

" You know that you are on the safe side"

Motivation, support, and daily routines influence PrEP initiation, adherence, and continuation among current users in South Africa

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BACKGROUND

Oral pre-exposure prophylaxis (PrEP) has been delivered to people at substantial risk of HIV in South Africa since 2016, but little is known about uptake and adherence outside of clinical trials. To inform rollout, the South Africa National Department of Health, the OPTIONS Consortium, and the Prevention Market Manager project conducted mixed-methods implementation research at facilities/sites serving sex workers (SW, 6 sites) and men who have sex with men (MSM, 3 sites).

RESULTS

Survey participants were on average 31 years old (range 18 to 66), and were primarily female at SW sites and male at MSM sites (Table 1). Most were single and had been using PrEP for three months to one year. Demographic characteristics of IDI participants were similar to those of the larger sample.

Table 1. Demographic information

| | SW sites (N=66) n (%) or mean (SD) | MSM sites (N=28) n (%) or mean (SD) |
|-------------------------|---------------------------------------|--|
| Age | 29.1 (7.3) | 34.3 (12.3) |
| Gender | | |
| Female | 61 (92.4%) | 2 (7.1%) |
| Male | 3 (4.5%) | 25 (89.3%) |
| Transgender man | 1 (1.5%) | 0 (0%) |
| Transgender woman | 1 (1.5%) | 1 (3.6%) |
| Relationship status | | |
| Single | 44 (66.7%) | 13 (46.4%) |
| Married/in relationship | 21 (31.8%) | 13 (46.4%) |
| Divorced/widowed | 1 (1.5%) | 2 (7.1%) |
| Time on PrEP | | |
| 1 - 2 months | 10 (15.2%) | 7 (25.0%) |
| 3 - 5 months | 16 (24.2%) | 13 (46.4%) |
| 6 - 12 months | 28 (42.4%) | 4 (14.3%) |
| More than 12 months | 12 (18.2%) | 4 (14.3%) |

Motivations for initiation and continuation

In IDIs, participants' perceived HIV risk and desire to remain HIV-negative were leading reasons to initiate and continue PrEP; some at SW sites wanted HIV protection beyond condoms due to partners' resistance and condoms "bursting." Among participants at both site types, providers, partners, family members, and peers positively influenced decisions to initiate PrEP and played "a huge role" for some by giving information and encouragement. Some participants described continuing to use PrEP due to intrinsic motivations to "keep my status" or "cover the bases."

... I was not using anything. Then, the other sister of mine, she explaining [to] me, you see this job is risking. The condom gonna burst, and some people they're gonna force you [to have sex]. So it's better to take PrEP. When the condom burst, or something happen, you know that you are on the safe side...

—23 year-old female, SW site

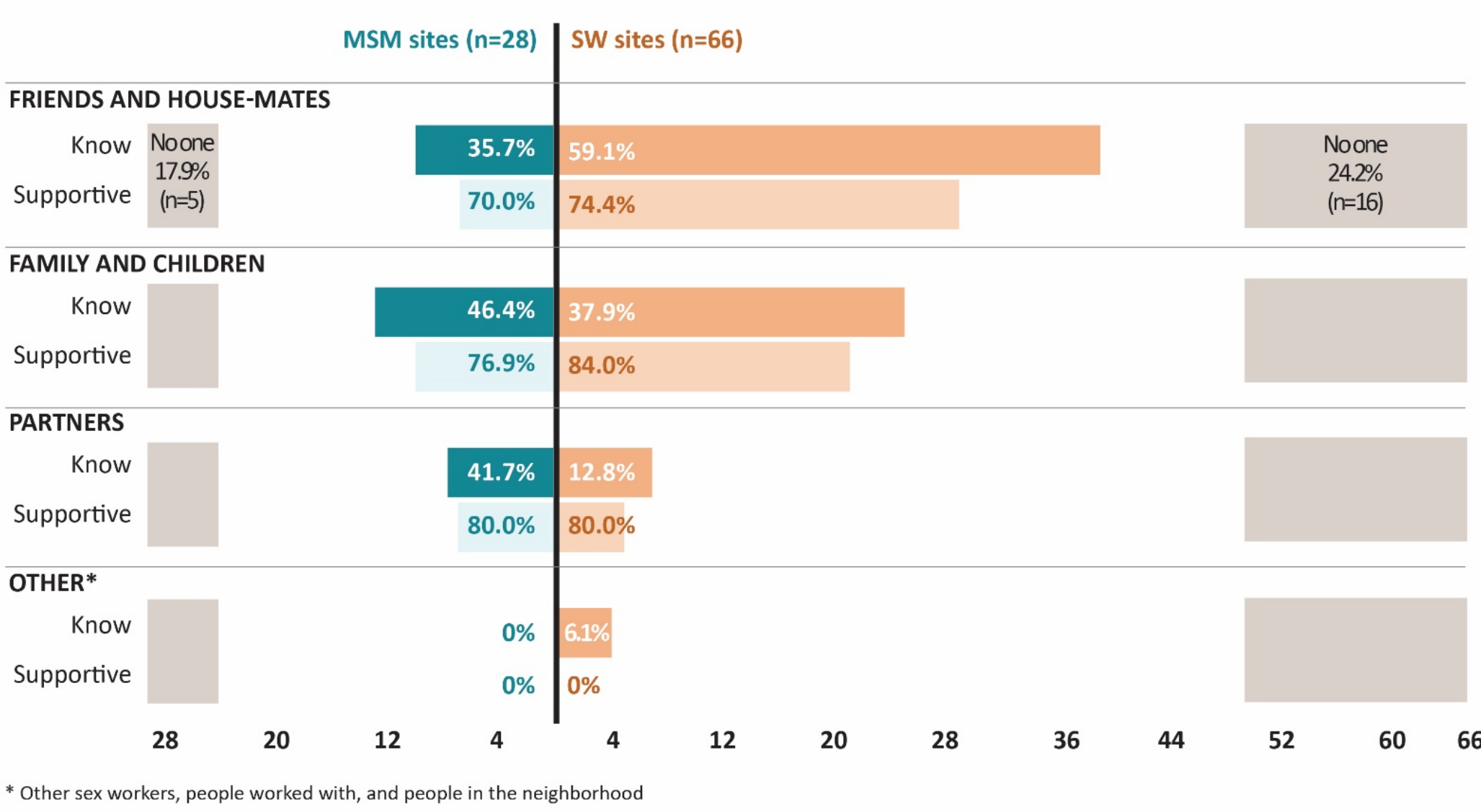
Disclosure, adherence and support

Survey participants most often disclosed their PrEP use to friends and house-mates (52%) and family members (40%); among those who knew, most were supportive of participants' PrEP use (74% and 81%, respectively) (Figure 1). Only 20% of participants with a partner reported that their partner knew, but 80% of those that knew were supportive. Disclosure to friends and house-mates was higher at SW sites (59%, vs 36% for MSM sites) while disclosure to partners was higher at MSM sites (42%, vs 13% for SW sites). In IDIs, participants from both site types described disclosing to partners, family, and friends although disclosure to family members was more common among SW site participants.

METHODS

From September through December 2017, we conducted cross-sectional surveys with 94 current PrEP users (66 at SW sites/28 at MSM sites) and conducted 17 follow-up in-depth interviews (IDIs) with survey participants (12 at SW sites/5 at MSM sites). Surveys queried adherence patterns, disclosure, and support; IDIs explored motivations for PrEP initiation and continuation, adherence and cycling, and managing side effects. We analyzed survey data in STATA 13 using descriptive statistics and conducted applied thematic analysis of IDIs in NVivo 11, exploring differences between SW and MSM sites.

Figure 1. Who knows about PrEP use; who is supportive



While some felt open to "spread the word" about their PrEP use, found that disclosing made taking PrEP easier, and received support from those they told; others preferred not to disclose because they felt it was simply unnecessary or they wanted to avoid questions and assumptions about their partners and sexual activity.

My friends know [about my PrEP use], but my family I never told. I don't feel that it's necessary coz that's my private life and I also don't want to drag them into my sex life. [...] we don't talk about sex, and I feel that I would be revealing my sex life to them and they might not understand the reason I'm on it, they might think I sleep around a lot.

—22-year-old male, MSM site

Although 97% found PrEP easy to use, 27% felt it was difficult or sometimes difficult to take PrEP on weekends (31% SW sites/18% MSM sites). A greater proportion of those who had reported missing a dose in the past month said PrEP was difficult or sometimes difficult to take on weekends (48%) compared to those who had reported not missing any doses (19%).

In surveys, 27% (32% SW sites/14% MSM sites) reported missing a dose in the past month; nearly half within the past three days (n=11/25, mostly SW sites) (Figure 2). The most common reasons for missing a dose in the past month were not being home (N=12: 10 SW sites/2 MSM sites), concerns about others such as fear of partner not agreeing and being around other people (N=6: all SW sites), and finishing the prescription (N=5: 4 SW sites/1 MSM site).

To facilitate adherence, participants used phone alarms, reminders from friends or family, and carried pills with them. In IDIs, participants noted that adherence got easier after acclimating to pill-taking and establishing routines, such as taking PrEP at the same time each evening.

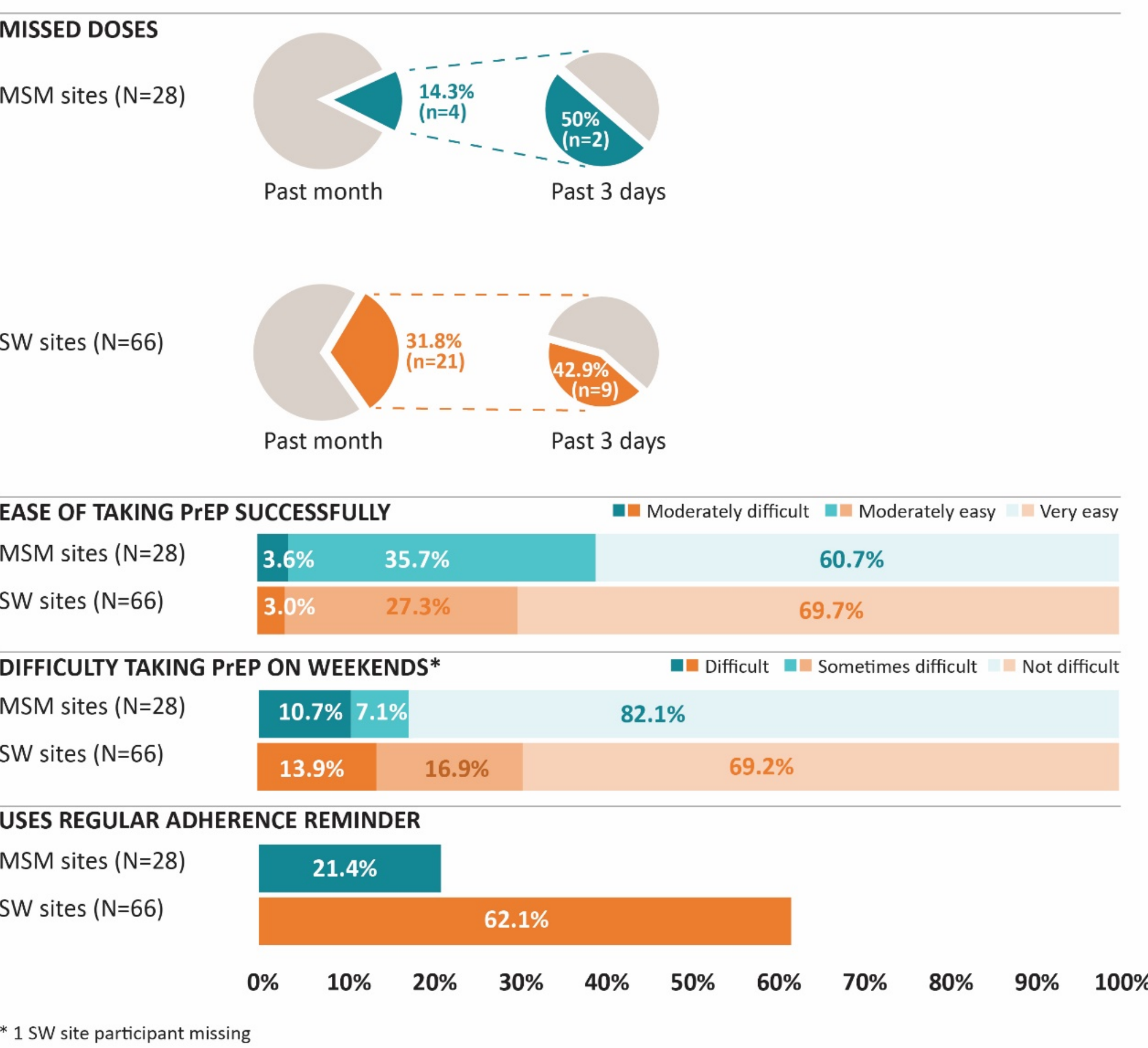
...I'll just use one of the old [pill] containers and I'll separate them, so one is almost always in my bag with me wherever I go, and then the other one is at home, so if ever I end up somewhere I already always have a stash with me...

—25 year-old male, MSM site

CONCLUSIONS

Support from others, HIV risk perception, and individual motivation were key facilitators of initiation, continuation, and adherence. Providers, family, and friends seemed to play a largely positive role in participants' PrEP use. SW site participants reported greater adherence challenges despite using reminders, indicating the need for targeted, site- or population-specific adherence support. Notably, the majority of the sample had used PrEP for over three months; clients new to PrEP use may have differing experiences. Findings are informing revisions to national provider training and are being shared with facilities and implementing organizations.

Figure 2. Adherence and ease of use



In IDIs, a few participants described stopping PrEP without consulting a provider due to losing pills, side effects, and partner opposition and restarting 5 to 30 days later.

Side effects and management

Some participants in IDIs said that a lack of burdensome side effects enabled them to continue taking PrEP, and a few noted that individuals may tolerate side effects differently. When managing side effects, some participants at SW sites sought advice from providers who recommended changing the time of taking medication and gave reassurance that side effects should decrease with time. No survey participants reported missing a dose in the past month due to being tired of side effects.

Interviewer: How have the pills changed how you live your everyday life? For example those dizzy spells you mentioned...?

Participant: It was very difficult. I used to call the nurse who initiated me [on PrEP], and she used to always tell me that it was a temporary thing and that those were the side effects of the medication as all medications have [...]. They [PrEP providers] sometimes came to the site we worked at, and they would give us their WhatsApp contacts, and I would sometimes WhatsApp her.

— Female, SW site

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