical trials.

What are the implications of our findings for implementing PrEP and for women's health overall? Recent studies have suggested the need to empower women around sexual health decisions and our findings strongly support this intervention need. Women in this study reiterated that they value relationship building and communication to preserve relationships. In addition to providing women with knowledge and negotiation skills to bring into discussions with male partners, PrEP messaging should be oriented strongly toward the idea of PrEP as a shared strategy to protect a relationship. These findings highlight the relevance of focusing on PrEP use for "us" to protect "us" (e.g. both partners in a relationship), to help women move beyond the threat that PrEP poses for some male partners, and to move beyond the idea that "I am using PrEP to protect myself from you" which suggests lack of trust. Indeed, framing PrEP as a way to "protect the relationship" was found to promote adherence in sero-discordant heterosexual couples,⁵⁰ suggesting the value of this framing for different user groups. Promotion of PrEP has also been

successful in populations other than heterosexual women, most notably among gay men in both southern and northern contexts.⁵¹ There may be important lessons learned from these examples.

The findings from this study are valuable in development of interventions that are highly specific to women's needs, in one of the world's highest HIV prevalence settings. In this study, we focused on available prevention methods, which in the South African context at that time were limited to oral PrEP. Yet, recent developments suggest that injectable methods for PrEP as well as the ring will soon be available. Thus, the findings from this study, in which women eloquently described their ideas for how PrEP could be a strategy to strengthen communication between partners, particularly in a scenario where both partners used PrEP, and also to engage with a partner about other prevention issues, could be used to create interventions to promote the full spectrum of PrEP options once they are available. Indeed, having interventions ready now to support the next generation of HIV prevention methods for women and their partners is invaluable, inclusive of all forms of PrEP that are likely to emerge for regular use soon, such as injectable PrEP and the ring. This suggests the need for interventions that focus broadly on women's sexual and reproductive health needs, including skills, knowledge, and the ability to implement their identified needs for successful use of PrEP and other HIV prevention.

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