FEM-PrEP: Participant Explanations for Non-Adherence

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Introduction

FEM-PrEP (FTC/TDF) is an antiretroviral daily oral pill for HIV prevention. A clinical trial conducted in 2008 found that participants who used FTC/TDF as part of their sexual risk reduction strategy reduced their risk of acquiring HIV.

Methods

The study included 232 FEM-PrEP participants who were being followed up for non-adherence in Pretoria and Bondo, Kenya. A qualitative study was conducted to understand the non-adherent women’s experiences and perceptions of the clinical trial pill. Women were interviewed using written and audio computer-assisted self-interviewing (ACASI) questionnaires.

Results

Many women described situations in which participants would talk with one another about the clinical research pill. Most women described a variety of discouraging comments from the community. We also conducted quantitative ACASI with 224 former FEM-PrEP participants.

Discussion

Participants were concerned about the possibility that the pill would not work or that it would cause sickness. Women also reported discouragement from others who believed they were taking an investigational drug. The pill was described as having negative health implications, putting it at odds with everyday beliefs and practices.

The disease was understood as something that one had to fight, which created a sense of stigma. Women described their adherence as a struggle, with many experiencing side effects and believing that the pill was not working as intended.

Conclusions

Most women described situations where they felt their partners were not encouraging them to take the pill. Women also reported feeling like the pill was not working and that they were putting themselves at risk. The pill was perceived as investigational, and women feared that others would think she was taking pills only when sick.

Models based on education on individual, community, and partner levels may not be sufficient to relieve people's anxieties about clinical research and non-adherence. Models based on the social-ecological framework, which considers the interaction between individual, interpersonal, and community factors, may be more effective.

Appendix

Table 3. Correlates of non-adherence

Table 4. Themes from narratives

Table 5. Conceptual model of factors influencing participant non-adherence

Table 6. Correlates of side effects

Acknowledgments

The study was supported by grants from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) to the FEM-PrEP study team. We thank the participants and their partners for their contributions to this research. We also thank the study staff, including the project coordinators and data managers, for their support in conducting the study.

References

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