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

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Background:

Investigations into both the factors related to new HIV diagnoses and reasons for discontinuation of pre-exposure prophylaxis (PrEP) have tended to focus on individual factors, in particular individuals' ability to accurately assess and manage HIV risk.

Methods:

Data were collected as part of an ongoing Australian qualitative cohort study of 34 people diagnosed with HIV since 2016. Drawing on in-depth interviews conducted between January 2019 and November 2021, we analysed participants' experiences of PrEP.

Results:

Study participants with any history of PrEP use were all gay and bisexual-identifying men, with eight out of these 27 men (or 30%) reporting current or previous PrEP use at the time they were diagnosed with HIV.

The accounts of three men taking PrEP at the time of diagnosis, all revealed issues related to linkage to – or continuity of – sexual health care. Among the five men who had discontinued PrEP, the majority reported no (or very little) clinical support at this time. None attributed their discontinuation of PrEP to reduced risk of HIV. Also, discontinuation was not described as a deliberate choice, and for most it was difficult to characterise it as a decision at all.

Findings from this analysis suggest that greater attention should be given to the continuity and quality of clinical care provided for PrEP users. And in particular, providers should pay greater attention to retaining PrEP users in care, minimising loss to follow up, and maintaining sexual health care for people who discontinue PrEP.

Conclusion:

By looking beyond accounts of PrEP failure that focus on HIV acquisition among PrEP users with adequate drug levels, and instead thinking about PrEP as something broader than the pills alone, it is possible to conceptualise HIV infection as occasions in which PrEP breaks down, rather than individual accounts of failed risk calculations.

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