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Formative assessment to identify perceived benefits and barriers of HIV oral self-testing among female sex workers, service providers, outreach workers, and peer educators to inform scale-up in Kenya

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Abstract

In Kenya, HIV prevalence estimates among female sex workers (FSWs) are almost five times higher than among women in the general population. However, only 68% of infected FSWs are aware of their HIV-positive status. We aimed to identify perceived benefits, opportunities, and barriers of HIV self-testing (HIVST) in improving testing coverage among FSWs. Twenty focus group discussions were conducted with 77 service providers, 42 peer educators (PEs) and outreach workers, and 37 FSWs attending drop-in centers (DiCEs) in four regions of Kenya. An additional 8 FSWs with HIV-negative or unknown status-completed in-depth interviews. Data were analyzed thematically. Acceptability of HIVST was high, with cited benefits including confidentiality, convenience, and ease of use. Barriers included absence of counseling, potential for inaccurate results, fear of partner reaction, possible misuse, and fear that HIVST could lead to further stigmatization. PEs and DiCEs were the preferred models for distributing HIVST kits. FSWs wanted kits made available free or at a nominal cost (100 Kenya Shillings or ~USD 1). Linkage to confirmatory testing, the efficiency of distributing HIVST kits using peers and DiCEs, and the types and content of effective HIVST messaging require further research.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

Disclaimer

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Keywords

HIV/AIDS; female sex workers; HIV self-testing; Kenya; implementation science

Introduction

Over the past 10 years, the proportion of individuals living with HIV who have received an HIV diagnosis has expanded rapidly from an estimated 10 to 81% by the end of 2019 (Joint United Nations Programme on HIV and AIDS (UNAIDS), 2019). This proportion, however, masks crucial gaps in HIV testing coverage, particularly among key populations (KPs, including female sex workers (FSWs), people who inject drugs, men who have sex with men, and transgender persons, and prisoners). In many parts of sub-Saharan Africa, the HIV prevalence among FSWs is 10–20 times higher than the prevalence among women of the same age in the general population (Baral et al., 2012; Beyrer et al., 2015). In Kenya, HIV prevalence estimates among FSWs range from 29.3% in Nairobi (National Key Populations Programme, NASCOP, Ministry of Health, 2014) to 56% in Kisumu (Odek et al., 2014; Vandenhoudt et al., 2013), compared to 6.6% among women in the general population (National AIDS and STI Control Programme (NASCOP), 2020) Despite this elevated risk, only 63.6% of HIV-infected FSWs in Kenya were aware of their status (Vandenhoudt et al., 2013). Stigma, discrimination, criminalization of sex-work and frequent arrests, unfriendly health care providers, inconvenient hours of operation and high transport costs all hinder access to traditional HIV testing services (HTS) among FSWs (Kenya National Commission on Human Rights, 2012; Shannon et al., 2015).

New approaches for closing the HIV testing gap among FSWs are needed to achieve UNAIDS's goal of 95% of people living with HIV knowing their status by 2030 (UNAIDS, 2014). HIV self-testing (HIVST) – whereby an individual collects and tests their own specimen – has been proposed as one way to increase HTS coverage among FSWs (World Health Organization (WHO), 2016). Self-testing addresses many of the challenges associated with traditional HIV testing by allowing individuals to test for HIV in a setting and at a time of their choice (Johnson et al., 2014; WHO, 2016). Several studies have shown high acceptability for HIVST among FSWs (Burke et al., 2017; Figueroa et al., 2015; Maman et al., 2017; Pal et al., 2016) and many countries, including Kenya, have included HIVST in their national HTS guidelines (NASCOP, 2015; WHO, 2016).

However, questions remain on the most effective way to distribute oral HIVST kits to FSWs and the potential social harms inherent in this HIV testing approach. The purpose of this qualitative study was to identify perceived benefits and barriers of oral HIVST among FSWs, outreach workers (OWs), service providers (SPs), and peer educators (PEs) to inform scale-up of this testing strategy among FSWs in Kenya. We also explored potential solutions to barriers identified.

Materials and methods

Study setting

This qualitative study was part of a larger, quasi-experimental crossover study implemented in four regions of Kenya (Kisumu/Siaya, Nairobi, Southern Nyanza/Kisii, and Mombasa). The parent study aimed to assess the acceptability and feasibility of oral HIVST in improving testing coverage among FSWs who have not been tested or who infrequently test for HIV. In that study, trained PEs distributed OraQuick Rapid HIV ½ Antibody tests (OraSure technologies Inc Bethlehem, PA18015 USA) to FSWs. As part of distribution, PEs also provided pre-test counseling, a brief demonstration, and a referral note to a specified drop-in centre (DICE) for confirmation of the self-test result, whether negative or positive. The purpose of this formative assessment was to identify perceived barriers and enablers of this testing approach among FSWs in order to inform the larger intervention study.

Study participants

Four types of participants were purposefully selected from eight drop-in centres (DiCEs, two per region): FSWs, PEs, OWs, and SPs. Eligibility for FSWs included: (1) identifying as a sex worker, (2) ≥18 years of age, (3) willing and able to provide written informed consent, and (4) willing to be audio-recorded. Peer educators and other DiCE staff assisted with identifying FSWs for recruitment. To obtain a range of viewpoints, purposeful sampling of FSWs factored in several considerations including time since last HIV test (<6 months or ≥6 months), length of time working as an FSW (<3 years or ≥3 years), and current enrollment at a DiCE.

Eligibility criteria for PEs, OWs, and SPs included: (1) being currently associated with a DiCE, (2) ≥18 years old, (3) willing and able to provide written informed consent, and (4) willing to be audio-recorded. PEs and OWs were purposefully sampled by the length of time in their roles (<3 years or ≥3 years) to explore if OST perceptions differed based on the length of time working with FSWs. Service providers were sampled to include a mixture of staff roles.

Data collection

A total of 20 focus group discussions (FGDs) and 8 in-depth interviews (IDIs) were conducted as part of the qualitative study. Separate focus group discussions were conducted for FSWs, PEs, OWs, and SPs to encourage participants to speak freely. Trained facilitators conducted all FGDs and IDIs in a private location in English, Kiswahili, Dholuo or Ekegusi, depending upon the participant's preference. A discussion guide outlining major topics and suggested probes was used to facilitate each discussion. Key topics included: (1) perceived benefits and barriers of oral HIVST, (2) belief in the accuracy of oral HIVST, and (3) the best ways to distribute HIVST kits among FSWs. All FGDs and IDIs were audio-recorded and transcribed verbatim.

Data analysis

All interviews were transcribed verbatim by the interviewer. A supervisor randomly selected 10% of transcripts for verification. Transcripts were then uploaded into NVivo (version 11.0)

for analysis. Only FSWs with a self-reported HIV negative or unknown HIV serostatus (n = 45) were included. A preliminary codebook based on the discussion guides was developed a priori. All transcripts were then reviewed to identify emerging themes and the codebook was revised to include these themes. A consultative meeting was held in Kisumu, Kenya, between the coder and the study staff for an in-depth review of the codebook; this review included discussions on contextualization and interpretation of initial transcript review and suggested codes. All transcripts were then independently coded by two analysts and resulting code sets compared weekly. Discrepancies were discussed until consensus reached. Main themes and sub-themes were identified, and illustrative quotes pulled out from transcripts to capture enablers and barriers for HIVST as described by participants.

Human subjects

All participants gave voluntary informed consent and were reimbursed up to 400 Kenya shillings (US $3.95) to cover transportation to the interview location. The study was reviewed and approved by Institutional Review Boards (IRBs) at the Kenya Medical Research Institute and the U.S. Centers for Disease Control and Prevention (CDC).

Results

Twenty FGDs were conducted with 77 SPs and OWs, 42 PEs, and 37 FSWs. An additional eight FSWs with HIV-negative or unknown serostatus completed individual interviews. Table 1 presents the demographic characteristics of the study participants. The majority of PEs and FSWs were single or divorced, and most had engaged in sex work for ≥3 years.

Perceptions of HIVST

Most participants had heard of HIVST but had never seen a saliva-based self-test kit. They felt that HIVST would be acceptable to FSWs since it would allow them to test in private, avoid the need to travel to a DiCE for testing, and offer the ability to test immediately with their client instead of traveling to an HTS location.

> We would like because it is easy. Sometimes you get to the DiCE to be tested and find that the kits are unavailable and sometimes the line is also long. And sometimes you have someone [a client] who is in a hurry. So that you get tested with him instead of being in the line. (FSW, Kisumu)

FSWs preferred receiving an oral HIVST kit from a PE or from a friendly site in their community (e.g., outreach program, DiCE, or bar). The overwhelming majority of SPs and OWs felt that HIVST should be free. However, most FSWs wanted to pay a nominal fee equivalent to the US $0.99 ($0.01–$9.83) in order “to attach importance” to the kit.

Trust in oral HIVST results

Most PEs and FSWs indicated that they would trust the results they received from oral HIVST. As one participant stated,

> I am the one who did the swabbing and dipped it myself and read the results. Why else should I doubt? (PE, Kisumu/Siaya)

However, even those who trusted the results expressed the need to confirm their self-test results at a DiCE or health facility, especially in the event they received a reactive (or positive) result.

> I will not trust in the [HIVST] result for the first time until I confirm. Even if the result is positive or negative. So if I use [the kit] and I find a positive or negative result then [I will] visit the DiCE and [if I] get the same result [that] is when I will trust it. I don't trust the firsthand result. (PE, Southern Nyanza/Kisii)

For those PEs and FSWs who expressed mistrust of the HIVST result, common reasons given were a confusion that oral fluid could be used to diagnose HIV and feeling unqualified to test themselves.

> Some will ask since when does saliva contain the virus? (PE, Southern Nyanza/Kisii)

> I can't rely on it because I am not trained fully on matters related to testing. (FSW, Kisumu/Siaya)

Others stated they would be suspicious of a reactive result because they had previously tested negative at a DiCE.

> Let's say she tested three months ago and found a negative result [and] in between you bring her the kit. She uses and finds she is positive. She does not trust the result. (PE, Southern Nyanza/Kisii)

Perceived benefits of HIVST

Participants listed several potential benefits for HIVST as described below and in Table 2, in order of frequency.

Privacy and confidentiality.—Many participants valued the fact that HIVST would allow them to test themselves in private, without the concerns that SPs or PEs would share their results with others (Table 2).

Perceived ease of use.—Interviewers demonstrated how to use the oral HIVST kits during FGDs and IDIs and asked participants to comment on how easy they thought the kit would be to use. SPs appreciated how easy the oral HIVST kit was to use and felt FSWs would be able to obtain an accurate result with minimal instruction (Table 2). In addition, participants felt that kits would be easy to dispose of since they used saliva not blood. Possible disposal methods mentioned by participants included the toilet, trash and burning.

Convenience.—Participants also appreciated that HIVST would allow them to test for HIV at any time and avoid long lines at the health facility (Table 2). This was particularly important since many slept during the day when the DiCE and other health facilities were open for HTS.

Facilitate testing of regular partners and clients.—Most FSWs expressed willingness to use a self-test kit with their regular partner (Table 2). HIVST kits would help them introduce the topic of HIV testing with their partner and allow them to test

immediately together in their home. Other FSWs described using HIVST before sex to protect themselves from having unprotected sex with an HIV-positive client. This was particularly important since many of their clients insisted on unprotected sex or offered them incentives for engaging in unprotected sex. Some FSWs also described how HIVST could help them attract clients by removing the need to go to a health facility prior to the sexual encounter.

Peer support for HIV testing.—Participants described how the availability of HIVST kits could encourage FSWs to support each other to overcome challenges related to HTS and would help them to engage in routine quarterly testing (Table 2).

Perceived barriers to HIVST

Perceived barriers to HIVST are presented below and in Table 3.

Lack of counselling and support.—The most common barrier to HIVST expressed by participants was the lack of counselling and the potential adverse consequences that could result (Table 3), including the possibility of suicide. In contrast, some FSWs saw no potential for adverse effects since accepting an HIVST kit meant one was prepared to accept the results.

> I think when you want to give out the kit, you first talk with the patient that you want to give [the test to], because she has gone through counseling and accepted to use the kit. That's why she went with the kit. (FSW, Kisumu/Siaya)

Inaccurate results.—Some participants expressed concern that they could receive inaccurate results if they did not receive proper instruction on how to use the kit, potentially delaying the onset of HIV treatment (Table 3).

Fear of partner reaction.—Participants also described fearing how partners would react in the event of a reactive test result, particularly in the absence of a counsellor to help mitigate any negative reactions and facilitate communication between the couple (Table 3). This was particularly true if the partner previously tested HIV negative at a testing site or with an HIVST kit.

Mistrust of PEs.—PEs expressed concerns about being abused or harmed by fellow FSWs if they began wide-spread distribution of HIVST kits (Table 3), as their efforts could be construed as impeding the ability of FSWs to attract clients. To avoid blame during the distribution process, PEs felt that FSWs would need to consent to receive a kit and receive a proper demonstration on how to use the kit.

Potential misuse.—A few SPs expressed concern that some PEs would attempt to hoard all of the HIVST kits for their own use, prioritizing friends and family for kit distribution, or sell the kits (Table 3).

Further stigmatization.—Finally, a few FSWs described feeling stigmatized by the community because of their sex work (Table 3). They felt community members blamed

them for spreading HIV and did not want them in their communities. They saw HIVST distribution targeted to FSWs as just another way to stigmatize them. In addition, several FSWs expressed concerns about how SPs in public health facilities would treat them in the event of an HIV-positive diagnosis.

Discussion

Our analysis indicates that oral HIVST is acceptable to a sub-sample of FSWs in four regions (Kisumu, Nairobi, Nyanza, and Mombasa) of Kenya. Oral HIVST was perceived as allowing flexibility in the location and timing of a test, alleviating time and cost barriers. Participants also felt that coping with a positive result would be easier in the privacy and familiarity of their own homes. Other benefits of oral HIVST mentioned included ease of kit use and disposal, and increased opportunity to test with sexual partners. Notable barriers included potential for self-harm, inaccurate results, and the possibility that HIVST could lead to further stigmatization. These benefits and barriers align with previous studies on HIVST conducted among heterosexual adults (Knight et al., 2017) and key populations in other settings (Figueroa et al., 2015; Logie et al., 2017; Phrasisombath et al., 2012; Wanyenze et al., 2017).

Participants' main concern about oral HIVST was the lack of pre-test counseling in the event of a reactive result. Respondents frequently emphasized proper counseling and instructions as keys to the success of HIVST programs with FSWs. Without this counseling, respondents worried that HIVST could lead to negative health outcomes like depression and suicide as well as inaccurate test results. There was confusion that oral fluid could be used for an HIV test, which participants felt contradicted previous information that HIV could not be transmitted via saliva. These concerns mirror findings from other studies (Figueroa et al., 2015; Krause et al., 2013; Pal et al., 2016) and highlight the need for more research into effective and appropriate oral HIVST messaging. In addition, HIVST programs should ensure that PEs are properly trained and are able to demonstrate kit use to FSWs. Equipping PEs with educational materials, including pictorial instructions and short demonstration videos, can improve the likelihood that FSWs use the test kit correctly and interpret the test results accurately (Choko et al., 2015; Kurth et al., 2016; World Health Organization (WHO), 2016). In addition, PEs should provide information on where to obtain confirmatory testing and HIV treatment in the event of a reactive result as a part of the demonstration process. Active interventions to encourage confirmatory testing and linkage to treatment following a positive result have been shown to be effective in a number of HIVST studies (Chanda et al., 2017; Choko et al., 2015; Ortblad et al., 2017).

While most participants preferred receiving an HIVST kit from a PE or at the DiCE, a minority of participants raised concerns over potential breaches of confidentiality, hoarding of kits, and PEs prioritizing friends and family for kit distribution. Other studies have also identified confidentiality concerns as a barrier to testing uptake among KPs including FSWs (Logie et al., 2017), particularly because of the dual stigma of being at high risk for HIV and criminalization of sex work. Systems need to be in place to reduce potential misuse of oral HIVST kits among PEs including following rigorous standards for selecting and training PEs for HIVST distribution and frequent monitoring to identify any irregularities.

Furthermore, HIVST does not eliminate the need for KP-friendly services, as several participants expressed concerns about potential mistreatment from SPs in public health facilities following an HIV-positive diagnosis. They requested that all providers receive KP-sensitization.

FSWs expressed interest in using HIVST with their regular partners and clients. This finding is similar to studies conducted in Kenya and the United States where HIVST was used to screen potential partners for HIV and FSWs were less likely to engage in unprotected sex with clients screening HIV-positive (Balan et al., 2014; Carballo-Diéguez et al., 2012; Thirumurthy et al., 2016). In Zambia, the distribution of HIV self-tests to FSWs was associated with fewer clients per night (Oldenburg et al., 2018). Taken together, these studies suggest that HIVST may contribute to HIV prevention efforts in addition to being a strategy for improving HIV case finding. Concerns have been raised, however, that FSWs may be less likely to use condoms with clients who receive HIV-negative results following HIVST (Burke et al., 2017; Maman et al., 2017; World Health Organization (WHO), 2016). WHO has recommended that self-test kits not be used for sexual decision making in groups at high risk for HIV, including FSWs (WHO, 2016), because of concerns that it could lead to high-risk behavior. HIVST programs targeting FSWs need to ensure that risk reduction counseling, including the importance of using condoms to prevent other STIs, unintended pregnancy and the risks associated with serosorting, is included in HIVST messaging (WHO, 2016).

This study had several limitations. Most participants and interviewers had never used an oral HIVST kit before, which limited their ability to probe or respond based on direct experience. Participants' perceptions regarding HIVST may have differed if they had been offered the chance to use oral HIVST prior to participation in interviews. All women enrolled in this study self-identified as a current or former FSW; thus, the study findings may not be generalizable to other women who may engage in transactional sex but not self-identify as a FSW. In addition, this study used qualitative methods which are context-specific and not generalizable to other settings. Quantitative work is needed to understand how generalizable these results are for the broader populations of FSWs in Kenya and other sub-Saharan African countries.

In summary, our analysis reveals that oral HIVST is acceptable to FSWs with the potential to mitigate many of the barriers inherent in traditional HTS at health facilities. Participants believed FSWs to be largely capable of correctly using oral HIVST and expressed willingness to use oral HIVST for themselves and with their partners and clients. Remaining questions on how best to ensure linkage to confirmatory testing following a reactive result, the optimal model for distribution of oral self-test kits to FSWs, and the types and content of effective messaging should be prioritized for future investigation and program improvement.

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Table 1.

Demographic characteristics of participants at baseline qualitative interviews on oral HIVST among female sex workers in four regions of Kenya, 2016.

Variables	Service providers and outreach workers (*n* = 77)	Peer educators (*n* = 42)	Sex workers (*n* = 37)	Sex workers (*n* = 8)
Mean age (SD)	33.4 (8.2)	29.8 (6.7)	29.9 (6.7)	28.9 (2.1)
Education				
None	–	–	1 (2.8%)	–
Primary	8 (10.4%)	10 (23.8%)	21 (58.3%)	3 (37.5%)
Secondary	17 (22.1%)	26 (61.9%)	12 (33.3%)	5 (62.5%)
Tertiary	52 (67.5%)	6 (14.3%)	2 (5.6%)	–
Marital status				
Single	36 (46.8%)	22 (52.3%)	20 (54.1%)	6 (75%)
Married	36 (46.8%)	2 (4.8%)	7 (18.9%)	–
Separated/divorced	3 (3.9%)	12 (28.7%)	8 (21.6%)	2 (25%)
Widowed	3 (3.9%)	6 (14.2%)	2 (5.4%)	–
Time in sex work				
≤2 years	–	5 (11.9%)	13 (35.2%)	2 (25%)
3–5 years	–	26 (61.9%)	14 (37.8%)	4 (50%)
>5 years	–	11 (26.2%)	10 (27.0%)	2 (25%)

Table 2.

Perceived benefits of oral HIV-self testing as described by service providers, peer educators, and female sex workers in four regions of Kenya, 2016.

Benefit	Sample excerpts
(a) Privacy and confidentiality	"I prefer that you test yourself in the house. If you are someone who likes crying, you just cry in your bedroom and tomorrow it ends. It has happened and there is no turning back. And you continue taking your drugs and life goes on." (FSW, Kisumu/Siaya)
(b) Easy to use	"With actual proper demonstration … many of them will follow the procedure. I believe it's a very simple test … they will actually know how to conduct it." (OW, Kisumu/Siaya)
(c) Convenience	"There are sex workers who go for work the whole night … You spend the whole day sleeping. At night again she leaves. She does not have time to go to the DiCE … .If a peer educator can be given [an oral HIVST], so that when they meet at the hotspot they give them. So that when you wake up, you can test yourself. Now you don't need to come to the DiCE." (PE, Mombasa)
(d) Facilitate testing of regular partners and clients	"If I have a partner, he should be conscious to realize that this is important; and conclude that this partner is a serious person who wants to be aware of her status in our house." (FSW, Kisumu/Siaya) "There is this Dira [slang for client] that has come to my hotspot or my house and he wants to have sex without a condom. He is offering me five thousand. Why should I test myself and I know my status? Let me test this Dira … So it will be like weighing the chances. After three months, I will go to the DiCE, I will test. But this test kit, let me test this person. If he is negative, let me take the five thousand." (OW, Kisumu/Siaya) "Maybe I have met a mzungu [white man]. He tells me, 'lets go to the VCT'. I tell him, 'no, there is no need. I have my test kit. Just give me money, we test ourselves here.'" (PE, Mombasa)
(e) Encourage peer support for HIV testing.	"The sex workers … will also encourage their fellow sex workers … that right now there are [oral self-test] kits. And it will give them courage to want to know their status." (SP, Kisumu/Siaya)

Notes: FSW: female sex worker; SP: service provider; PE: peer educator; OW: outreach worker; FGD: focus group discussion; Oral HIVST: oral self-testing; DiCE: drop-in centre; VCT: voluntary HIV testing and counseling

Table 3.

Perceived barriers of oral HIV-self testing as described by service providers, outreach workers, peer educators, and female sex workers in four regions of Kenya, 2016.

Barriers	Sample excerpts
(a) Lack of counselling and professional Support.	"You may go to test yourself, collapse and there is no one to pick you up." (FSW, Nairobi) "You will be found hanging with your result on the table." (FSW, Nairobi)
(b) Inaccurate results	"One may not know how [to] read the instructions or to interpret the results. So she may not know if she is sick or not …you assume that you are not infected when you actually are." (FSW, Kisumu/Siaya)
(c) Fear of partner's response	"Sometimes I am given the kit and I use it to test myself. I was sure that I was clean. I had told my boyfriend that if this thing reacts like this then I am going to be like this [HIV positive]. Then I go and discover that I am positive and my boyfriend knows that he is clean … all hell will break loose and somebody can die." (FSW, Kisumu/Siaya)
(d) Mistrust of peer educators	"You can be chased away [by the FSW] that you have come to spoil their business." (PE, Southern Nyanza/Kisii) "Yes, that will give problems because you will give even the people that you did not consent. You didn't talk to her prior to giving it. So, we can have a problem if I just decide to distribute it [the oral HIVSTST kit] like tomatoes in the market. We will have a problem." (PE, Kisumu/Siaya)
(e) Potential misuse of the self-test kit	Like a peer educator … just goes with them [the oral HIVST kits] and maybe for their own use. And then they come to the clinic and say that they have been stolen. (SP, Nairobi)
(f) Further stigmatize FSWs	"This [oral HIVST] is just a way of getting rid of sex workers because sex workers … are not wanted by some communities." (PE, Southern Nyanza/Kisii)

Notes: FSW: female sex worker; SP: service provider; PE: peer educator; IDI: in-depth interview; FGD: focus group discussion; oral HIVST: oral self-testing.