Prioritising the values of potential users to promote uptake of HIV pre-exposure prophylaxis

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Benefits of pre-exposure prophylaxis (PrEP) extend beyond HIV risk reduction. Users report a range of physical, emotional, and social effects, including reduced anxiety, increased intimacy, and greater sexual satisfaction. For some people, these benefits are the primary motivation for using PrEP. To successfully engage in shared decision making about HIV prevention methods, clinicians need to be able to discuss all potential risks and benefits of PrEP. These risks and benefits include not only those related to HIV risk reduction and other clinical outcomes, but also those related to experiences and relationships that people value. However, national and international clinical resources on the provision of PrEP do not include user-reported outcomes that are values-based or reflect positive effects on personal, social, or sexual wellbeing. To better integrate the values of potential users into discussions about PrEP, clinician training programmes and clinical guidelines need to be guided by community-driven frameworks and expanded to include user-reported outcomes of PrEP use, including beneficial effects. Achieving PrEP uptake and equity goals will require an approach to PrEP provision that centres the values and desired experiences of potential users, particularly those from populations with the greatest unmet need for PrEP.

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Introduction

Since pre-exposure prophylaxis (PrEP) was first shown to be protective against HIV infection, a decade of evidence has accumulated on the additional benefits identified by many users, such as reduced anxiety, increased intimacy, and greater sexual satisfaction.[1] For some people, these benefits are the primary motivation for using PrEP.[2] To successfully engage in shared decision making about HIV prevention methods, clinicians need to be able to discuss all potential risks and benefits of PrEP. This includes not only those related to HIV risk reduction and other clinical outcomes, but also those related to experiences and relationships that people value. Despite ongoing calls for a more person-centred approach to PrEP delivery,[3,4] clinicians remain unprepared to have these discussions with potential users. This oversight is a crucial missed opportunity to improve PrEP use, equity, and impact.

Prioritising values of potential users

Physical, emotional, and social benefits of PrEP use have been well documented across a broad range of study settings and populations. Some PrEP users experience a greater sense of ownership, agency, and control over their health, facilitating new relationships with primary care providers and increased access to health-care services unrelated to HIV.[5] For some people, PrEP plays a role in identity and community cohesion, with some users feeling empowered by protecting their partners and community from HIV and some reporting stronger relationships with people living with HIV after initiating PrEP.[2] Some PrEP users also report feeling more sexually liberated, being able to explore new sexual activities without fear of acquiring HIV (eg, being the receptive partner during anal intercourse), and experiencing reduced anxiety overall.[1,6]

These user-reported benefits are conspicuously absent from guidelines for clinicians on PrEP discussions and prescribing. Guidelines from the US Centers for Disease Control and Prevention recommend that clinicians inform all sexually active adults and adolescents about PrEP and engage in conversations about its potential risks and benefits.[7] Likewise, the grade A recommendation for PrEP by the US Preventive Services Task Force includes a systematic review on the potential risks and benefits of PrEP.[8] However, in both resources, user-reported outcomes are limited to changes in sexual behaviour, or risk compensation, which is framed as an adverse effect despite being a potentially desirable outcome from the user's perspective.[8] Although guidelines issued by WHO include sexual and reproductive outcomes of PrEP use,[9] these outcomes are again limited to sexual behaviour change, in addition to interaction with hormonal contraception and gender-affirming hormone therapy. The omission from these resources of user-reported outcomes—particularly those that are values-based or reflect a positive impact on personal, social, or sexual wellbeing—leaves clinicians with an unbalanced perspective on the potential effects of PrEP.

The role of clinicians

Clinicians have a crucial role in PrEP dissemination, including introducing PrEP to people who were previously unaware of it and guiding discussions with people who are deciding whether to initiate PrEP. To provide person-centred care, clinicians need to understand the full range of potential benefits and risks associated with PrEP use (including logistical and social considerations, such as cost, remembering to take pills, the need for ongoing visits, and concerns about stigma) and should be prepared to discuss these with potential users. Shared decision making is a collaborative, person-centred process that is particularly appropriate for preference-sensitive decisions, such as those related to HIV prevention methods.[10] The goal is not to convince

someone to use PrEP, but to ensure that decisions about use, including whether to use alternative prevention approaches (such as condoms, serosorting, reliance on undetectable equal untransmittable, or monogamy), are congruent with people's values. WHO defines health as a state of physical, mental, and social wellbeing, not merely the absence of disease, and its definition of sexual health includes the possibility of having pleasurable and safe sexual encounters.[11] Accordingly, the goals of providing health care, and sexual health care specifically, should not be restricted to disease prevention. Clinicians can explore people's sexual and intimacy goals and the challenges they might face with different HIV prevention options, with the understanding that values and circumstances can change over time. By improving communication, trust, and satisfaction with care services, this approach to shared decision making has the potential to increase engagement in HIV preventive care, particularly for people who have been deterred by negative health-care experiences, including stigma and discrimination.[12]

Given long-standing inequities in PrEP access and use, approaches to shared decision making for PrEP must be particularly responsive to the needs and preferences of underserved populations. An initiative from the Black Women's Working Group to Reframe Risk—a collaborative of advocates, clinicians, communication experts, and researchers of HIV—calls for an end to the stigmatising and counterproductive paradigm of risk (eg, high risk, risky behaviour) when communicating with Black women about HIV.[13] The initiative recommends focusing instead on the reasons for HIV prevention, a more expansive and affirming framework that invokes the values and desired experiences that could motivate PrEP use, such as autonomy, intimacy, and self-care.[13] In a study among Black men who have sex with men, those who more strongly valued sexual freedom, intimacy, and pleasure were more likely to report medical mistrust, anticipated provider deception, and PrEP conspiracy beliefs.[14] As concluded by the study's authors,[14] discussions about PrEP that balance risk and prevention framing and address people's personal goals—including those related to health, intimacy, and freedom—might cultivate greater trust and promote PrEP uptake in communities with high unmet need for PrEP.

Although systemic barriers to PrEP access and use cannot be overcome by clinicians alone, efforts to end the HIV epidemic need to include multiple strategies to better integrate the values of potential users into discussions about PrEP in clinical settings. First, clinician training programmes about PrEP need to be expanded and guided by community-informed frameworks.[13] Many clinicians feel undertrained to discuss and provide PrEP; incorporating the values of potential users into clinician education about PrEP can better support clinicians in providing person-centred PrEP care, including shared decision making about PrEP use. Second, professional guidelines—including those issued by the US Centers for Disease Control and Prevention, US Preventive Services Task Force, and WHO—should be expanded to include user-reported outcomes of PrEP use, including positive effects on wellbeing. There is precedent from clinical guidelines in other areas of medicine—such as the American Urological Association's guidelines for treatment of erectile dysfunction[15]—for integrating people's desired experiences, such as sexual satisfaction, into shared decision making. Guidelines and recommendations should also highlight gaps in research on desired experiences and user-reported outcomes related to PrEP, such as those among people who inject drugs. Finally, as clinical encounters are brief and often involve competing priorities, optimising encounters by implementing structural changes to health-care systems, such as clinical decision support tools, might support clinicians in shared decision making in general and specifically for PrEP.[16]

Conclusion

New approaches are urgently needed to engage people in HIV prevention. In 2021, only 30% of the 1·2 million people who could benefit from PrEP in the USA were issued with a prescription, with coverage ranging from 11% in Black people to 78% in White people with PrEP indications.[17] The federal Ending the HIV Epidemic initiative aims to double overall PrEP coverage in the USA by 2025, with a focus on scale-up in underserved populations.[18] Achieving national and international PrEP use and equity goals will require a community-responsive approach to PrEP provision that centres the values and desired experiences of potential users—particularly those from populations with the greatest unmet need for PrEP.

Contributors

MWT and JLM contributed to conceptualisation. JLM was responsible for supervision. MWT was responsible for writing the original draft. All authors contributed to the review and editing of subsequent drafts.

Declaration of interests

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