When PrEP breaks down: Experiences of HIV diagnosis among current and previous PrEP users

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Introduction

- Where PrEP is readily available, low HIV incidence can be maintained. (Grulich et al. 2021)
- A high proportion of gay and bisexual men in Australia report current or previous PrEP use.
- Analyses of HIV acquisition among people who were taking – or had discontinued – PrEP, offer unique insights into how care for PrEP users might be improved.

Background

- Both HIV infections and PrEP discontinuation usually attributed to individual factors, in particular a person's (in)ability to accurately assess and manage HIV risk.
- Discussions of PrEP 'failure' focused on biomedical typology – documented seroconversion with adequate drug levels in blood. (Serota et al. 2018)

Methods

- Qualitative cohort study of people diagnosed with HIV since 2016.
- In-depth interviews
  - Experiences of HIV acquisition, diagnosis, and early post-diagnosis period.
- Data collected 2018–2021.

Participants

- Total participants 34 (32 men; 2 women).
- Of the 27 gay and bisexual men in the study, 8 had any experience of PrEP (i.e. 30%).
- (No other participants had experience of PrEP).
- Median age 30 years.

"I don't have a sexual-health GP, or I didn't at the time. I had just been in [city] for a year, so I hadn't really got all that stuff sorted. I just went to the ones that were closest to work, essentially."

"I think there was definitely an 'I-told-you-so' moment because [my doctor] doesn't promote on-demand PrEP. […] They were like, 'Now, you know, we, I, don't promote on-demand PrEP!'"

Discussion

- Discontinuation of PrEP was not an explicit choice
  - (Difficult to characterise as a decision at all.)
- These accounts raise questions about the quality and consistency of clinical care
  - When *initiating PrEP*.
  - While *on PrEP* (incl. when changing dose strategies).
  - When *discontinuing PrEP*.

HIV diagnosis w*hile taking PrEP*

- 3 men diagnosed while taking PrEP
- Daily dosing
  - High self-reported adherence ('97%'); however no regular doctor; approx. one year since previous HIV test.
  - Attempted to obtain prescription at hospital clinic in India; purchased over the counter; tenofovir only; no HIV test prior to starting.
- Event-based dosing
  - Clinician unsupportive of strategy.

"I don't have a regular GP. I have been very transient my whole life."

HIV diagnosis *after discontinuing PrEP*

- 5 men previously taking PrEP.
  - Only one had stopped PrEP in consultation with doctor.
  - All others – little or no clinical support.
- Discontinuation associated with:
  - Moving interstate while on local PrEP implementation studies.
  - Exhausting supply when overseas – did not restart.
  - Side effects.

"There wasn't really any test done though, which is, kind of, looking back on it, a bit weird. I just described how I was feeling, and they just suggested for me to come off [PrEP]."

Recommendations

- Better continuity and quality of care for PrEP users:
  1. Retain PrEP users in clinical care.
  2. Minimise loss to follow up.
  3. Maintain sexual health care for people who discontinue PrEP.
- Expand definition of PrEP failure.
  - HIV infections as occasions where PrEP *breaks down*, rather than individual accounts of failed risk calculations.

Conclusions

- Current discussions of PrEP 'failure' draw attention away from the complexity of PrEP provision and consumption.
- Need to look beyond accounts of PrEP failure that focus on HIV acquisition among PrEP users with adequate drug levels.

References

Grulich A et al. (2021) Long-term protection from HIV infection with oral HIV pre-exposure prophylaxis in gay and bisexual men. *Lancet HIV* 8(8):e486–e494.

Serota DP at al. (2018) Beyond the Biomedical. *Clinical Infectious Diseases* 67(6):965–970.

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