



**A QUALITATIVE STUDY OF HIV PRE-EXPOSURE PROPHYLAXIS JOURNEYS
OF MEMBERS OF KEY POPULATIONS IN SOUTH AFRICA**

Yogan Pillay, Hasina Subedar & Natsai Shoko

ABSTRACT

To improve the provision of HIV pre-exposure prophylaxis (PrEP) to adolescent girls and young women, female sex workers, men who have sex with men and transgender people, understanding their PrEP journeys is important. Members of these groups living in South Africa were interviewed to understand what facilitates initiation on PrEP and the factors that help them to adhere.

KEY MESSAGES

- Despite having the largest HIV burden in the world, the majority of South Africans are HIV negative.
- Adding PrEP to the HIV prevention toolbox is a potential game changer especially for adolescent girls and young women and key populations.
- Understanding the PrEP journey of members of key populations is key to strengthening the prevention program.

INTRODUCTION

South Africa has the largest burden of HIV, estimated at 7.97 million people in 2019, an increase from 4,64 million in 2002 (Statistics South Africa, 2019). The majority of South Africans (86,5%) continue to remain positive and it is important that they remain HIV

negative. The prevalence of HIV in adolescent girls and young women (AGYW) and key populations is high with an estimated 66 000 new infections in AGYW in 2017 (George et al., 2020) with prevalence as high as 71.8% in female sex workers and 58.4% in men who have sex with men (Stone et al. 2021).

The introduction of pre-exposure prophylaxis (PrEP) was a significant addition to the HIV prevention toolbox. Before PrEP became available the toolbox consisted of the following key prevention interventions: (a) information; (b) abstinence; HIV testing – knowing one’s status; (d) prevention of vertical transmission; (e) consistent condom use (male and female); (f) ensuring a safe blood supply; and (g) post-exposure prophylaxis.

PrEP promised to revolutionize HIV prevention by decreasing the pill burden to a single pill a day – which reflecting on the history of the HIV treatment programme with a handful of pills that were required daily – was certainly a significant medical advance. However, some commentators did caution that PrEP had the potential to re-medicalize HIV and called for a ‘re-integration of interdisciplinary approaches to prevention that will take the lived reality of potential beneficiaries into account (Syvertsen et al 2014).

BRIEF LITERATURE REVIEW

There are a number of qualitative studies that have explored the facilitators and barriers to PrEP in both low-and-middle-income countries as well as in high income countries.

A number of structural, behavioral and health system barriers to PrEP uptake have been cited. These include: “knowledge/awareness of PrEP, perception of HIV risk, stigma from healthcare providers or family/partners/friends, distrust of healthcare providers/systems, access to PrEP, costs of PrEP, and concerns around PrEP side effects/medication interactions. Importantly, these barriers may have different effects on specific populations at risk” (Mayer, Agwu and Malebranche, 2020, p 1778).

Access to PrEP assumes some level of knowledge of its availability as part of the range of prevention tools available. Surprisingly, a recent study of people living with HIV in Brazil found that knowledge of PrEP as well as post exposure prophylaxis was low (Sousa, 2021).

In a study in Zimbabwe Gombe et al (2020) found that PrEP use was driven by risk perception – those that initiated on PrEP self-identified as being at high risk. They also report that condom use declined with PrEP use and that family and partner support was critical for both starting and continued PrEP use.

A study amongst men to have sex with men in Chicago, found that knowing one or two PrEP users was a facilitator of PrEP initiation (Schueler, et al. 2019). This signals the importance of peers in promoting the use of PrEP.

Sun et al (2019) uncovered three themes in interviews with a sample of self-identified cisgender gay men in Oregon. These were: the centrality of the patient-provider relationship; (b) personally advocating for access to PrEP; and (c) experiences of barriers to access.

PrEP stigma has been suggested as a reason for low PrEP uptake and poor adherence. Golub (2019, p 190) suggests that: “Ironically, PrEP stigma is also inextricably linked to HIV stigma because it is specifically designed to prevent HIV infection”. A related barrier to use of PrEP among a sample of transgender women and men who have sex with men was believing its use signaled that they were promiscuous (Eaton et al., 2017).

While there are qualitative studies of facilitators and barriers to PrEP use, studies have not explored these issues in a single study across a range of key populations in a single study.

This study attempted to explore these issues in adolescent girls and young women, female sex workers, transgender individuals and men who have sex with men to understand their PrEP journeys.

OBJECTIVES

The objective of this study was to understand the PrEP journey of a group of experienced PrEP users from a range of different populations that are at substantial risk of contracting HIV infections.

METHODS

A purposive sample of 12 individuals were selected for interviews by the managers of organizations that provided PrEP services to key populations and adolescent girls and young women who were using PrEP: adolescent girls and young women (n=5); female sex workers (n=2); men who have sex with men (n=2); and transgender individuals (n=3). They were recruited from various non-governmental organizations that provide sexual reproductive health, HIV prevention and treatment including PrEP and other support services. The interviewees ranged in age between 19 and 35 years and all provided either written or verbal consent. A structured set of questions were posed to each of the interviewees.

The interviews were conducted using an online platform and telephonically by one of the researchers with at least one of the two researchers involved in the research present. The interview data were reviewed by all three researchers independently for themes after which they met to discuss and agree on the themes that characterized the journeys of the interviewees.

RESULTS

Risk perception

All interviewees reported that the reason for initiating PrEP was to prevent acquiring HIV. One respondent said that she started on PrEP because she did not trust her partner and that she was not always with him to know if he was being faithful to her. Two interviewees

reported that their partners were HIV positive and they wanted to protect themselves. There were also concerns about HIV transmission if condoms broke during sexual intercourse, especially with clients whose HIV status they did not know.

Provider-patient relationships

The relationship between the health provider and the person initiating PrEP was considered important to the latter. A positive relationship with the provider was more likely to ensure initiation as well as sustained use of PrEP. One respondent noted that because of his positive relationship with this provider and the organization he decided to volunteer at the organization. Another interviewee attributed her decision to take PrEP was influenced by the information and the support she received from the health care providers at the clinic she attended.

One interviewee thought that PrEP was only available from non-governmental organizations and not from public clinics. This illustrates the need for additional information on access.

Duration on PrEP and side effects

Most of the interviewees were on PrEP for more than one year. One person was on PrEP for a shorter period (6 weeks) after stopping PrEP after taking it for seven months because he was not sexually active, and another has been on PrEP for four months. Three persons reported that they were taking PrEP for over five years.

Side effects were reported by all but one of the interviewees. These included headaches, nausea, vomiting and dizziness. These symptoms were typically experienced during initiation of PrEP and typically lasted a few days, but these side effects did not appear to deter patients from continuing on PrEP.

Support from partners and family

Support from partners and family was reported by some of the interviewees. One interviewee noted that her entire family knew that she was on PrEP. She had disclosed to them and promoted PrEP use to her peers.

Dealing with stigma

Only one interviewee reported PrEP use being stigmatized. She noted that her peers argued that as PrEP was an antiretroviral, being on PrEP mean the person was HIV positive. Most of the adolescent girls and young women interviewed were able to speak about PrEP freely to their peers.

Adherence and cycling

All but one interviewee claimed to be adherent. Interviewees either took their pill at or after breakfast or in the evening. Associating pill taking with breakfast or with a daily airing of a favorite TV program (soapie) reminded interviewees to take their pill. The one person who reported forgetting to take his pill on two successive days took his pill mid-morning though he confessed that this was usually when he was busy. After discussion with the interviewee, he decided to change the time he took his pill to the evening.

Promotion of PrEP to peers

Most of the interviewees reported that they were comfortable to promote PrEP use amongst their peers. Three of the adolescent girls and young women interviewed claimed to be 'PrEP ambassadors'. The adolescent girls and young women also reported that they made use of social media platforms to share their positive experiences. Two of the PrEP users also reported that they encouraged their partners to take PrEP.

Long-acting PrEP and choices

All interviewees were asked if they had a choice of long-acting PrEP, either the monthly pill, the monthly injectable or for the women the vaginal ring, which would they prefer. All but two interviewees opted for the monthly pill - they were afraid of needles or of the pain associated with injections. One interviewee was concerned about the efficacy of the monthly pill relative to the daily pill. Two interviewees preferred the monthly injection with one already using the injectable contraceptive and the other injecting insulin. None of the interviewees preferred the vaginal ring.

Contraceptive use and STIs

Most of the women reported being on contraceptives. Consistent condom use appeared to be seldom practiced by the majority of interviewees. When asked about the possibility of being infected with a sexually transmitted infection the typical response was that STIs are easily treated by the clinic! Two interviewees that had sex with more than one partner indicated that they did not use condoms with their regular partners, but consistently used condoms with their clients.

DISCUSSION

The PrEP journey and experiences of the interviewees, despite being part of different at-risk population groups were largely similar. Interestingly, their experiences also resonate with those reported in the literature from other parts of the world.

Risk perception and a friendly provider or organization appear to be key to the start of the PrEP journey. Similarly, in a study to promote PrEP uptake in high-risk young women in Malawi, Hill et al., (2020) found a positive correlation between perceived risk and PrEP interest.

Having the correct information as well as supportive peers, partners or family members are also important. Peers and social networks were found to serve three primary functions in a study amongst young gay black men: filling gaps in information; promoting trust; and reducing stigma (Quinn et al., 2020).

Only one interviewee mentioned stigma as a barrier to PrEP use. This is despite many studies reporting that stigma was prevalent. This may be because many of the interviewees appeared to be advocates of PrEP with high levels of adherence suggesting significant levels of empowerment. Amongst adolescent girls and young women stigma appeared to be associated with reluctance to disclose PrEP use and poor adherence (Velloza et al, 2019). This suggests that agency and empowerment are important in taking action to protect oneself (Raifman and Sherman, 2018).

Side effects, if informed about and discussed during PrEP initiation, did not appear to deter interviewees from continuing with PrEP. Most appeared to experience mild side effects that remitted after a few days of continuous PrEP use. Fear of side effects were found to deter 41% of potential PrEP users in a study by Pillay et al. (2020), who also found that provision of printed information was important in facilitating PrEP initiation.

Consistent condom use was not widespread and largely confined to use with clients by the two sex workers. There did not appear to be much concern with STIs despite the increasing incidence of STIs in the country as well as increasing antimicrobial resistance. Attention needs to be paid to making those on PrEP more aware about the dangers of STIs. The risk of contracting an STI did not motivate condom use due to the perception that it can be treated.

One of the key questions included in the interview was to understand the interviewee's choice of long-acting PrEP. It was clear that fear of needles and pain may deter many from the injectable PrEP. However, this may change over time given that the most popular contraceptive in South Africa is injectable! There were no takers for the vaginal ring. This

may be related to concerns of having a foreign object in one's vagina - this is similar to the intra-uterine device which is also not very popular. It may also be because of lack of information about the ring. It seems that much more work needs to be done in providing information and increasing awareness of these long-acting products.

CONCLUSIONS

The Interviews of AGYW and key population PrEP users provides useful contextual information about their PrEP journey and experiences. This information can be used to inform and strengthen information provision and service delivery strategies that could address barriers to PrEP access. It is also helpful to gain a better understanding of the facilitators of PrEP uptake, including the importance of provider-patient relationships and support from peers, partners and family members for the continued use of PrEP. Agency and empowerment may be an important consideration to include in the package of activities to support individuals who seek PrEP initiation.

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