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I Knew I Would Be Safer. Experiences of Kenyan HIV Serodiscordant Couples Soon After Pre-Exposure Prophylaxis (PrEP) Initiation

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Abstract

Pre-exposure prophylaxis (PrEP) for HIV-uninfected persons is highly efficacious for HIV prevention. Understanding how people at risk for HIV will use PrEP is important to inform PrEP scale-up and implementation. We used qualitative methods to gather insights into couples' early experiences with PrEP use within the Partners Demonstration Project, an open-label implementation study evaluating integrated delivery of PrEP and antiretroviral therapy (ART). PrEP is offered to HIV uninfected partners until the HIV-infected partner initiates and sustains ART use (i.e., PrEP as a ''bridge'' to ART initiation and viral suppression). From August 2013 to March 2014 we conducted 20 in-depth dyadic interviews ($n=40$) with heterosexual HIV serodiscordant couples participating at the Thika, Kenya study site, exploring how couples make decisions about using PrEP for HIV prevention. We developed and applied deductive and inductive codes to identify key themes related to experiences of PrEP initiation and use of time-limited PrEP. Couples reported that PrEP offered them an additional strategy to reduce the risk of HIV transmission, meet their fertility desires, and cope with HIV serodiscordance. Remaining HIV negative at follow-up visits reinforced couples' decisions and motivated continued adherence to PrEP. In addition, confidence in their provider's advice and client-friendly services were critical to their decisions to initiate and continue use of PrEP. Strategies for wide-scale PrEP delivery for HIV serodiscordant couples in low resource settings may include building capacity of health providers to counsel on PrEP adoption while addressing couples' concerns and barriers to adoption and continued use.

Introduction

HIV SERODISCORDANT COUPLES, in which one partner has HIV and the other does not, are an important population at high risk for transmitting HIV. In Kenya, an estimated 45% of married or cohabitating couples in which one partner has HIV are HIV serodiscordant.[1] Recent clinical trials and demonstration projects have demonstrated that antiretroviral pre-exposure prophylaxis (PrEP) for persons at risk of HIV acquisition is highly efficacious for HIV prevention, including for HIV serodiscordant couples[2] and other populations.[3] The World Health Organization has recommended PrEP as part of HIV prevention options for HIV serodiscordant couples,[4] and ongoing demonstration projects among couples[5] and other at risk populations have confirmed high acceptability and effectiveness of PrEP. [6,7]

Studies among a variety of populations enrolled in PrEP clinical trials, including serodiscordant couples, men who have sex with men, and women at risk, have reported motivations related to PrEP initiation and adherence, including acceptance and support from clinic staff, peers, friends, and sexual partners, and indirect benefits (e.g., medical care).[8,9] In contrast, concern and apprehension about the investigational product (e.g., potential side effects, harm, and sickness) often led to non-adherence.[10,11] One theme that appeared to be important for HIV serodiscordant couples was that PrEP offered couples a solution to living with serodiscordance (the ''discordance dilemma'') and partners' support contributed to high PrEP adherence.[12]

For HIV serodiscordant couples, antiretroviral treatment (ART) for the HIV-infected partner is a potent HIV prevention strategy.[13] But delays in ART initiation are common and

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once initiated, adherence to ART is needed to attain a state with HIV viral suppression over the first few months of therapy and continued high adherence is of lifelong importance for optimal benefits.[14,15] In the Partners Demonstration Project in Kenya and Uganda, we are offering PrEP to HIV-uninfected partners in serodiscordant couples as a ''bridge'' to ART initiation by the HIV-infected partner, providing additional HIV protection until HIV-infected partners typically are virally suppressed on ART.[5]

Data on PrEP uptake are needed to guide PrEP implementation and counseling in existing public health clinics, particularly for HIV serodiscordant couples, who are a priority population for PrEP. Such data include understanding the acceptability of PrEP for HIV serodiscordant couples outside of clinical trials and the feasibility of the delivery strategy of ''PrEP as a bridge to ART.'' This study explored how serodiscordant couples navigate and make decisions about using PrEP for HIV prevention in an open-label PrEP demonstration project in which couples were counseled about the known efficacy of PrEP and ART. We used qualitative methods to gather insights into couples' decision-making, motivations for PrEP uptake, and experiences soon after PrEP initiation.

Methods

Study design

From August 2013 to March 2014, we conducted dyadic in-depth interviews with heterosexual HIV serodiscordant couples participating at the Thika, Kenya site of the Partners Demonstration Project.

Setting

The Partners Demonstration Project is an ongoing open-label implementation project evaluating integrated delivery of PrEP and ART for HIV prevention among 1013 high risk HIV serodiscordant couples, of whom approximately one-third (332) were enrolled at the Thika, Kenya site.[5,16] PrEP is recommended for HIV-uninfected partners until HIV-infected partners initiate and sustain ART use for at least 6 months.[5,17] ART is offered following Kenyan policies, which since 2014 recommend ART for all HIV infected people with an HIV uninfected partner, regardless of CD4 count. All participants were members of a mutually-disclosed HIV serodiscordant couple, aged ≥18, and not using PrEP or ART at enrollment.

Sampling

Our purposeful sample included couples in which the HIV uninfected partners had initiated PrEP, and some in which the HIV infected partners had initiated ART. The couples who were sampled included HIV infected women and men across a range of ages and baseline CD4 counts.

Data collection

We used a semi-structured interview guide to address couples' decisions to use PrEP and/or ART and their early experiences of using these antiretroviral-based prevention strategies. Members of couples were interviewed together, as a dyadic interview, to enable assessment of the couples' dynamics and communication patterns; interviewers completed a post interview questionnaire to capture these details. Interviews were conducted in the couples' preferred language (Kiswahili or English) at a time mutually convenient for the participants and study staff. SV and MN produced English transcripts from the local language recordings.

Data analysis

We developed and applied deductive and inductive codes and identified key themes related to PrEP initiation and use experiences. Four analysts (KN, SV, KC, MN) read through all the transcripts, and SV and KC coded the interviews using an agreed codebook. KN, KC, and SV reviewed the coded transcripts for code agreement. Coding was done using with Atlas.ti [version 7.1.2, Berlin].

Ethics

The study was approved by the Kenyatta National Hospital Ethical Review Committee and the University of Washington Human Subjects Division. All participants provided written informed consent.

Results

Participant characteristics

A purposeful sample of 20 couples ($n = 40$ individuals, including 9 couples with HIV-infected male partners and 11 with HIV-infected female partners) participated in the in-depth, dyadic interviews. The median age was 29 years (range 20–57) and the median duration of partnership was 2 years (range 0–20 years). Half of couples had at least one child together (median = 1, range 0–4). All 20 HIV-uninfected partners had initiated PrEP in the prior year (median = 8 months, range 2 weeks to 12 months), and HIV-infected partners in 11 couples had also initiated ART by the time of the interview (median = 5.6 months, range 1.8–9.9). Prior to joining the study, none of the couples had heard of antiretroviral-based prevention (both ART and PrEP for prevention) and few were aware of their HIV serodiscordant status [median time from learning HIV discordance to study enrollment was 1 month (range 0–26)] (Table 1).

Table 1. Demographic Characteristics of Male and Female Study Participants

	Women (n = 20) n (%) *or median (IQR)*	*Men* (n = 20) n (%) *or median (IQR)*
Age	29.1 (20–43)	36.6 (27–57)
HIV infected	11 (55%)	9 (45%)
Married	18 (90%)	18 (90%)
Number of children in the partnership		
0	9 (50%)	
1	4 (22%)	
2+	5 (28%)	
Time since learning of HIV serodiscordance, months	1 (0–26)	
Time since initiating PrEP, months	6.3 (1–12)	
Time since initiating ART, months ($N = 11$)	5.6 (1.8–9.9)	

Couples' dynamics during the interviews

There was a general consensus within the couples about their responses. Couples expressed themselves mostly verbally to connote agreement or disagreement on most of the issues discussed in the interviews. In a few instances, nonverbal gestures including nodding or shaking the head and at times silence were also used to suggest agreement or disagreement on an issue by the participants. Shared glances from time to time, nodding of head in agreement when one member of the couple said something, and moments of silence, were among the most observed nonverbal responses from the participants. In many of these interviews the male participants primarily took the lead in responding to most of the questions, but there was also valuable contribution from the female participants who were responding whenever asked and sometimes interjecting as the male partners were responding either to add, agree or disagree—thus making answers reflective of the couple as a unit. In one interview, the male participant dominated the conversation and this was perhaps consequent of the age difference between the couple (female, 20 years; male, 46 years).

The main themes that emerged from these couple interviews were: (1) resuming a normal life, (2) PrEP providing additional protection, (3) early PrEP use experiences, and (4) the clinical encounter.

Resuming a normal life was a motivation to initiate PrEP

Most participants cited that feeling committed to their relationship was an important motivator for PrEP initiation and continuation; PrEP provided a method for couples to stay with their partner and deal with their HIV serodiscordance (i.e., a solution to their challenges with being in a serodiscordant partnership).

The medicine [PrEP] has been beneficial because since she knew her status and I knew my status, our lives have gone on as normal (29-year-old man, HIV uninfected).

Since we started taking [PrEP] we feel like we have a good future, earlier on we had seen death. (23-year-old woman, HIV uninfected)

Importantly, PrEP engaged HIV-uninfected partners in prevention strategies, making HIV prevention a joint effort including a component of protecting the uninfected partner from HIV acquisition.

The time we have been together since we knew our status, and we have been having sex, and after following the instructions we were given, his status is still negative. Using condoms and taking medicine without being late or skipping. (28-year-old woman, HIV infected)

There is one thing I would like, I would like her to continue or I would like us to just stay that way because now when she takes that medicine, it prevents…we were told by the doctor it usually prevents. (29-year-old man, HIV infected)

Additionally, many couples reported that PrEP could help them meet their aspirations for fertility, as PrEP could protect the HIV uninfected partner in instances where couples chose not to use condoms in order to conceive. Health providers had reportedly informed the couples that PrEP could protect them, if it was used as recommended. Becoming pregnant would assist the couples to stay together and give them hope of raising children, a norm within Kenyan marriages.

I have hope, I know I will get a child…I want just one more child, or even if God blessed [us] we get even two at once, it's okay. But what we were told, when the time will come, we will be told how we can have that sex and get a child. (32-year-old man, HIV uninfected)

I expected to get another child. It [PrEP] will help me to get a child who does not have the virus if I follow your instructions. (26-year-old woman, HIV uninfected)

PrEP provided additional protection

Many couples—both those with uninfected men and those with uninfected women—were in agreement that PrEP provided additional protection and that they felt safer when using it. Several participants were able to cite the estimated protection reported from clinical trials of PrEP. Some HIV-uninfected women reported PrEP could act as a 'back-up' to protect them when their partners refuse to use condoms and in cases of condom breakage.

FEMALE: Like now if I don't use it [PrEP] and then he uses it (condom) then it bursts. You see now that can be a problem, but now with that I have a little of that…I felt that I am… (male interrupts)

MALE: She is safe

FEMALE: I am a bit safe if I am using even if it is 75%. It has that little…[protection] that is how I see it being beneficial''. (38-year-old HIV uninfected woman and 45-year-old HIV infected man)

I knew I would be safer, cos [because] when we came here we were told we can…she will be using those ARVs and I will be using travuda [Truvada] and we will continue protecting. It will continue protecting and reduce chances yeah [of infection]. (28-year-old man, HIV uninfected)

Many participants reported continued condom use in addition to PrEP. However, some participants, particularly the women, described situations when they did not use condoms consistently, resulting in pregnancy. A few men reported deliberate failure to use condoms to '*see if PrEP worked.*' Consistent condom use was one of the main areas of disagreement between couples. In general, the male participants initially responded to say there were no challenges with condom use but their female partners occasionally interjected to raise a concern.

We have failed to use condoms because you see now I am pregnant. The first days, we were not using it [condoms]. (20-year-old woman, HIV-uninfected)

Early PrEP use experiences reinforced the decision to use PrEP

Most couples reported adjusting quite well to the daily use of PrEP by the HIV uninfected partner and had developed measures to optimize their adherence, such as use of text reminders and incorporating PrEP taking into daily routines. Additionally, partner support was reported as helpful for adherence of both PrEP and ART.

Now I will continue with it till it is finished. I just wanted to motivate my wife so that she can [see] that she is not alone. While she takes medicine, I also take. (29-year-old man, HIV uninfected)

I can stop, but the reason I am deciding not to stop, is because, you know sometimes people stay and they disagree a bit…She will reflect and think because she is the one who is taking the medicine that is why I am disregarding her, shouting at her.

That is why I feel she takes hers and I take mine, we live the way we have been living. (51-year-old man, HIV uninfected)

These HIV uninfected partners felt their daily PrEP use supported their HIV-infected partners' ART adherence and showed shared commitment to HIV management and the relationship. In addition, couples reported that the HIV-uninfected partners remaining HIV negative after a few months of PrEP use reinforced the couples' confidence in their decision and motivated continued adherence to PrEP. This was evidenced through quarterly HIV testing.

Up to now, I have not turned to be positive, so I feel maybe…that in a bigger percentage, it [PrEP] is contributing, it has contributed to me not getting infected with the virus. (20-year-old woman, HIV uninfected)

This Truvada has helped him stay negative. We were told it helps reduce the chances. Of passing the virus… (27-year-old woman, HIV infected)

Some PrEP users reported experiencing headache and nausea in the first few weeks, but they continued use since they had been forewarned of side effects and anticipated time-limited duration.

I am finding it okay, although there are times it troubles me, although the doctor had mentioned it would disturb me a while before I get used to it… (26-year-old woman, HIV uninfected)

Others expressed concerns related to adherence especially long-term adherence (''*taking medicine every day can be exhausting''*) and a few reported that being seen taking PrEP may make others think they are HIV infected or arouse questions which would lead to disclosure of their HIV serodiscordant status. All the informants reported being aware that PrEP is ideally a time-limited strategy and agreed on the importance of the HIV uninfected partner using PrEP until the HIV-infected partner sustains ART use. For a majority of the couples, the partners were in agreement with each other in terms of when the HIV-uninfected partner would discontinue using PrEP, but some expressed concerns of losing protection from PrEP before their HIV-infected partner's ART adherence was adequate. A key reason for couples' agreement about the timing of PrEP discontinuation was the understanding that reduced viral load for the HIV-infected participant greatly reduced their transmission risk to the HIV-uninfected partner. As such, most of the couples acknowledged the importance of ART for the HIV-infected participant.

Because when I use ARVs my viral load will be reduced and I will not transmit. You see when he takes Truvada it will only help him not to contract the virus, but I will not benefit from Truvada. (27-year-old woman, HIV infected)

A positive clinical encounter was a motivation to initiate PrEP

The clinical encounter, with discussions with clinicians and counselors, was depicted as informative, empowering, and a key motivation for PrEP initiation. Many participants described the welcoming environment of the clinic, high quality services, and positive interactions with study staff as helpful in their decision to take PrEP.

We agreed to join because we did not know so many things, about how people [HIV serodiscordant couples] can live. I did not even know that there is medicine that can reduce chances of infection if one is infected and the other is not. (26-year-old woman, HIV-1 uninfected)

*We were happy by the way it [PrEP and ART] was explained to us and the way we were being taught…It became of importance for us to come and get taught a lot on how we can reduce chances of transmitting [HIV]. (*30-year-old man, HIV-infected)

Many interviewees often described their decision to take PrEP, as ''*following the doctor's advice*.'' They reasoned that health providers ''*know better*'' and ''*doctor knows best*.'' Most participants therefore believed the health providers' message that PrEP could help them to prevent HIV acquisition. Additionally health providers played a key role in giving hope and reassurance.

You know at first we had been discouraged but after we came here, the way those doctors have taken us, they have counseled us, told us on how we can live, what we can eat, we feel we are okay and have a future. (28-year-old woman, HIV-uninfected).

…otherwise there would be no hope for people whose status are not the same, maybe I would have gotten infected with the virus or we would have broken up, but now that we know and with the doctor's advice we can continue together and plans for our life will continue as planned. (27-year-old man, HIV-uninfected)

All participants were in agreement with their partner about the decision to join the study. They gave various reasons for their motivation to join, including the additional information on HIV serodiscordance and HIV prevention, being offered PrEP for the HIV negative partner, counselling support, and even being at a place where service is offered to them both as a couple. Some participants referred to receiving ''*service beyond the medicine*.'' The counselling and the time given to explain HIV discordance and HIV prevention options assisted the couples to accept their HIV serodiscordant status. This component was particularly important for many couples who had only recently learned of their HIV serodiscordant status and were still coming to terms with the concept of HIV serodiscordance.

Discussion

Among these Kenyan HIV serodiscordant couples who were early adopters of PrEP for HIV prevention, critical drivers influencing their PrEP initiation and continuation included the meaning of PrEP as HIV protection, a return to normalcy within the couple and in life, and confidence in their clinical provider's advice. Counseling and follow-up visits for participants taking PrEP prepared them to cope with side effects and often reinforced their belief in the efficacy of PrEP to prevent HIV.

The HIV serodiscordant couples interviewed perceived themselves at risk of HIV transmission to the HIV uninfected partner, which was an important motivation for their decisions about PrEP uptake. PrEP met couples' needs for reducing their HIV risk, in some cases during unprotected sex in order to become pregnant, and some participants were reluctant to discontinue PrEP use even after sustained ART use by their HIV infected partner. Both men and women reported that PrEP provided protection in addition to condoms, serving as a 'back-up' method when a condom was not used or broke. To optimize delivery of HIV prevention for HIV serodiscordant couples, programs should aim to include both partners during

Table 2. Implications for PrEP Implementation for HIV Serodiscordant Couples

Theme	*Implications for PrEP delivery*
Resuming a normal life was a motivation to initiate PrEP	Including messaging on the role of PrEP in helping couples cope with their serodiscordant status and fulfil their fertility intentions during counseling sessions could increase initiation and continuation of PrEP in real world settings. Additionally counseling for PrEP for HIV serodiscordant couples should be provided to both members of the couple together to enhance joint decision making and should incorporate their values and preferences.
PrEP provided additional protection	HIV serodiscordant couples should be counseled on the role of PrEP to provide protection prior to ART initiation, particularly if ART is delayed or declined and during periods when condoms are not used, for example, during periconception periods. This message should be included during counseling on risk reduction strategies for HIV serodiscordant couples.
Early PrEP use experiences reinforced the decision to use PrEP	HIV serodiscordant couples who have had positive experiences with PrEP could be play a role in educating their peers on PrEP through their personal testimonies to address some of their concerns. Having the early PrEP adopters work alongside health providers in PrEP delivery programs would increase initiation and continuation of PrEP.
A positive clinical encounter was a motivation to initiate PrEP	Building the capacity of health providers will benefit PrEP delivery, therefore programs should invest in providing the correct information PrEP to both public and private health providers.

risk reduction counseling and consider values and preferences as well as address any couples concerns associated with PrEP and ART-based prevention (Table 2).[18–20]

Provider counseling about PrEP and ART to prevent HIV strongly influenced couples' decisions to initiate these methods. A positive patient-provider relationship has been reported to influence the use of other preventive medications.[21] Contrastingly, dissatisfaction with care, reports of being treated rudely, and feeling that the clinic staff ''didn't care'' have been associated with disengagement from HIV care.[22] Alternatively, following doctor's advice may reflect a broader cultural attitude or norm, or a perceived power differential between patients and medical providers. Public health approaches to PrEP delivery may benefit from well informed health providers (Table 2).

At this critical time of learning of their HIV serodiscordant status, the project offered counselling, education, and HIV prevention options, and PrEP initiation ultimately offered a way for these serodiscordant couples to conceptualize how they could ''live together'' as they previously had and see their future together. The context of being in a relationship provided a motivation for PrEP initiation to help the HIV serodiscordant couples to cope with their serodiscordancy status and fulfil their future aspirations, including fertility intentions. PrEP use demonstrated shared ownership of the management of HIV infection and commitment as a couple. This notion of social capital, which was previously reported as key to PrEP adherence and retention was also critical to the decision to initiation PrEP in our study.[12]

A few participants expressed concerns about the side effects they experienced; similar concerns have been reported by participants in other PrEP demonstration projects.[9–11] Providing clear and accurate information on PrEP possible side effects and their expected duration is key to continuation of PrEP use[9–11,23] and is potentially part of an ideal PrEP clinical encounter.

Some participants reported not wanting to be seen taking PrEP which could inadvertently disclose their HIV serodiscordance status, similar to studies reporting that daily use of PrEP [9] or ART may generate stigma[24–26] in many contexts, health providers and a positive clinical encounter could play an integral role in building trust and relieving internalized stigma experienced by HIV infected persons and their serodiscordant sexual partners.[9,24–26]

The strengths of our study included a strong sample of mutually disclosed HIV serodiscordant couples to explore PrEP decision-making. Involving the couple as a unit was important to the clinical encounter and the decision to initiate PrEP; it was therefore helpful to simultaneously interview the couple. Interviews were conducted with serodiscordant couples who stayed together and had initiated PrEP in the context of a research study; future interviews should be conducted to understand refusal to initiate or maintain high adherence to PrEP, especially at public health clinics which have a different setup than a clinic that is primarily a research center. It is possible that the presence of the partners influenced participant's responses, biasing results towards the opinions of more dominant partners.

In this low resource setting, patient provider dynamics combined with clear explanations, and friendly, non-judgmental/stigmatizing services were critical to HIV serodiscordant couples' decisions to initiate PrEP and see a future together. During the implementation of PrEP, health providers have an influential role in HIV prevention and can greatly impact the success of this novel HIV prevention strategy. Capacity building of health providers will be important for successful implementation of PrEP for HIV serodiscordant couples and other key populations in low resource settings that will directly impact PrEP initiation and continuation (Table 2).[27]

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