

Title: Rumors about reimbursements in the MDP 301 microbicide trial in Johannesburg, South Africa

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Background and objectives

Rumors about the sale of blood, body part theft and purposeful HIV infection, are frequently encountered in community-based clinical trials and potentially discourage enrollment and retention. This paper investigates rumors concerning trial participant reimbursements that arose during an ongoing microbicide trial in Johannesburg, South Africa.

Methods

Qualitative research methods included in-depth interviews (IDIs) with enrolled women, focus group discussions (FGDs) with community members and trial participants, and participant observations in clinical and community settings. These were noted, audio-taped, transcribed, translated, and coded using Nvivo qualitative analysis software.

Results

150 IDIs, 20 FGDs, and 20 observations are included for analysis. Community rumors purported that younger women enrolled in the trial solely for the travel reimbursements (R150.00) paid at each clinic visit. This money was said to compensate for HIV infection caused by iatrogenesis and through purposeful exposure to HIV by having sex with an infected partner. Other related rumors alleged that trial participants dumped their gel and fabricated reports of gel use so they could make money from the trial. Women enrolled in the trial countered these rumors and emphasized the importance of trial participation in managing their health through cervical screening, HIV tests, STI diagnosis and treatment, counseling, and HIV information.

Conclusions

Cash reimbursements probably play a small role in encouraging participation in clinical trials. However, access to excellent clinical services appeared to be far more persuasive for promoting enrollment and retention in the MDP 301 study. Rather than assessing the 'truth' of the rumors it is important to explore what they express, which we argue in this case is a moral concern regarding women's autonomy over their bodies and criticisms aimed at younger women's sexuality.

300 words