

Motivations for starting, stopping and restarting oral PrEP: Experiences of adolescent girls and young women in the HPTN 082 trial

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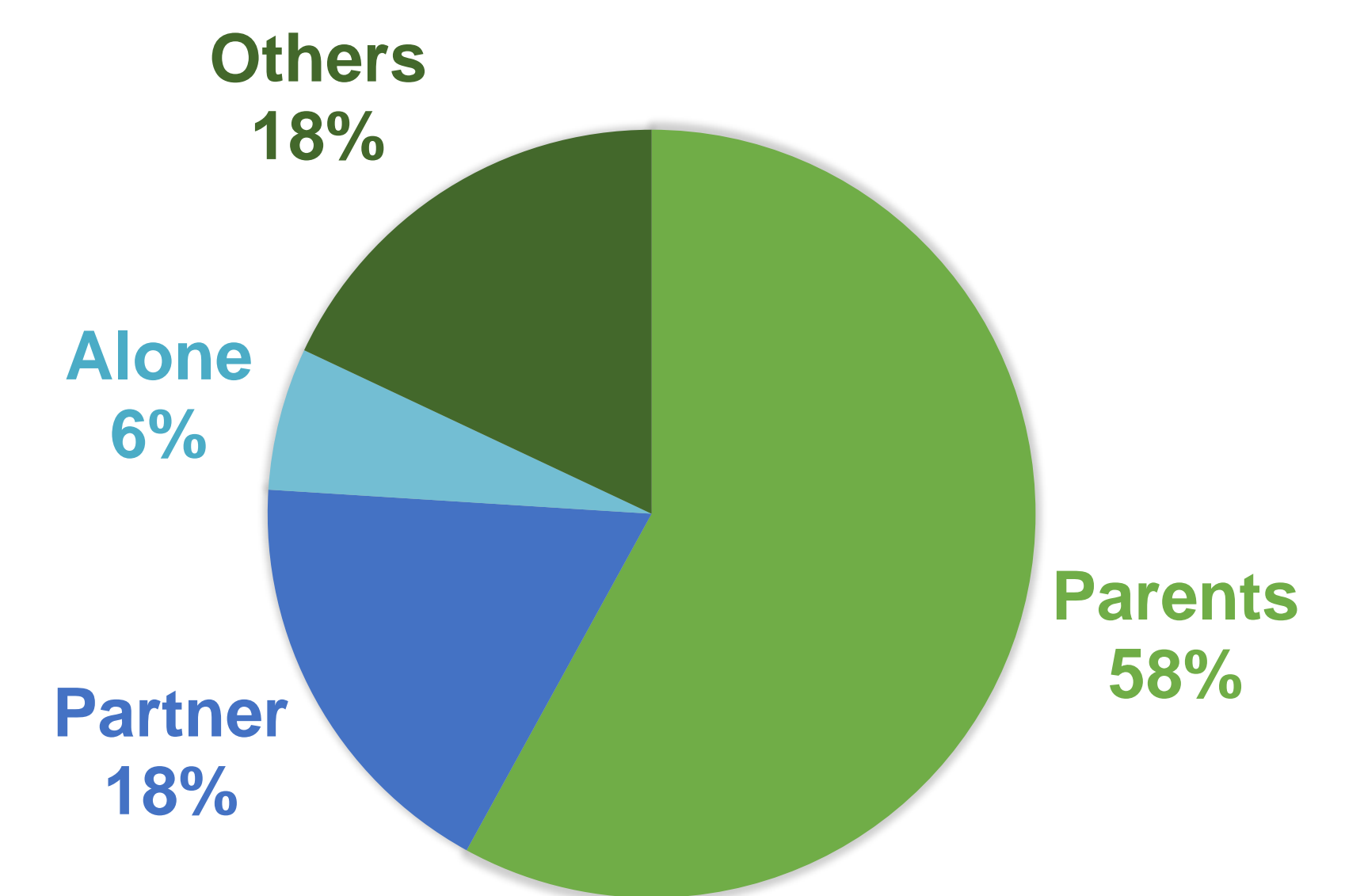
BACKGROUND

Adolescent girls and young women (AGYW) in sub-Saharan Africa are disproportionately affected by HIV, but daily oral PrEP use remains a significant challenge for AGYW

The aim of the study was to qualitatively explore the motivations of South African and Zimbabwean AGYW for starting, stopping and restarting oral PrEP.



Living arrangements of AGYW in the sample (n=67)



HIV risk perception frequently motivated adolescent girls and young women to start oral PrEP. Social factors such as stigma and interpersonal support were central in decisions to stop and restart PrEP.

METHODS

- HPTN 082: evaluation of adherence in an open-label study of daily oral PrEP (2016-2018)
- 426 AGYW from Cape Town, Johannesburg, Harare
- 16-25 years, HIV negative, sexually active, and PrEP-eligible
- Randomised to standard support (adherence counselling, weekly SMS reminders, monthly in-person adherence clubs) or standard support plus drug level feedback (PrEP levels tested at week 4 and 8 with 30-minute adherence counselling)

QUALITATIVE SUBSTUDY

- N=67 qualitative interviews between 2017 and 2018
- Purposive sampling to include adherers, non-adherers, decliners, special cases (adherence based on PrEP drug levels at week 4)
- Interviews were audio-recorded, transcribed and translated into English
- Inductive coding and a thematic approach to analysis was used

RESULTS

THEME	SUPPORTING QUOTE
HIV risk perception often motivated PrEP start but was less central in AGYW motivations to stop and restart PrEP	<i>"I have been dating one guy and I think he may give me problems. So let me join [the study]. The way I view it, it's for my own safety."</i> (Berenice, 24, Johannesburg).
HIV and PrEP-related stigma (experienced and anticipated) from friends, partners, family, community often motivated skipping doses or pausing PrEP. This included beliefs that PrEP is used by sex workers, 'promiscuous' individuals, sick people, those living with HIV; or that PrEP will cause HIV, weight gain or infertility	<i>"So, when he [husband] saw me taking pills he forbid it... he just asked me, that what I have to do with the pills. Then he started to say that 'Maybe you will be doing what, you will be prostituting in Zimbabwe.' Then I just stopped taking the pills."</i> (Tendai, 24, Harare).
Product characteristics – anticipated side effects often motivated a delay in PrEP start, and experienced side effects were often linked to a practice of skipping doses. The challenge of a daily regimen and the large pill size often motivated skipping doses	<i>"Yeah, they used to keep me worried, that you, I will have a headache, I will be this and that, but at the end of the day I said let me test and try them maybe it's not going to be that bad."</i> (Rita, 24, Johannesburg)
Interpersonal influence – peers important in introducing and motivating PrEP uptake. Information and encouragement from clinic staff frequently motivated PrEP restart. AGYW received motivation to restart from peers at retention events. Zimbabwean participants were often motivated to restart after encouragement from a maternal figure	<i>"I stopped taking PrEP because he [husband] had said that if I continued taking them it meant that our marriage would be over. That is when I told my grandmother what was happening and then they took him and explained to him. When he had understood that is when I started taking PrEP again."</i> (Iris, 20, Harare).

CONCLUSIONS

- Given stigma at home and AGYW cohabitation with parents, **older generations** should be targeted in interventions to destigmatize AGYW HIV prevention
- Support from **female/maternal figures** could be enhanced with training on sexual health communication with AGYW and female support figures
- **Peers** should be considered for demand creation and adherence support strategy
- Educational materials and information-sharing sessions should include content on **prevention-effective adherence** - providing an alternative to long-term daily use of PrEP may assist AGYW in effectively using PrEP during seasons of risk and mitigate the challenge associated with daily use.

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