# Disclosure of PrEP use by young women in South Africa and Tanzania: qualitative findings from a demonstration project

[Fiona Scorgie](https://www.tandfonline.com/author/Scorgie%2C%2BFiona), [Nomhle Khoza,](https://www.tandfonline.com/author/Khoza%2C%2BNomhle)[Deborah Baron,](https://www.tandfonline.com/author/Baron%2C%2BDeborah)[Shelley Lees](https://www.tandfonline.com/author/Lees%2C%2BShelley), [Sheila Harvey,](https://www.tandfonline.com/author/Harvey%2C%2BSheila)[Lethabo Ramskin,](https://www.tandfonline.com/author/Ramskin%2C%2BLethabo)[Anne Stangl,](https://www.tandfonline.com/author/Stangl%2C%2BAnne)[Manuela Colombini](https://www.tandfonline.com/author/Colombini%2C%2BManuela), [Emma Mashauri,](https://www.tandfonline.com/author/Mashauri%2C%2BEmma)[Sinead Delany-Moretlwe &](https://www.tandfonline.com/author/Delany-Moretlwe%2C%2BSinead)[for the EMPOWER study team](https://www.tandfonline.com/author/For%2BThe%2BEMPOWER%2BStudy%2BTeam)

**Abstract**

Investigating how young women handle disclosure of oral pre-exposure prophylaxis (PrEP) use to others is important given evidence that disclosure is associated with higher adherence. We report qualitative results on PrEP disclosure among adolescent girls and young women (AGYW) in South Africa and Tanzania who participated in a PrEP demonstration project (EMPOWER). In total, 81 in-depth interviews were conducted with 39 AGYW aged 16-24 years—25 from Johannesburg and 14 from Mwanza—at approximately 3, 6, and/or 9 months post-enrolment in EMPOWER. Analysis of data was thematic and inductive. Most Johannesburg participants were students in the inner-city; in Mwanza, all worked in recreational venues, occasionally engaging in sexual transactions with customers. A continuum of approaches was evident in partner disclosure—common in Johannesburg but less so in Mwanza, where many partners were feared as judgmental and potentially violent. In both sites, AGYW commonly disclosed to family to secure support, and to friends and work colleagues to advocate about PrEP and encourage uptake among at-risk peers. Adherence clubs appeared helpful in building AGYW’s skills and confidence to disclose, particularly in gender-inequitable sexual relationships. PrEP delivery counselling with AGYW should focus on strengthening communication skills and help develop strategies for safe disclosure.

**Keywords:** oral pre-exposure prophylaxis; disclosure; young women; east and southern Africa

# Introduction

Nearly three decades have passed since the idea of a female-controlled HIV prevention method was first put forward, when it became apparent that young women in sub-Saharan Africa were disproportionately affected by HIV (Stein 1990). Women needed prevention methods they could initiate and control themselves – unlike male condoms – and which they could potentially use without their partner’s knowledge or participation (Becker and et al 2004; Heise 1999) From the earliest commentaries on vaginal microbicides and the diaphragm, to more recent studies of oral pre-exposure prophylaxis (PrEP) and long-acting methods such as the vaginal ring , injectables and implants, candidate biomedical HIV prevention methods for women have held the promise, at least theoretically, of independent and covert use.

Largely thanks to the inclusion of ancillary social science studies in many clinical trials of these products, we have a better understanding of the social and relational dynamics that shape how women use trial products and integrate them into their everyday lives (Stadler et al. 2014; Montgomery et al. 2015; Mngadi et al. 2014; MacQueen et al. 2014; Lanham et al. 2014; Montgomery et al. 2008). This research has shown that the question of independent and covert use is more complex than first thought. While early work on the use of female-controlled barrier methods suggested that women favoured covert use (MacPhail et al. 2009), efficacy studies of candidate microbicides have showed that overall, the risks of secrecy are often burdensome for women. Most women participating in HIV prevention trials in sub-Saharan Africa have in fact pro-actively chosen to disclose product use with their sexual partners (Montgomery et al. 2012; Montgomery et al. 2015; Mngadi et al. 2014). Some product characteristics, such as the lubricating qualities of microbicide gels, may make covert use inherently more difficult to achieve (Woodsong 2004). In some settings there may be social expectations of partner involvement in the decision to use a product (Gafos et al. 2015; Woodsong 2004), especially where product efficacy is not known, as in many of the studies cited above. Women may want to pre-empt the anger of a partner discovering the product himself – an especially likely motivation in violent or inequitable relationships and in highly patriarchal societies (Lanham et al. 2014; Sahin-Hodoglugil et al. 2009).

Research in southern and east Africa has further suggested that telling partners about product use tends to involve more negotiation than the mere provision of information. Instead, there is often permission-seeking as well as cajoling, persuading, explaining and justifying, as women skilfully weigh up the risks and benefits of disclosure, and strategically tailor communication with partners to maximise support for ongoing use (Gafos et al. 2015). As this picture has solidified, together with emerging evidence of the impact of disclosure on adherence, trials and demonstration projects have increasingly encouraged product use disclosure to partners (Woodsong et al. 2013).

To date, most of the research on this topic has involved methods requiring vaginal insertion or application, such as topical vaginal gels and bulkier diaphragms or vaginal rings (Succop et al. 2014; Gafos et al. 2015; Montgomery et al. 2019), methods that have shown mixed success in efficacy trials (Baeten 2013). A product such as tenofovir-based Truvada as oral PrEP marks a departure from these earlier methods on several levels. Firstly, it is known to be effective when used consistently in periods of high risk (Marrazzo 2015), and is the first woman-initiated product for HIV prevention to be licensed. Secondly, PrEP signals the shift to systemic rather than topical methods of HIV prevention, and thirdly, its physical form – a daily pill that can be discretely swallowed – may have implications for disclosure that are quite distinct from vaginal products. When considered against the historical background of HIV prevention for women, these novel dimensions to PrEP warrant closer investigation, especially given emerging evidence from blinded trials and open-label demonstration projects showing associations between disclosure and higher adherence (Montgomery et al. 2015; Ware et al. 2012; Corneli et al. 2015), potentially because it allows the PrEP user to marshal support from others. Understanding how and why women choose disclosure over covert product use could therefore help inform interventions to support disclosure, particularly in settings where young women face stigma or intimate partner violence, both of which remain extremely common in southern and east Africa (Decker et al. 2015).

In this article we report on results from a qualitative study among adolescent girls and young women (AGYW) in South Africa and Tanzania who participated in a demonstration project that included daily oral PrEP. We describe how participants approached product use disclosure, both to sexual partners and to family members and friends. Since much of the literature to date on novel HIV prevention methods for women has understandably focused on negotiation of product use with male partners, not enough is known about disclosure beyond sexual partnerships. Broadening the scope of enquiry to include others also recognises that such networks may be critically important for young women as they embark on the challenge of taking a daily pill to prevent HIV.

# Methods

Between February 2017 and February 2018, we conducted serial in-depth interviews (IDIs) with a sub-sample of study participants in a larger demonstration project that sought to assess the acceptability and feasibility of a package of prevention interventions, including oral PrEP. This project – named EMPOWER (Enhancing Methods of Prevention and Options for Women Exposed to Risk) – recruited women aged 16-24 years in inner-city Johannesburg, South Africa, and Mwanza city, Tanzania. At the time of the study, PrEP was already licensed in South Africa, with government phasing in the introduction of PrEP among prioritised populations, and information and advocacy materials about PrEP increasingly available in the public sphere. In Tanzania, PrEP was not yet licensed, and outside of this study setting, largely unheard of as an HIV prevention method.

Women who were HIV negative, not pregnant and interested in taking daily PrEP were enrolled, offered Truvada, and followed up for 6-15 months. At each clinic visit, women also received HIV testing and counselling, screening for gender-based violence (GBV) and sexual and reproductive health services. Referrals were provided as needed. Women received adherence counselling and follow-up messaging through SMS, while half the participants were randomly chosen to participate in monthly adherence support clubs which included a four-session empowerment curriculum. These clubs were designed not only to offer women additional PrEP adherence support, but also to build resilience to stigma, intimate partner violence, and relationship conflict. Facilitators discussed possible scenarios for disclosing study involvement and PrEP use with partners, and support for disclosure was further offered during the individual counselling at study visits.

The study was approved by the Human Research Ethics Committee of the University of the Witwatersrand, the London School of Hygiene and Tropical Medicine Ethics Committee, and the Tanzanian National Health Research Ethics Committee of the National Institute for Medical Research.

## Qualitative sub-study: sampling and data collection

Participants who had been in the study for at least three months and accepted PrEP were purposively sampled to capture a spread of PrEP experiences and to match the demographics of the main study sample as far as possible. Specific efforts were made to sample participants who had: initially declined PrEP at enrolment, disclosed experience of GBV at screening, or been placed on product hold for medical reasons, including pregnancy. Participants were approached by telephone or in person by a member of the qualitative research team during routine study clinic visits and invited to participate in the IDIs. The target sample size was 25 participants in each site.

Serial IDIs were chosen as a method for capturing how participants’ overall experience of PrEP-taking changed over time. In Johannesburg, participants were interviewed after the three-month clinic visit, about motivations for PrEP uptake and initial challenges experienced with product use. A second-round interview was held around six months after uptake, focusing on barriers to adherence, while a final interview, 9-12 months after PrEP initiation – assessed participants’ experiences of the study interventions. Owing to a shorter study duration in Mwanza, only two rounds of interviews were held.

Detailed IDI guides for all rounds of interviews were developed by the EMPOWER qualitative research team. The guides were field tested with members of the HIV prevention Community Advisory Board (CAB) in Johannesburg, and finalised. After completion of the first-round interviews, the guides were reviewed and adapted to include new questions and refine probes. PrEP disclosure was asked about in all rounds of interviewing, using probes that encouraged participants to talk about influences on their decision to disclose, whether disclosure had been intentional or inadvertent, and how the person had reacted to news of their PrEP use. Three trained qualitative interviewers carried out the interviews in private venues at the study clinics and in the participant’s preferred language (English, isiZulu, seSotho or Swahili). Interviews lasted between 20 minutes and an hour. They were audio-recorded, and later transcribed verbatim, and translated into English, where necessary. Quality and accuracy of transcriptions were checked against audio recordings by the interviewers, before being uploaded to a central, secure database. Refresher training of interviewers was undertaken as necessary, following quality control reviews of interview transcripts.

## Data analysis

Analysis followed a thematic, inductive approach (Glaser and Strauss 1967), with key themes identified directly from interview data. A provisional codebook was developed following open coding of a small selection of transcripts by all members of the qualitative team. Two team members independently coded the same transcript and inter-coder reliability (ICR) was assessed using QSR NVivo V.11. ICR was set at 0.75 and re-coding of a common transcript continued until this level of agreement was achieved. Thereafter, the codebook was finalised and the remaining interview data inductively coded by six members of the qualitative team. Coding was reviewed by the first author at regular intervals, and discrepancies in coding were discussed with the relevant coder until agreement was reached on the best applicable code. Reports were generated for specific nodes and summary matrices developed to examine intersecting themes. Two coding and analysis workshops were held to discuss interpretation of the data.

Analysis of PrEP disclosure data made use of a matrix setting out summarised information on disclosure patterns across all qualitative participants and interview rounds. ‘Full disclosure’ was defined as telling another person that one is taking oral PrEP to protect oneself from HIV acquisition, while ‘partial disclosure’ was defined as revealing some but withholding other aspects of this information.

## Study settings

In Johannesburg, participants in the EMPOWER trial were recruited from among attendees at a research clinic in the inner-city neighbourhood of Hillbrow. This is a densely populated neighbourhood with high-rise apartment blocks, small retail shops, entertainment venues and informal traders. Service delivery to the area is generally poor, and residences are overcrowded and often unsafe, with frequently interrupted power and water supply. Given the presence of a number of schools and tertiary education colleges in the inner-city, the area has many young people who are resident here or who travel into it daily from townships and other areas on the outskirts of Johannesburg.

Mwanza is the second largest city in Tanzania, located in the northwest of the country, on the shores of Lake Victoria. Around 10 per cent of the half a million people that make up Mwanza city’s population are estimated to have migrated from a rural area ([Mwanza City Director, 2008](#_ENREF_210)). Despite the proliferation of industrial activities, the majority of Mwanza people are “self-employed” and are involved in micro-enterprises (*biashara ndogondogo*). Opportunities for poorly educated migrant women in urban areas in Tanzania are often limited to setting up small businesses selling prepared food or beer, hairdressing, or petty retailing, which require low levels of capital ([Black et al., 2004](#_ENREF_28), [Ellis et al., 2007](#_ENREF_74), [Bryceson, 2002](#_ENREF_37)). Somewhat more formal employment for women is found in the proliferation of bars, guesthouses, and clubs across the city, where the women in this study work..

# Results

In Johannesburg, 25 participants were recruited, nine of whom completed all three interviews, 12 were interviewed twice and four were interviewed once. In Mwanza, 14 participants were interviewed at the three-month clinic visit, 12 of whom completed the six month interview.

## Key characteristics of study sample

Overall, the qualitative samples reflected the demographics of the parent study and captured key differences by study site (Table 1). Participants across both sites were a median 20.5 years old (IQR 19-22). Just over half of the Johannesburg sample were tertiary-level students in the inner-city, while a third had completed high school and were looking for employment. All participants were living with parents, other relatives or in student residences. By contrast, most of the Mwanza participants had completed only primary school; all worked in recreational venues or in food and alcohol outlets, where occasional sexual transactions with customers were the norm. Most were living alone or with family members.

There was high prevalence of GBV, with roughly half of both samples reporting that they had ever experienced physical, sexual or emotional violence. PrEP uptake was high: 23 of the 25 IDI participants in Johannesburg and all 14 participants in Mwanza accepted PrEP at enrolment (94% and 100% respectively in the parent study (Delany-Moretlwe et al. 2018).

[Table 1 about here]

## Disclosure to sexual partners

A high proportion of Johannesburg participants had disclosed PrEP use – either fully or partially – to partners by the first interview (16/25), compared to only two of the 14 Mwanza participants, and this pattern did not significantly change over the duration of the study. Across both sites, a range of approaches towards partner disclosure of PrEP was evident, from reluctance and prevarication to pragmatism and bold decisiveness. This spectrum may be placed along a continuum from non-disclosure to full disclosure in a manner similar to that used in studies of other candidate HIV prevention methods (MacPhail et al. 2009; Lanham et al. 2014; Sahin-Hodoglugil et al. 2009). In disclosing to partners, participants tended to explain PrEP use as a procedure required for study participation, and thereafter as “*a pill that prevents HIV*”. In some cases, extra care was taken to distinguish PrEP from Truvada or “*ARVs*”. .

Full disclosure was mostly evident at the Johannesburg site (Jhb), where a number of women framed the decision to start PrEP as a choice already made – a *fait accompli* – with no need for partner input and apparently little regard for what his response might be. Portia’s[[1]](#endnote-2) view on this was unambivalent:

*If I want to take [PrEP], I can take it whether he likes it or not (laughs) because it’s me, it’s my body.* (21 years, Jhb; IDI-113B)

Buhle told her partner in the first week after starting PrEP, commenting:

*I didn’t fear anything, actually. I didn’t care what people said, after all, it’s my life. His response was ‘OK, it’s fine’.* (18 years, Jhb; IDI-153F)

In many cases this confident approach to disclosure was influenced by a desire for honesty and openness in the relationship. Most participants in Johannesburg reported that their partners were supportive of their PrEP use. Some partners allegedly asked if they, too, could join the study and access PrEP, while others helped by reminding women to adhere to their daily regimen. At times, the response was reported to be less positive, especially where partners were sensitive to doubts about their fidelity and possible HIV-positive status. Disclosure had the potential to bring latent or unspoken mistrust in the relationship into sharp relief, potentially triggering conflict and counteraccusations.

But women in both sites navigated these situations with enormous skill, developing various tactics to manage their partner’s response and retain control of the narrative when met with resistance or anger. One such tactic involved openly asserting one’s right to be protected from infection, mobilising an argument about ‘self-preservation’. Portia, for example, acknowledged her partner’s other relationships, but did not back down on asserting her right not to be infected.

*He was like, ‘so you don’t trust me, you think that I’m not faithful?’ and all that. And then I told him, like, that because he once cheated on me… I told him that ‘I trust you but I don’t want mistakes. What if you get tempted and cheat and cheat with a wrong person and you come and infect me?’ and then that’s how he understood.* (21 years, Jhb; IDI-113B)

Similarly, Olivia – one of only two women in Mwanza (Mwz) to disclose PrEP use to a sexual partner – claimed her husband’s untrustworthy behaviour posed a threat to her own wellbeing.

*He had two other girls out there…. I continued using the pills and I made sure that he knew about it and I told him that he wasn’t settled and so it’s better if I protected myself. He asked me where I got the pills, I explained, then he allowed me.* (24 years, Mwz; IDI-ET0017D)

Part of this strategy involved justifying PrEP use as an act of self-care or as a step they were compelled to take in order to *‘be safe’*. When Lerato’s partner questioned her decision to take PrEP, she responded:

*…it’s just PrEP but I’m just taking care of myself, at the end of the day I have to think about myself and not another person.* (23 years, Jhb; IDI-235Z)

Other strategies involved playing up how PrEP use could benefit women’s partners as well. Theresa used this approach to win her partner’s support:

*Eh, at first he was like, ‘why are you taking PrEP?’ [I said] ‘I want to prevent myself.’ ‘From what? [he asked] – am I HIV positive?’ I said ‘no, I don’t think so. At the end of the day I’m protecting you from your side’, So when I told him ‘I’m protecting you’, ja, he started being happy and said ‘fine, at least I’m not gonna be infected’.* (18 years, Jhb; IDI-440G)

A third approach used by women – and one that perhaps falls closer to the ‘non-disclosure’ than the ‘full disclosure’ side of the continuum – involved strategically guiding a partner’s attention to something *other* than PrEP. Katleho, for example, told her boyfriend she was taking PrEP but said she had been motivated by the benefits of study participation, rather than access to PrEP itself.

*…he was a bit angry, ‘how come you don’t trust me?’ Then I said I wanted to be in the study…I want to be checked [for HIV and other health conditions] after every 3 months.* (20 years, Jhb; IDI-206G)

Nsekelwa managed to secure her partner’s permission to use PrEP by diverting attention away from a potentially uncomfortable discussion of sex and trust.

*On the first day when I told him he asked why I didn’t trust [him], to begin using the medicines... And I also told him ‘Aaaah! [No] it’s not that HIV can be caught in sex only, it could happen maybe by sharing sharp objects then you catch HIV. After that explanation, he allowed me because I explained and he understood and agreed.* (22 years, Mwz; IDI-ET0083I)

A fourth strategy involved partial disclosure through the telling of a ‘half-truth’ or simply not correcting a partner’s misperception of the pills’ purpose. For example, a handful of women in Johannesburg allowed their partners to assume the Truvada pill they were taking was actually for contraceptive purposes. In South Africa, contraception is often colloquially referred to as ‘prevention’, making it possible to exploit this slippage of terms to conceal PrEP use.

In most cases, it was the fear of conflict, stigma and judgement that necessitated such evasive approaches to disclosure; these were prominent themes in the interviews, regardless of setting. Rosemary remarked that if her partner found out she was taking PrEP, ‘*he may even beat me up’* (20 years, Mwz; IDI-ET0079Q). Fear of partner response also appeared as a strong motive for non-disclosure in the narratives of Johannesburg participants, about a third of whom had not disclosed to their partners by the second (six-month) interview. They anticipated a range of angry responses from partners; one woman said he would ‘*throw the pills away’;* another said, *‘World War III will start’*. Cecilia insisted she would never disclose to her partner and maintained that by doing so, ‘*I’m avoiding many problems…it would be a long conversation…I don’t even touch the subject’* (18 years, Jhb; IDI-346Z). Unsurprisingly, non-disclosure of PrEP use was more common in relationships with low levels of trust and where women feared violence and sexual stigma. Dikeledi described her partner of six years as jealous and controlling and said he had tried to strangle her in the past. She was adamant that disclosure was out of the question and believed that by staying HIV negative through taking PrEP, she could avoid conflict and recrimination later on.

*I don’t tell him that I am taking PrEP because if he is doing things outside [having other partners] …I don’t expect him to say I am the one who made him sick because I will be safe and he will be the one who is sick at that time* (22 years, Jhb; IDI-084Q)

Importantly, not all decisions to use PrEP secretly were based on fear of partner response. In Johannesburg, sharing such sensitive information was not considered appropriate when the relationship itself was still relatively new. Zukiswa (Jhb) had recently gotten back together with her partner after a break-up, and relations between them were still too fragile for her to disclose, although she planned to do so eventually to pre-empt his suspicion about her multiple clinic trips. Maria had also not spoken to her partner of two months about PrEP but planned to in future: *‘if I see that things now are getting too serious…. Then I will tell him the truth’* (20 years, Jhb; IDI-418D)*.* Partner type, in other words – new or casual versus stable, long-term partner – in part determined whether women considered covert use of PrEP to be necessary, an assessment that could shift as the relationship itself changed.

These findings on the challenges of communicating about PrEP use within relationships raise the question of whether the study interventions had any impact on women’s ability or willingness to disclose to partners. In the interview data, most commentary on this issue focused on the experience of participation in the adherence clubs. In the Johannesburg site we explored whether partner disclosure patterns were shaped in any way by study arm allocation. In the parent study, 50% of club arm participants attended at least one club session (Delany-Moretlwe et al. 2018), and almost all (11/13) of the qualitative participants assigned to the club arm had disclosed PrEP use to their partner. Among participants receiving standard adherence support, however, only half (6/12) had told their partner they were using PrEP. Club participants reported boosted confidence levels and strengthened communication skills, often through the use of practical role-play exercises, which in turn may have made disclosure to an intimidating partner easier. Lerato’s reflection on what she valued about club participation was typical:

*You see there [in the clubs], I was able to speak my mind, you see…Like everything I have inside, I was able to talk about….And I learned a lot of things, to believe in yourself as a person, you see, to be confident, lot of things.* (23 years, Jhb; IDI-235Z)

Additional support for disclosure to partners may have come from the strong emphasis in the clubs on open communication and shared responsibility for decision-making within sexual partnerships:

*In terms of relationships, eh, I have learned that communication is key, you see when you communicate, you do not do something just because another person wants you to do it, you both need to take decisions as a couple, you need to be responsible for those decisions.* (Nomzamo, 21 years, Jhb; IDI-112Y)

## Disclosure to family members, friends, and work colleagues

Compared to partner disclosure, with family members there were clear shifts in the patterns of disclosure across time, i.e. between the first and the final interviews. Full disclosure to trusted female family members (mothers, aunts and sisters) featured prominently in the first interview; participants described being “*close*” to these family members and actively seeking them out to share their decision about PrEP with them. Parents and other adult family members believed to be potentially disapproving or judgemental of this decision were usually not told until much later in the study. Xoliswa from Johannesburg, for example, initially only told her mother and sisters about her PrEP use but delayed telling others in her family as she feared their response.

*My father, my grandmother, okay, ja, all of them because I was scared that maybe they will think I am doing something like… maybe I am sleeping around or that’s why I am doing that.* (21 years, Jhb; IDI-200I)

By the time of the 6-month interview with Xoliswa, she reported having disclosed to her grandmother. Still nervous of how her father might respond to the news of her PrEP-taking, however, Xoliswa had asked her grandmother to pass the information on to her father.

In Mwanza, the strongest motivation for telling family members about their PrEP use was overwhelmingly women’s need to explain their frequent clinic visits and the presence of PrEP pills in the home. In keeping with a social norm of children displaying respect for parents and older relatives, women believed they needed “*permission*” for PrEP uptake, particularly if living with their parents. Rosemary, who works as an attendant at a hotel, disclosed to her father, mother and sister, and explained:

*How do I go out from home without permission and I must explain where I am going? …I also chose consciously not to hide because I live with them.* (20 years, Mwz; IDI-ET0079Q)

Agnes also told her mother, because:

*When I thought of what she would think if she was to find the medicine in the house and she asks me about them, so I thought it was wise to tell her.* (21 years, Mwz; IDI-ET0082A)

Across both sites, however, some women had hidden their PrEP use from parents. For a full month Nomzamo had used PrEP in secret, taking the pill discreetly in her bedroom, quietly opening the container, and placing the pill under her tongue before going to fetch water in the kitchen. But adherence was difficult under such circumstances. She recalls, ‘*I had to hide the pills...ya, you are not free in the house’* (21 years, Jhb; IDI-112Y)*.*

Like Nomzamo, there were other participants who initially found it difficult to be open about PrEP with parents and other family members, but at the same time struggled to conceal PrEP in the home. Phindile started to take PrEP surreptitiously after initially showing her mother the study pamphlet:

*I told her that they want me to take PrEP and she just said no, she said ‘if you do it, then just know that you would be doing it against my will.’ You know when a parent says that, yoh, yoh, it’s heart-breaking, she makes you feel bad”. [But] I just had no say. She just said that that was it.* (19 years, Jhb; IDI-26U)

Phindile would watch her mother’s movements and ‘*look if there is anybody watching, and… sneak into the room [to take PrEP]. It’s a bit difficult…exhausting’*. In Johannesburg, participants who attempted covert PrEP use at home did so largely because they wanted to hide from their parents the fact that they were sexually active. Refiloe, a 19-year-old student, hid her PrEP pills among her clothes in her wardrobe to prevent them being discovered by her mother. She reflected on the consequences of being found out:

*I don’t want to see their reaction, first of all, they would ask, they will be shocked that I am even sexually active. […] That would lead to so many questions.* (Jhb; IDI-095X)

In Mwanza, however, having sexual partners was not something participants needed to conceal from parents, who often knew about the kind of work they were doing in local bars, taverns and other food and entertainment venues. Both participants and their families seemed acutely aware of the heightened risk of HIV acquisition they faced in the workplace and the lack of alternative employment options for women in this setting. Being open about their PrEP use to family members thus became a way for women to reassure them that they were safe. Rodia used this approach with her mother:

*I told her the environment where we work is filled with risks... You might be caught up in a relationship with an infected person, so the pills help you prevent the risks of infections.* (24 years, Mwz; IDI-ET0089N)

For the same reason, many participants were motivated to disclose PrEP use to female peers and colleagues at work, in the hope that they, too, would join the study and protect themselves from infection. Indeed, this is often how PrEP was pitched to this group. Wakuru advised her co-workers at the bar that PrEP offered an alternative to male condoms.

*For example, you have a lover and maybe he doesn’t want to use condoms... Since there is PrEP which helps you; even if he has his own other doings, when you rightly focus on taking the pill everyday...even if they meet with their lovers and they are infected, but due to the immunity that is already built up with PrEP, it’ll be a safe way to avoid infections.* (20 years, Mwz; IDI-ET0018E)

Participants in Johannesburg were equally aware of the elevated HIV risks faced by young women in their environment, citing their peers’ (and partners’) reluctance to be HIV tested and the high rates of sexual assault as motivations for PrEP use. Telling friends about PrEP therefore often involved directly pointing out *their* risk and encouraging them to take PrEP. Tumi, who joined the study because she once had a friend who was HIV positive and didn’t want to see herself ‘*in the same situation’,* told all her friends she was taking PrEP and urged them to do so as well. Being open about this strengthened Tumi’s sense of purpose in being among the first among her peers to adopt PrEP: *‘I feel proud about myself. So that they know that we are bringing change’* (21 years, Jhb). Refiloe similarly turned disclosure to friends into an opportunity to educate:

*I know we are all sexually active so I told them so that they could think about joining… Ja, and they always complaining about HIV, pregnancies and all that. So I was like, ‘let me just give you one option to think about so that you could decrease your worries’.* (19 years, Jhb; IDI-095X)

Indeed, some of these participants went beyond mere disclosure to embrace pro-active promotion of PrEP among peers and even among strangers in the broader community. Alice, for example, felt strongly about this advocacy role.

*There is nothing to hide...It’s PrEP, it’s for everyone, so I shouldn’t wait for people to ask me ‘hey what are you doing?’ No, it’s a feeling like I should let people know about this. It should be all over the world, people should be asking about it…’cos it’s not for myself, it’s for everyone else…I feel very open, like I should be having a mic[rophone] and telling everyone about PrEP (laughs).* (22 years, Jhb; IDI-446R)

Disclosure to a friend was extremely common across both sites (23/25 in Jhb, 10/14 in Mwz), and tended to happen early on in participants’ experience of taking PrEP. By the final interview, a number of participants had also disclosed to an additional layer of people in more public settings, such as church members, work colleagues, and acquaintances in the community.

The reported responses of family members and friends to the news that participants were taking PrEP were mixed. The novelty of PrEP and its relatively unknown status, especially in Tanzania, where PrEP was not licensed at the time of the study, meant that – as participants recalled – some family members simply did not believe in its existence. Rosemary maintained that her mother and brother insisted that she was living with HIV and taking antiretrovirals, even challenging her to bring ‘*documentation*’ back from the clinic to prove her HIV-negative status. Responses of outright disbelief were reported as less common in Johannesburg but did appear in the form of scepticism that a pill alone could prevent HIV infection, or mistrust in clinical research more generally. While in most cases, friends expressed interest in PrEP and in joining the study, some had apparently teased the participants about taking antiretrovirals or about being tested as ‘*guinea pigs’* in research.

Fortunately, negative responses from family and friends appeared to be the exception rather than the rule. The omnipresence of HIV in the broader environment meant that family members more often openly welcomed participants’ decision to use PrEP. In both sites, overwhelmingly, parents reportedly expressed relief that their daughters were actively doing something to protect themselves from HIV. Xoliswa’s mother responded *‘aah, at least you are safe’* (21 years, Jhb; IDI-200I), while Amina’s grandmother was happy the clinic was providing PrEP to young women because *‘many girls are ruined’* (22 years, Mwz; IDI-ET0013Q).

In Johannesburg, the response of parents and other family members was, in addition, often shaped by their direct, personal experience of HIV. Zama’s mother is living with HIV; she apparently understood immediately when her daughter told her about PrEP and saw it as *‘a good thing’* (24 years, Jhb; IDI-192H)*.* When asked by her mother why she was taking PrEP, Dikeledi recalled that her response was:

*Remember one of your cousins passed on because of HIV and got it from the boyfriend? So I don’t want history to repeat itself, my child is still young.* (22 years, Jhb; IDI-084Q)

Karabo told her parents about PrEP because *‘they know this container...I don’t want them to think otherwise’* (22 years, Jhb; IDI-08J). She recalled that her mother was not surprised and saw Karabo’s decision as a positive one because it set her apart from the actions of a cousin, *‘the one they trusted so much’,* who had contracted HIV. In the Johannesburg site, a number of participants mentioned that their decision to initiate PrEP was admired and praised by their mothers, who appeared to interpret this as a sign of adult maturity. Naledi described her mother’s response when she first disclosed:

*She said it’s best to protect yourself… ‘I’m very proud you are doing something, you have a child now, now you know what’s wrong, what’s right’.* (22 years, Jhb; IDI-263J)

Similarly, Theresa’s mother, who is a nurse, had approved of her daughter’s decision to take PrEP and said, ‘*now you are actually grown up, you decided to go there by yourself’* (18 years, Jhb; IDI-440G)*.* When Buhle told her sisters,

*‘They were proud of me actually, ‘cos they didn’t know about the pill, ja and I was seen as this responsible young lady. I was very happy.* (18 years, Jhb; IDI-153F)

# Discussion

In assessing patterns of and motivations for PrEP disclosure among AGYW in South Africa and Tanzania, we found a number of important distinctions that likely derive from the not insubstantial socio-demographic differences between samples in the two study sites. In Johannesburg there was evidence of fairly autonomous decision-making about HIV prevention – possibly a function of the higher education levels in this site – and a strong trend towards disclosing PrEP use to sexual partners. Disclosure to a broader network of family and friends also occurred here, partly influenced by acute awareness of HIV risk and sexual violence at community level, and was often received with empathy and support where family members themselves were directly affected by HIV. By contrast, in Mwanza the dominant pattern was non-disclosure to partners, who were positioned as highly likely to judge and condemn women taking PrEP. This may reflect the participants’ lower education and relative lack of power vis-à-vis male partners, as well as the existence of local stigmatising discourses about sex, gender and disease. In this site we also saw a strong trend of women disclosing PrEP use to friends and work colleagues, mainly as a way to encourage PrEP uptake among this broader, at-risk group. Disclosure to parents was equally common in Mwanza, as in Johannesburg, and took the form of deferring this important health decision to parents and offering them reassurance that – as young women working in a high-risk environment – PrEP made them ‘safe’. In both sites, there seemed to be a pattern of first disclosing to supportive female members of the family, and later to older and male family members – or at least to those initially feared as potentially judgmental of young women’s sexuality. More ‘public’ disclosure also seemed easier for women to handle in the later compared to early months of the study.

Overall, this was a relatively young cohort, with many women unmarried and still living with their parents or other family members rather than with sexual partners, a feature of both settings that likely shaped disclosure decisions. Especially for younger women in the study, their parents seemed to be more obvious ‘gate keepers’ to PrEP uptake than their partners. This may point to shifts in inter-generational relations between adolescents and parents or adult caregivers that facilitate more open discussions about sensitive issues like sexual activity and HIV than was possible in the past. It is significant, perhaps, that in Johannesburg some parents approved of PrEP-use and regarded it as a positive sign of maturity and responsibility – a possible framing that could help to counteract PrEP stigma against young women. In Mwanza, there are signs of a change in family dynamics resulting from rural to urban migration. Young women are often first-generation migrants to the city and their parents are transitioning from a rural to an urban mode of family. There is also evidence that sexual education tends to be administered by mothers in urban areas now, whereas this role was largely played by grandmothers and female elders in the past (Lees 2013).

Yet participants’ experiences of attempted covert use in the home illustrate the social obligations and gendered norms that especially younger women in the Johannesburg site were under pressure to respect, namely, the expectation that they delay sexual debut. These experiences also bring to light the practical challenges of daily pill-taking under the watchful eyes of others who share the same living space. Since residences in these settings are often cramped and overcrowded (Scorgie et al. 2018), this may have restricted the privacy available to those who wished to hide their PrEP pills, ultimately forcing disclosure to parents and other household members. Arguably, PrEP’s ‘visibility’ in this context is increased by its resemblance to antiretrovirals, its daily regimen, and need for pill storage, suggesting that the physical characteristics of the product itself may also have shaped disclosure within households. Other, more discreet, forms of systemic PrEP currently under development, such as long-acting injectables or implants, may be less visible by comparison, thereby removing this challenge altogether.

The high proportion of participants across both sites who told at least one friend or colleague about their PrEP use points to the ‘social and connected lives’ (Haberer et al. 2019) that AGYW live, where decisions and experiences are frequently shared with peers. Increasingly, peer relations in these settings are shaped by widespread use of social media, with young people increasingly attuned to the crafting of new, gender equitable identities – even if social norms and institutions lag behind. The importance of these early PrEP adopters sharing their experiences with peers who are similarly at high risk of HIV acquisition cannot be overstated. Through participation in projects such as EMPOWER, they have the potential to influence future uptake among peers and male partners and to shape attitudes at community level, potentially normalising women’s autonomous use of HIV prevention methods. Given the prevalence of stigma in both study sites, this aspect of disclosure potentially gives it a potency beyond impacting on the individual PrEP user alone.

Across the continuum of approaches or tactics used when disclosing to partners, it was evident that women considered the nature of the relationship, anticipated how their partners would respond, and skilfully controlled what information was conveyed, even resorting to deceit if the circumstances demanded it. For a significant portion of both samples, low levels of trust and partners’ controlling behaviours determined how much communication about PrEP use was possible with partners, if any at all. This was particularly true for the Tanzanian site, where sexual relationships were marked by stark gender inequalities and participants’ economic dependence on male partners. Consequently, there was a stronger pattern of covert use with partners here than in South Africa, an environment where gender norms are more in flux. The framing of PrEP use in the latter site as an act of legitimate self-care, and as an act to which women are entitled, speaks to the prominence of discourses about gender equality and women’s empowerment in this fast-paced urban environment, where independence and agency are highly valued among young people. In this context, it makes sense that PrEP use should be claimed by them as an individual right. More broadly, the trend of a new generation of young women becoming more aware and assertive about their sexual and reproductive health rights is partly attributable to the widespread implementation of sexual health and HIV research in Africa over the past three decades, including early trials of microbicides and other women-controlled prevention methods.

Together with advocacy work to introduce PrEP to communities, interventions like adherence clubs appear to be important for building positive social norms around women’s use of new HIV prevention technologies. Although not examined here in detail, there were signs that club attendance may indeed have offered women greater support or encouragement to disclose to partners, by helping to create a ‘safe space’ for women to discuss using a female-controlled HIV prevention method. Through the use of practical scenarios to rehearse safe disclosure with partners, confidence and communication skills were strengthened, suggesting that clubs went some way towards supporting women who chose to disclose. Indeed, PrEP adherence clubs used in other studies have been effective in offering peer support for adolescents taking PrEP, including support to disclose to others and overcome stigma (Celum et al. 2019). Initiatives that include participants’ support networks in retention and adherence strategies and those that help participants to convey simple, factual information about PrEP are also potentially important (Toledo et al. 2015).

There were limitations to the study. Interviewing participants at the clinic may have led them to avoid saying anything negative about the study or about PrEP use. The small study samples make it difficult to be definitive about trends such as the apparent association between club attendance and disclosure to partners. We also did not interview the partners, family members and friends of study participants, and our conclusions about *their* responses to PrEP disclosure should be read with caution.

Understanding young women’s decision-making around PrEP disclosure may help inform PrEP delivery services and scale-up, as well as efforts to ‘normalise’ PrEP use among young women more generally. Where possible, PrEP counselling needs to help young women strengthen communication skills and develop strategies for safe disclosure. In doing so, the risk of partner violence must be recognised in relationships with controlling behaviours, insecure partners or a history of violence. Women require support in such situations and careful discussion of their fears. Future messaging around PrEP may also need to address the assumption that a male partner of a woman taking PrEP is directly protected from acquiring HIV. Not only is this perception potentially harmful, it could unfairly place the onus for *men’s* HIV prevention on women.

Finally, our study findings support recent recommendations in the HIV prevention field that PrEP be marketed to AGYW as an empowering ‘lifestyle choice’ rather than more narrowly as a biomedical HIV prevention tool (Haberer et al. 2019). Where young women can see PrEP initiation as a self-affirming, positive step, there is potential for the claiming of a new, socially empowered identity. Supporting women to talk openly about their PrEP use and spread the word about its efficacy lays a foundation for scaling up PrEP but also for introducing future technologies – like long-acting injectables or implants – and moves us closer to a time when young women’s use of HIV prevention is ultimately regarded as unexceptional.

**Acknowledgements**

**Declaration of interest**

The authors have no conflicts of interest to declare.

**References**

Baeten, J. M.; Haberer, J. E.; Liu, A. Y.; Sista, N. 2013. "Preexposure prophylaxis for HIV prevention: where have we been and where are we going?"  *J Acquir Immune Defic Syndr* 63 Suppl 2:S122-9. doi: 10.1097/QAI.0b013e3182986f69.

Becker, J., and . et al. 2004. "Paving the Path: Preparing for Microbicide Introduction." In. New York: EngenderHealth, International Partnership for Microbicides, University of Cape Town, Population Council.

Celum, C. L., S. Delany-Moretlwe, J. M. Baeten, A. van der Straten, S. Hosek, E. A. Bukusi, M. McConnell, R. V. Barnabas, and L. G. Bekker. 2019. "HIV pre-exposure prophylaxis for adolescent girls and young women in Africa: from efficacy trials to delivery."  *J Int AIDS Soc* 22 Suppl 4:e25298. doi: 10.1002/jia2.25298.

Corneli, A., B. Perry, K. Agot, K. Ahmed, F. Malamatsho, and L. Van Damme. 2015. "Facilitators of adherence to the study pill in the FEM-PrEP clinical trial."  *PLoS One* 10 (4):e0125458. doi: 10.1371/journal.pone.0125458.

Decker, M. R., A. D. Latimore, S. Yasutake, M. Haviland, S. Ahmed, R. W. Blum, F. Sonenstein, and N. M. Astone. 2015. "Gender-based violence against adolescent and young adult women in low- and middle-income countries."  *J Adolesc Health* 56 (2):188-96. doi: 10.1016/j.jadohealth.2014.09.003.

Delany-Moretlwe, S., M.F. Chersich, S. Harvey, A. Stangl, D. Baron, M. Colombini, F. Scorgie, N. Naicker, and S. Kapiga. 2018. "Empowerment clubs did not increase PrEP continuation in AGYW in South Africa & Tanzania: Results from EMPOWER trial." In *International AIDS Society (IAS) Conference, 27 July 2018*. Amsterdam.

Gafos, M, R Pool, MA Mzimela, HB Ndlovu, S McCormack, J Elford, and . MDP Team. 2015. "Communication About Microbicide Use Between Couples in KwaZulu-Natal, South Africa."  *AIDS Behav* 19:832–46.

Glaser, B.G., and A.L. Strauss. 1967. *The discovery of grounded theory.* Chicago: Aldine.

Haberer, J. E., N. Mugo, J. M. Baeten, M. Pyra, E. Bukusi, and L. G. Bekker. 2019. "PrEP as a Lifestyle and Investment for Adolescent Girls and Young Women in Sub-Saharan Africa."  *J Int Assoc Provid AIDS Care* 18:2325958219831011. doi: 10.1177/2325958219831011.

Heise, L. 1999. "Topical microbicides: missing link for HIV prevention."  *Sex Health Exch* (1):3-5.

Lanham, M., R. Wilcher, E. T. Montgomery, R. Pool, S. Schuler, R. Lenzi, and B. Friedland. 2014. "Engaging male partners in women's microbicide use: evidence from clinical trials and implications for future research and microbicide introduction."  *J Int AIDS Soc* 17 (3 Suppl 2):19159. doi: 10.7448/IAS.17.3.19159.

Lees, S. 2013. "Mashaka na Uwezekano. Uncertainty and Possibilities: Everyday Life and Sexuality among Women HIV Prevention Trial Participants in Tanzania." University of London.

MacPhail, C., F. Terris-Prestholt, L. Kumaranayake, P. Ngoako, C. Watts, and H. Rees. 2009. "Managing men: women's dilemmas about overt and covert use of barrier methods for HIV prevention."  *Cult Health Sex* 11 (5):485-97. doi: 10.1080/13691050902803537.

MacQueen, K. M., M. A. Weaver, F. van Loggerenberg, S. Succop, N. Majola, D. Taylor, Q. A. Karim, and S. A. Karim. 2014. "Assessing adherence in the CAPRISA 004 tenofovir gel HIV prevention trial: results of a nested case-control study."  *AIDS Behav* 18 (5):826-32. doi: 10.1007/s10461-014-0753-8.

Marrazzo, J. M.; Ramjee, G.; Richardson, B. A.; Gomez, K.; Mgodi, N.; Nair, G.; Palanee, T.; Nakabiito, C.; van der Straten, A.; Noguchi, L.; Hendrix, C. W.; Dai, J. Y.; Ganesh, S.; Mkhize, B.; Taljaard, M.; Parikh, U. M.; Piper, J.; Masse, B.; Grossman, C.; Rooney, J.; Schwartz, J. L.; Watts, H.; Marzinke, M. A.; Hillier, S. L.; McGowan, I. M.; Chirenje, Z. M. 2015. "Tenofovir-based preexposure prophylaxis for HIV infection among African women."  *N Engl J Med* 372 (6):509-18. doi: 10.1056/NEJMoa1402269.

Mngadi, K. T., S. Maarschalk, A. C. Grobler, L. E. Mansoor, J. A. Frohlich, B. Madlala, N. Ngcobo, S. S. Abdool Karim, and Q. Abdool Karim. 2014. "Disclosure of microbicide gel use to sexual partners: influence on adherence in the CAPRISA 004 trial."  *AIDS Behav* 18 (5):849-54. doi: 10.1007/s10461-014-0696-0.

Montgomery, C. M., S. Lees, J. Stadler, N. S. Morar, A. Ssali, B. Mwanza, M. Mntambo, J. Phillip, C. Watts, and R. Pool. 2008. "The role of partnership dynamics in determining the acceptability of condoms and microbicides."  *AIDS Care* 20 (6):733-40. doi: 10.1080/09540120701693974.

Montgomery, E. T., M. Atujuna, E. Krogstad, M. Hartmann, S. Ndwayana, S. O'Rourke, L. G. Bekker, A. van der Straten, and A. M. Minnis. 2019. "The Invisible Product: Preferences for Sustained-Release, Long-Acting Pre-exposure Prophylaxis to HIV Among South African Youth."  *J Acquir Immune Defic Syndr* 80 (5):542-50. doi: 10.1097/QAI.0000000000001960.

Montgomery, E. T., A. van der Straten, H. Cheng, L. Wegner, G. Masenga, C. von Mollendorf, L. Bekker, et al. 2012. "Vaginal ring adherence in sub-Saharan Africa: expulsion, removal, and perfect use."  *AIDS Behav* 16 (7):1787-98. doi: 10.1007/s10461-012-0248-4.

Montgomery, E. T., A. van der Straten, J. Stadler, M. Hartmann, B. Magazi, F. Mathebula, N. Laborde, and L. Soto-Torres. 2015. "Male Partner Influence on Women's HIV Prevention Trial Participation and Use of Pre-exposure Prophylaxis: the Importance of "Understanding"."  *AIDS Behav* 19 (5):784-93. doi: 10.1007/s10461-014-0950-5.

Sahin-Hodoglugil, N. N., A. van der Straten, H. Cheng, E. T. Montgomery, D. Kacanek, S. Mtetwa, N. Morar, J. Munyoro, N. Padian, and Mira Team. 2009. "Degrees of disclosure: a study of women's covert use of the diaphragm in an HIV prevention trial in sub-Saharan Africa."  *Soc Sci Med* 69 (10):1547-55. doi: 10.1016/j.socscimed.2009.08.014.

Scorgie, F., J. Stadler, D. Baron, S. Ju, T. Ikaneng, Z. Mabude, S. Makgopa, et al. 2018. ""It Was Not My Aim to Sleep There": The Impact of Timing and Location of Sex on Adherence to Coitally-Dependent HIV Pre-exposure Prophylaxis."  *AIDS Behav* 22 (11):3692-704. doi: 10.1007/s10461-018-2195-1.

Stadler, J., S. Delany-Moretlwe, T. Palanee, and H. Rees. 2014. "Hidden harms: women's narratives of intimate partner violence in a microbicide trial, South Africa."  *Soc Sci Med* 110:49-55. doi: 10.1016/j.socscimed.2014.03.021.

Stein, Z. A. 1990. "HIV prevention: the need for methods women can use."  *Am J Public Health* 80 (4):460-2.

Succop, S. M., K. M. MacQueen, F. van Loggerenberg, N. Majola, Q. A. Karim, and S. S. Karim. 2014. "Trial participation disclosure and gel use behavior in the CAPRISA 004 tenofovir gel trial."  *AIDS Care* 26 (12):1521-5. doi: 10.1080/09540121.2014.938014.

Toledo, L., E. McLellan-Lemal, F. L. Henderson, and P. M. Kebaabetswe. 2015. "Knowledge, Attitudes, and Experiences of HIV Pre-Exposure Prophylaxis (PrEP) Trial Participants in Botswana."  *World J AIDS* 5 (2):10-20. doi: 10.4236/wja.2015.51002.

Ware, N. C., M. A. Wyatt, J. E. Haberer, J. M. Baeten, A. Kintu, C. Psaros, S. Safren, E. Tumwesigye, C. L. Celum, and D. R. Bangsberg. 2012. "What's love got to do with it? Explaining adherence to oral antiretroviral pre-exposure prophylaxis for HIV-serodiscordant couples."  *J Acquir Immune Defic Syndr* 59 (5):463-8. doi: 10.1097/QAI.0b013e31824a060b.

Woodsong, C. 2004. "Covert Use of Topical Microbicides: Implications for Acceptability and Use."  *Int Fam Plan Perspect* 30 (2):94–8.

Woodsong, C., K. MacQueen, K. R. Amico, B. Friedland, M. Gafos, L. Mansoor, E. Tolley, and S. McCormack. 2013. "Microbicide clinical trial adherence: insights for introduction."  *J Int AIDS Soc* 16:18505. doi: 10.7448/IAS.16.1.18505.

1. All participant names are pseudonyms. [↑](#endnote-ref-2)