

"When you are alone and find out that you are HIV positive, you have no one to talk to"; Perceptions of adults in Kenya about the role of counseling in HIV self-testing .

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ABSTRACT

HIV self-testing is a useful strategy to reach individuals who may not be reached through facility-based testing services. Concerns, however, have been raised about the need to ensure that people who self-test are properly linked to counseling and care. This paper draws on quantitative and qualitative data collected from individuals aged 15-49 years in urban and rural Kenya to examine community perceptions about the role of and modalities for counseling if HIV self-testing were to be rolled out. Results indicate that the majority of study participants believed that counseling is important. Qualitative responses indicated that the stigma associated with HIV/AIDS was an important reason for counseling support. Participants who had received counseling were more likely to report that counseling for self-testers was important. Suggested avenues to provide counseling included point-of-sale counseling, phone-based counseling, and through community health workers. Study results are expected to inform guidelines on self-administered HIV tests.

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EXTENDED ABSTRACT

Background

HIV testing has been identified as a critical component of HIV prevention efforts [1, 2]. However, the stigma associated with HIV/AIDS may act as a barrier to the uptake of facility-based HIV testing due to concerns around privacy. Self-test kits, which allow individuals to test themselves in the privacy of their homes, provide a useful avenue to reach those who may be unwilling or unable to use facility-based testing services [3]. However, self-testing presents several challenges, including potential social harms and abuses that might stem from people being able to self-test for a highly stigmatized disease in the absence of counseling support, as is largely the case for facility- or home-based HIV testing and counseling.

This study examines the potential role of counseling in mitigating the potential harms and abuses associated with oral self-testing for HIV. This paper draws on quantitative and qualitative data from males and females aged 15-49 years in one urban and one rural area in Nairobi, Kenya. These data were collected as part of a larger study investigating potential harms and abuses that would stem from public use of oral HIV self-test kits at home. In defining harms, we distinguish between individual level adverse events and social harms including adverse effects of self-testing on inter-personal relationships, including intentional infection of others or coerced testing of others.

METHODS

We report on qualitative and quantitative data collected as part of a cross-sectional study to assess the perceived social harms associated with HIV self-testing among adults aged 15-49 years. The study was implemented in Nairobi (urban) and Machakos (rural) Counties. In Nairobi, data were collected in two urban informal settlements (Korogocho and Viwandani) and two urban formal settlements (Jericho and Harambee). The formal settlements include a mix of middle and low income households.

Sampling

Participants for the quantitative survey were randomly-selected to ensure adequate numbers of males and females, as well as urban and rural residents. Within each study site, we randomly selected enumeration areas (EAs) as defined by the Kenyan National Bureau of Statistics. For the sites in Nairobi, every household within selected EAs was visited and selected alternately one young female (15-24 years), an older female (25-49 years), young male (15-24 years), or an older male (25-49 years) from the household. Recruitment continued until the desired sample size was achieved. In Machakos, the sampling procedure was slightly adjusted in the rural site because of the sparse distribution of households. Specifically, in every other household, fieldworkers could interview two females, one younger and one older. A total of 1,139 men and women aged 15 to 49 years old were interviewed. Six individuals with extensive missing data were dropped from the analytical sample (N=1,133). For the qualitative interview we purposively recruited participants representing a mix of participants from urban and rural areas, as well as younger (15-24 years) versus older (25-49 years) adults. We conducted a total of 13 focus group discussions (FGDs). Focus groups were held separately for men and women as well as for younger versus older adults. Each FGD comprising between 6-10 persons (N=118). We also conducted 26 in-depth individual interviews (IDIs) with a diverse group of participants from the study areas.

Procedures

Data were collected between August and November 2013 by a team of trained fieldworkers. The quantitative survey captured participants' sociodemographic characteristics, HIV-related knowledge, HIV stigma, HIV testing history, willingness to self-test for HIV, and perceived social harms or disadvantages and risk stemming from self-testing. HIV stigma was assessed using four questions: if respondents would buy fruits or vegetables from a known HIV infected shop keeper, if respondents would like the HIV positive status of a family member to stay secret, if respondents were willing to care for an HIV infected person in their own households, and if respondents thought a HIV positive teacher should be allowed to teach. Willingness to self-test for HIV using the oral testing kit was assessed with a single question having a *yes* or *no* response option: *"If you can buy an oral HIV self-test [kit] from the supermarket or shop, would you get it and do the test on your own?"*

Qualitative data were collected using semi-structured interview guides developed by sexual and reproductive health experts. The interviews elicited responses on respondents' perspectives about the ways through which HIV/AIDS affects the community; factors that prevent people in the community from getting an HIV test; perceived benefits of HIV self-testing; potential challenges associated with letting people in the communities test themselves; ways people in the communities might misuse/abuse HIV self-testing; and perceptions on people in the communities who were more at risk of misuse/abuse HIV self-testing or to be victims of abuse/harms. All interviews were conducted in Swahili, the national language. Both the quantitative survey and qualitative interview guides were pilot-tested prior to fieldwork.

Ethical considerations

Ethical and research clearance to conduct the study were granted by the African Medical and Research Foundation (AMREF) Ethics and Scientific Review Committee, and the National Council for Science and Technology. Verbal consent was obtained from the participants prior to the interviews. For participants aged 15-17 years, who were not living on their own, assent was also obtained from their parents or caregivers.

Data Analyses

Descriptive statistics of the participants' socio-demographic characteristics by area of residence were computed. Participants' responses about the importance of counseling and suggested approaches to receive counseling for people self-testing for HIV were summarized using descriptive analysis. We then ran multivariable logistic regression models to assess the association between the explanatory variables (socio-demographic characteristics, HIV-related knowledge, HIV stigma, HIV testing history, and previous counseling experience) and the outcome variables (perceived importance of counselling when self-testing and whether the respondent would seek counselling if he/she self-tested and had a positive result). Qualitative transcripts were coded into themes capturing participants' views about the importance of counseling during HIV testing and suggested approaches to overcome the challenges associated with the lack of counseling when people self-test for HIV.

SELECTED RESULTS

Ninety-one percent of survey participants reported that they would purchase and use oral HIV self-testing kits. However, 93 percent of those willing to self-test (n=1020) felt that it is necessary to have a trained counselor when self-testing. A major reason for counseling was the need for support in case the test was positive. Based on qualitative reports, many of the perceived harms and abuses associated with oral HIV self-testing (e.g., non-consensual testing, improper use of the kits, and poor linkage to treatment) were linked to the lack of counseling or inadequate information. Suggested avenues to provide counseling and information included point-of-sale counseling; phone-based counseling, information inserts; and distribution of self-test kits through community health workers.

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