PrEPing for a PrEP Demonstration Project: Understanding Awareness and Perspectives among Women in Southern California

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Background: Pre-exposure prophylaxis (PrEP) with emtricitabine/tenofovir disoproxil fumarate (FTC/TDF) has been shown to be effective in preventing HIV, although data is conflicting among women due to poor adherence and biological differences in pharmacokinetics. In preparation for an adherence-based study using daily text messaging with individual drug-level guided counseling support, we sought to understand women’s knowledge and perspectives about PrEP as well as what would be useful to support at-risk women taking PrEP.

Methods: We conducted three focus groups of HIV- and HIV+ women in San Diego and Los Angeles between November 2015 and January 2016. Women were recruited through local testing sites, community-based organizations and social media. Focus group questions elicited discussion about PrEP awareness, candidates and concerns, methods to facilitate PrEP use, HIV prevention strategies, PrEP awareness, barriers and facilitators of potential PrEP use, and text message frequency and content. All focus groups were audio recorded, transcribed and coded by hand.

Results: Focus group 1 consisted of 4 HIV- and 4 HIV+ women (ages 26-64; 1 Black, 7 Caucasian), focus group 2 of 10 HIV- women (ages 20-57; 5 Black, 4 Latina, 1 mixed) and focus group 3 of 4 HIV- women (ages 30-65; 4 Latina). Across all focus groups, there was limited knowledge about PrEP. In focus group 1 with HIV- and HIV+ women, there was misinformation about PrEP from HIV+ women, but the women highlighted the importance of dialogue between HIV- and HIV+ women about HIV prevention and transmission to support their potential PrEP use. In aggregate, concerns about PrEP included potential misuse, side effects, possibility for resistance, medication diversion, effect on pregnancy, stigma related to its use, a reminder of HIV/AIDS and no studies examining the long-term effects of PrEP use. Women described children, competing priorities, other people’s needs, lack of partner support and judgmental physicians as potential barriers to PrEP use. On the other hand, facilitators included the importance of health, family and partner support, not wanting to become HIV-infected, support from other women taking PrEP, and physician trust. Women described ways to facilitate PrEP-taking including practical tools such as phone apps, pill boxes, pamphlets, watches and sensors but they also noted support of a trusted doctor as well as individual responsibility and empowerment. In terms of text message content, women discussed the importance of greater choice in receiving messages with an emphasis on positive content, including affirmations, jokes, do-it-yourself ideas, quotes, things to do in Southern California, HIV facts and messages of hope from HIV-infected individuals.
Conclusions: In these focus groups of HIV- and HIV+ women, the majority of HIV- women expressed interest in participating in a PrEP demonstration project using daily text messages as prompts for adherence and using this HIV prevention strategy. Despite limited PrEP knowledge and concerns about taking PrEP, women highlighted the importance of PrEP use and ways to facilitate PrEP-taking. These findings were fundamental to the development of the first PrEP demonstration project in the US designed specifically for women.