

# Female sex workers perspectives and concerns regarding HIV self-testing: An exploratory study in Tanzania

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## Research article

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# Abstract

Background HIV testing is a gateway to HIV care and treatment for those testing positive, and can link those with negative reactive tests to HIV preventive services, including enrolment into pre exposure prophylaxis (PrEP). While benefits of HIV testing services (HTS) are known, uptake of HTS among female sex workers (FSWs) in Tanzania and across sub-Saharan Africa (SSA) remains suboptimal. Introduction of HIV self-testing (HIVST) may mitigate some of the barriers for the uptake of HTS, and contribute to greater linkage to care and prevention services. This study explored perspectives of FSWs towards HIVST, to inform a large-scale combination HIV prevention program addressing key populations (KPs) in Tanzania. Methods We conducted an exploratory study employing in-depth interviews (IDI) and participatory group discussions (PGD) with FSWs. PGD collected normative data e.g. perceptions and attitudes towards HTS, whereas IDI collected personal information e.g. sexual practices and HIV risk perceptions. Study participants were recruited through snowball sampling. Data were thematically analysed using NVivo software. Emerging themes were explored in the tradition of Grounded Theory. The analysis was informed by the social ecological model and focused on factors associated with feasibility of scale up of HIVST. Results A total of 20 PGD sessions were conducted involving 227 participants. We also conducted IDIs with 21 FSWs. Study participants were enthusiastic toward HIVST. Convenience (time and cost saved), and belief that HIVST will increase privacy and confidentiality were primary in participants' support for the HIVST. Participants did express concerns about their ability to interpret and trust the results of the test. Participants also expressed concern that HIVST could cause personal harm, including severe distress and self-harm for the FSWs with reactive test – this was related to the lack of professional counselling support in the self-testing environment. Conclusions Increased confidentiality, reduced cost for care, and increased autonomy were among the leading motivations to use HIVST. Major concerns included fear of HIV positive results, and not trusting self-diagnoses. We underscore the importance of providing adequate support services in conjunction with HIVST, e.g. access to counselling and referral services, and user-accessible support to the interpretations of test results.

## Background

Since most new HIV infections are caused by persons unaware of their HIV sero status[5,6], HIV testing services (HTS) are a necessary step to getting people into care and treatment (or prevention) services. A variety of approaches are employed to deliver HTS (including integrated into family planning or antenatal care services[7], outpatient services[8–10]. To complement facility based HTS approaches, countries in SSA have also employed other approaches such as home/community-based testing[9,11–16]. Community based HTS delivery approaches have shown to have positive impact both at linkages to care and treatments and also for the uptake of other HIV control interventions including

voluntary medical male circumcisions[19]. In Uganda[17] and Tanzania[18], community based HTS have improved enrolment into care and initiation of treatment in the general population. Also, examples of community based HTS approaches designed specifically to increase HTS uptake among marginalized groups such as FSWs exist, including mobile services in Benin[20], using mapping in South Africa[21] and drop in centers in the Democratic Republic of Congo[22]. Despite successes of these delivery models, uptake of HTS among FSWs is still suboptimal[23,24].

FSWs face particular barriers to accessing HTS, including high levels of stigma associated with sex work[25–28] and fear of loss of livelihood if HIV status becomes known[29–31]. In Tanzania, extremely high stigma has been documented towards FSWs, causing reluctance to seek family planning services[32] and for initiation and progressions into continuum of care[33]. Thus, more efforts are needed to reach FSWs, proportional to their increased risk of HIV infection. In 2017, the World Health Organization (WHO) recommended HIV self-testing (HIVST) and partner notification services in countries with a generalized HIV epidemic[34]. Self-testing is thought to be a good service delivery modality for FSWs due to the noted structural barriers which keep FSWs away from attending health services in the facility setting.

## Methodology

### Theoretical framework

Based on socio ecological model (SEM), HIV risk perceptions or and behaviours leading to HIV infections can take place at different levels, including, individual, relational, community or social groups, and national policy (enabling environment) levels[38–40]. However, realising that SEM is flexible and that 'no one model is sufficient to describe factors that influence individual behaviour across the diverse domain', Baral and colleagues proposes for a "modified social ecological model" (MSEM) which incorporates the '*stages of HIV epidemic*[41]. This modification underscores that apart from the fact that HIV infections and transmissions occur in diverse social cultural contexts, *stages of HIV epidemics*

informed not only HIV risk perceptions and behaviour for HIV acquisitions and transmissions[41,42], but also public discourses and strategies regarding HIV preventions. Although, the modified version of SEM was formulated to analyze people's risk behaviour for HIV infections, we find it to be a relevant framework to understand FSWs' perspectives toward HTS including HIVST, particularly regarding public discourses on risk perceptions and contribution of KPs in HIV transmissions.

### Program setting

The study was conducted to inform a comprehensive HIV combination prevention program which delivers biomedical, behavioural and structural interventions to FSWs and other key populations in Tanzania (the Sauti program). Sauti is a five-year program funded by PEPFAR through the US Agency for International Development (USAID), administered by Jhpiego in consortium with other implementing partners and in conjunction with Tanzania's Ministry of Health, Community Development, Gender, Elderly and Children (MoHCDGEC).

This study was conducted in 2017 in Dar es Salaam municipality, and Iringa, Mbeya and Shinyanga regions, all of the regions where the Sauti program implemented interventions in that year. With exception of Dar es Salaam (4.7%), the other three regions have HIV prevalence higher than the national average (5%) [43]. Dar es Salaam is the largest city in Tanzania located at the eastern part of Tanzania. Iringa and Mbeya regions are in the Southern highlands, and Mbeya borders Zambia and Malawi. Shinyanga is located around Lake Victoria. Iringa and Shinyanga regions have timber/tea plantations and mining sites respectively, which attract a high number of seasonal migrants including FSWs and labour forces. Dar es Salaam and Mbeya attract heavy traffic of travellers entering and leaving the country.

## Study Design

We conducted a qualitative study utilizing two methodologies for capturing views and experiences. In-depth interviews (IDI) were used to capture experiences / opinions which were sensitive or of a personal nature, and participatory group discussion(s) (PGD) were used to capture less sensitive community or societal norms towards HIVST.

### Sampling and recruitment of study participants

We conducted IDIs with FSWs from seven wards across the four regions, with three participants per ward (overall, 21 IDIs). We anticipated that by the time we conduct 21 IDIs, we shall have reached data saturation. In case the saturation was not reached by the 21 IDI we planned to continue recruiting new batches of FSWs and interview them until the saturation point is reached. Eligible participants for this study were; females, aged 18 years or above, self-identified as a sex worker, consenting to participate in the study. The Sauti Program definition of a sex worker is someone whose primary source of income (i.e. over half of their income) derives from payment for sex.

Both purposive and snowball (i.e. peer referral) sampling strategies were used to recruit IDI participants. Community gatekeepers/ stakeholders, including owners of entertainment venues and civil society organisations (CSOs) provided us an initial list of FSWs to contact. The first batch of FSWs were influential, outspoken or peer leaders of FSWs. The first batch of FSWs group was asked to recruit up to three FSWs counterparts (second batch of FSWs).

We also conducted PGD sessions. Similar to the procedures used to recruit participants for IDI, we employed snow ball sampling to recruit participants for PGD sessions. Initial list of PGD participants were drawn by researchers in consultations with the CSO providing HIV

control services to FSWs. A total of 23 PGD sessions involving 227 participants were conducted across the four regions.

## Data collection

Data collection was conducted by six interviewers trained in social science disciplines and experienced in qualitative study methods. During a two-week training, interviewers were trained on research ethics, consenting procedures, confidentiality and techniques to elicit sensitive information as well as being oriented to study tools and processes. This included a practical period piloting study tools and conducting interviews.

IDIs were conducted in a private location, such as guest house rooms, or in the offices of civil society organizations serving FSWs. IDI were conducted by a single interviewer in Swahili. Since at the time of this study, HIVST had not yet been introduced in Tanzania, prior to the interview, we read to the participant a description of HIVST. After obtaining consent to participate as well as to audio record the interview, the interviewer started with general questions on awareness and access toward HIV testing services. This was subsequently followed by questions about HIV risk perceptions, sexual behaviour and treatment seeking for sexual and reproductive health problems issues. On average, each IDI took about 45 to 60 minutes.

Similar to IDIs, PGDs sessions were conducted in private rooms in the community setting, including offices of CSOs or guest house rooms. PGD took a form of modified focus group discussion with participants ranging from between 8 and 12 persons. Prior to the PGD sessions, participants filled in a form to collect socio demographic data (but no identifying information was collected).

Three members of the study team facilitated the PGD: a facilitator, a moderator and a note taker. Alongside audio recording PGD sessions, the interviewers took notes which were typed into a laptop computer for further analysis. Two senior social science researchers

fluent in both Swahili and English (SN and DN) reviewed the notes from PGD session and provided feedback in real-time to the research team. On average, a PGD session took 90 to 120 minutes.

## Data Management and Analysis

On a daily basis, audio files were transferred to a secure server using terms described by a File Transfer Protocol. All audio files were transcribed verbatim in Swahili and translated into English. The written notes from PGDs were typed and merged with corresponding transcribed texts.

The two senior research scientists (SN and DN) were responsible for analysis, including development of themes and codes. A three-stage data analysis process was conducted. In the first analysis stage, a narrative including verbatim transcripts from each PGD and IDIs were written. In this narrative, the researchers used both inductive and deductive methods to identify emerging themes of interest. The predetermined (*a priori*) themes were coded using the codes developed during the study design stage as well as new ones that emerged during content analysis. The second analysis stage consisted of transferring the compiled data by themes into the qualitative software (Nvivo 11) which allowed to identify regularities and patterns. The conclusions were drawn based on the predetermined and emerging themes, regularities, patterns, and causal flows towards study objectives.

## Results

### Socio demographic characteristics

A total of 227 FSWs participated in 20 sessions of PGDs. Twenty one of the FSWs who participated in PGD sessions were also interviewed through IDIs. At recruitment, the mean age of the study participants was 24 years. Of the 227 participants, 8% had never been to school, or 51.5% had completed primary school education. 64.4% of the FSWs had been involved in sex work for more than 1 year. Sixty three percent of FSWs used entertainment

venues (e.g. hotels, bar, disco halls) as a working site; the others worked elsewhere (Table 1).

### Awareness and attitude about HIV testing

Knowledge about the availability of HIV testing, and testing practices, was generally high according to participants report, with 93.0% of the participants reported having tested for HIV in the past two year. Of those tested, 13.6% were told to be HIV positive at the time of the test. Among those testing HIV negative, 80% were willing to test again. Over half (56.3%) of those who indicated that they would test again believed that HIV testing services were only offered in the health facility setting.

When participants were asked if they have heard about HIV self-testing, only 25% reported to know it. The participants who had heard of self-tests were not aware that the test consisted of oral fluid testing. The majority of IDI participants were in favour of this method, since they felt the puncture process would be painful.

### Participants' positive viewpoints about HIVST

#### Improved confidentiality, convenience and empowerment

In all PGDs, a majority of participants agreed that availability of HIVST will be welcomed. FSWS anticipated availability of HIVST will minimize dependency on health workers, and inconveniences they encounter when seeking services from the health facilities. Participants described challenges to visiting health facilities for HIV testing, including long travel and transport cost, and substantial wasted time waiting for the services at the facility. They expressed their hopes that availability of HIVST will help to save the transport cost and time they lose when seeking services from the health facilities.

Participants in all 23 PGD sessions reached a consensus that, availability of HIVST will guarantee complete confidentiality and privacy during IV testing. The view that availability of HIVST would improve confidentiality was also echoed during IDI with 17 FSWs (out of the 21 who participated in IDI). Three IDI participants thought that the HIVST might actually enable FSWs to request clients to undertake HIV testing before sex (Table 2).

**Table 2: Perceived advantages of availability of HIVST**

<b>Dimension(s)</b>	<b>Theme</b>	<b>Viewpoints of participants</b>
<b>Intra personal</b>	Autonomy	<i>If test kits become available at our homes, people will not be forced to go far away to seek the service [...] Instead they will do it immediately instead of delaying. Unlike going to the hospital which requires people to make some preparations to reach there. <b>PGD_Iringa</b></i>
	Convenience	<i>Some FSWs feel shy to seek HIV testing service at public health facilities [If the test kits become available] they will go and buy the kits and test themselves. <b>IDI_21yrs_Shinyanga</b></i>
<b>Community</b>	Improved confidentiality	<i>Don't you know that if you are tested by someone else s/he will know your status and start telling other people that you are already infected? [...]If they bring kits to us [we shall test ourselves] and, nobody else will know [the results]. <b>IDI_30yrs_Shinyanga</b></i>
	Mitigation of stigma	<i>Nowadays people are not trustful. We cannot even trust our siblings [since] they will inadvertently tell [...] that you know somebody is sick [...]and remember there is a possibility of being stigmatised [and] that's the end of your business. <b>IDI_44yrs_Mbeya</b></i>
<b>HIV test policy</b>	Reduced reliance on health facility protocols	<i>[...] If you go to test at the hospital you will be given a special document [card] which you cannot hide from other people. [...]It's impossible to hide it. Other people will also see it. Availability of test kits will enable us to do it ourselves [instead of depending on health workers]. <b>IDI_20yrs_Mbeya</b></i>

## Preferences on HIVST delivery points and willingness to pay for HIVST

Participants reported that they will be willing to contribute modest amount of money to access HIVST. In most PGDs, participants felt that they would be willing to contribute roughly USD 1-2 [equiv. Tshs 1,200-2,500] per kit. This is further described by a participant:

*I wish the price [of HIVST test kit] to be around five thousand shillings [...] because we earn about ten thousand shillings from a single client. A person may use five thousands for HIV testing and spend the remaining for the home chores. [IDI\_21yrs\_Shinyanga region]*

In all PGDs, participants expressed preference toward HIVST over health facility-based testing. Participants would like to see HIVST kits to be available in nearby pharmacies (highest priority), private health facilities (medium priority) and public health facilities (lowest priority). A few participants preferred the test kits to be available in informal sites including community spots, guesthouses, public washrooms and pubs. Alternatively, some participants suggested that the test kits be dispensed through nongovernmental organisations serving FSWs.

## Participants negative viewpoints about HIVST

### Social narratives and discourses about sex workers and HIV transmission

Participants described another side to self testing relating to the social narrative of stigma and risk which is both external and internal to them. First, participants acknowledged their own increased risk for HIV infection due to their high-risk sexual behaviour. They also described a fatalistic view among FSWs that they are likely to be infected, and thus have greater fear of testing. A number of participants further felt that FSWs would be reluctant to test because of their uncertainty on coping with reactive test results. The concept that

knowing an HIV positive status would allow FSWs to deliberately expose their clients to HIV infection came up in multiple IDIs. This perspective (self testing will create room for FSWs to maliciously expose clients to HIV) was raised in two PGDs.

### Fear of social harms

Despite considerable support for HIVST, concerns were expressed about potential adverse outcomes related to conducting an HIV test without oversight by trained professionals. Four participants expressed concern that since HIVST does not include pre-test counselling, people who have a reactive test result may undergo severe distress and consider suicide (Table 3).

### ***Table 3: Perceived disadvantages of availability of HIV self-testing***

<b>Dimension(s)</b>	<b>Theme(s)</b>	<b>Viewpoints of participants</b>
<b>Intra personal</b>	Self efficacy	<i>There is a Swahili proverb that says, a doctor cannot diagnose himself. [...]. (Laughter). We don't have the courage and skills to test ourselves [...] You may test and deceive yourself that you have tested negative while you are HIV positive. IDI_32yrs_Mbeya</i>
<b>Interpersonal</b>	Adverse outcomes	<i>If testing is done secretly, there will be an increased spread of HIV, because after a person has discovered to be infected she will deliberately transmit HIV to other people. However, if other people know that you have HIV, they will alert others to be more careful when having sex with you IDI_30yrs_Iringa</i>
	Psychological and social support	<i>Most of the time I think of the outcomes, [...] what if the test shows that I am [HIV] positive? [...]What will I do? [...]I like to be tested by someone else so that when it will happen that I am positive and the service provider is nice, then she will know how to make me feel like a normal person. IDI_21yrs_Mbeya</i>
<b>Community</b>	Fear of reactive test	<i>When people discover that they have HIV, they always get shocked. Having HIV may cause people to commit suicide. So it's hundred times better if the test is done by a trained person who provides counselling so that persons who test HIV positive come to term with their condition IDI_41yrs_Iringa</i>
<b>Health facility</b>	Concern about linkage to care and treatment	<i>Everyone will like to know his/her [HIV] status [but] when you test at the public health facility [and] for you to be enrolled into treatment someone closer to you must know your status to assist you in case you become terminally ill. [...]Availability of self testing kits will be disastrous. [...]How do you help the one who wants to start using the medication? IDI_21yrs_Shinyanga</i>
<b>Stage of HIV epidemic</b>	Public discourse about HIV and sex work	<i>Most of the women involved in sex work are not safe [...]. So they will never disclose their HIV positive status to their partners. However, if they go to test together at health facilities, I do not think she will be able to hide her HIV status PGD_ Dar es Salaam</i>

Some participants were sceptical about the credibility an individual would put in a result they obtained him or herself. The Kiswahili saying "*mganga hajigangi*" (a healer cannot heal/treat her/himself), to describe how even if FSWs were trained, they cannot diagnose themselves. Multiple participants also raised concern about users' error, especially relating to low literacy among FSW.

In two PGDs, participants raised the concern that HIVST might damage or strain marital relationships. Main fears included potential harm or distress in case of HIV status discordancy within marriage. Some participants wondered if availability of HIVST kits might encourage male partners to force their spouses to test and disclose her status.

## Discussion

HIVST is a new method for HIV testing in Tanzania – at the time of this study, HIVST was not included in the Tanzania comprehensive national HIV control package[44]. Despite its novelty, the majority of study participants were enthusiastic towards HIVST. Belief that HIVST will increase privacy and confidentiality was the leading factor that attracted FSWs toward HIVST. Studies conducted in SSA around facility-based HTS have associated low uptake with concern about breach of confidentiality[45] and fear about HIV stigma[46]. Participants in our study described their 'lived experience' of stigma and the societal perceptions that portrayed FSWs as drivers of HIV transmissions. This discrimination has health care seeking impacts, as shown in a study documenting FSWs being treated badly by health care providers[54]. In our study, participants related stigma to both fatalistic attitudes (i.e. perceptions that FSWs have HIV) and a feeling that they did not want to test. In Kenya, persons with high risk profiles were less likely to accept HIVST than those with low risk profiles[53]. This may impact the success of rollout of HIVST – this should be addressed both structurally with programs to change stigma, as well as practically with programs which address stigma and barriers to care on an individual level. Participants in our study believed that introduction of HIVST will bring a major change in the landscape of being aware of one's HIV status by minimizing dependence on health workers, and saving time and money on testing. This concern about the time and cost has been echoed by a study in Tanzania which looked at obstacles to syphilis diagnosis and treatment[48]. A study in South Africa showed that introduction of HIVST resulted in increased frequency of testing among MSM[49] - this raises hopes that this could occur similarly in Tanzania should HIVST be introduced to key populations. Enthusiasm toward HIVST was punctuated with concerns about potential self-harm or harm from others in case of a positive test. The most prominent concern was that HIVST could cause adverse social outcomes, including psychological distress, partner violence and even suicide. This was linked to the lack of professional counselling associated with HIVST. Fear about potential social and psychological harm linked to the absence of pre-testing counselling has also been reported in Malawi[50,51]. This may be more of a fear than a reality, since a recent systematic review did not find any strong evidence that HIVST lead to serious social harm (partner violence and suicides)[52]. However, any risk of harm must be taken seriously. Thus, rollout of HIVST among FSWs should follow all current evidence and guidelines to reduce risk of harm, keeping in consideration their increased risk associated with societal norms. To achieve success with this novel approach, incorporating user perspectives is important. Furthermore, research on partnership,

communication, discordancy, and health care seeking choices for FSW in relation to HIVST will help clarify the best way to roll out HIVST. In this study, some participants were concerned about both the accuracy of test results as well as user ability to interpret results. User errors were perceived to be particularly problematic for FSWs given low literacy levels. The participants were not unique in expressing this concern: misgivings about user error with HIVST has also been reported by other key populations in studies across SSA and beyond[36,53]. However, a recent systematic review on HIVST has shown that most laypersons can perform HIVST accurately without or with little help or supervision of health care providers[35]. However, authors from that study cautioned that accuracy in reading the test must be closely monitored[35]. Findings from the current study support that note of caution.

## **Limitations**

This study should be viewed in light of some limitations. Since HIVST was not introduced in Tanzania at the time this study was conducted, all perceptions about the testing method are theoretical. It is not clear to what extent these views would translate into real health care choices by FSWs' populations. Since some FSWs in the study had already been exposed to the Sauti Project structural interventions in these regions, they may have provided what they thought were socially desirable responses, particularly with regard to uptake of HIV testing. The study sample for this study was small, which limits the generalizability of the study to the larger FSWs population in Tanzania. In sum, additional research into lived experiences of FSWs with HIVST would be beneficial to build on the findings of this and other exploratory studies.

## **Conclusions**

Our study results indicate strong support from FSWs for the use of HIVST when it becomes available in Tanzania, for reasons of convenience (time and transport related cost that will be saved, confidentiality). Our findings confirm that FSWs ideation about confidentiality and stigma will influence their decisions around HIVST, mainly creating a positive association with the increased privacy and confidentiality associated with HIVST.

Enthusiasm toward HIVST, was punctuated with concerns about potential self-harm or harm from others in case of a positive test, as well as apprehension about FSWs ability to interpret test results, in light of high rates of illiteracy. Some important supportive factors

could include: hotline or other support to allow users to access counselling or other social support, use of peer educators or other immediately available advocates, and access to alternative instructions for users with low literacy levels. With the right support in place, there is a strong possibility that HIVST will be an appropriate intervention for FSWs as a population at high risk of HIV acquisition in Tanzania.

## Abbreviations

ART	Antiretroviral Therapy
FSW(s)	Female sex worker(s)
HIV	Human Immunodeficiency Virus
HIVST	HIV Self Testing
HTS	HIV testing services
IDI	In Depth Interview(ing)
KP	Key populations (for HIV infection)
PGD	Participatory Group Discussions
PrEP	Pre Exposure prophylaxis
SSA	sub Saharan Africa
WHO	World Health Organization

## Declarations

### **Ethics approval and consent to participate**

The ethical clearance for the study was sought and obtained from NIMR (IRB No: *NIMR/HQ/R.8c/Vol.I/432*). The protocol for this study was also approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB No: 00006985). Before enrolment into the study, verbal consent was obtained from each eligible participant. After a participant consented to participate in the study, the interviewer signed a consent form in front of the participant to certify that she has willingly accepted to participate in the study. Permission for audio recording was also sought from the participants prior to IDI and PGD sessions. Participants in the PGD were asked to use a pseudonym rather than their real name to protect their identity.

## **Competing interests**

None of the authors have any competing interests to declare. The funding Agency has no role in study design, data collection and analysis, preparation of the manuscript or decision to publish this paper.

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## **Authors' contributions**

SN, DN, WM, AS & EK participated in the conceptualization of the study, design, implementation of the study, analysis, interpretation of data and drafting the manuscript. CC, AK & JC participated in the conceptualization of the study, design, interpretation of data and drafting the manuscript. All authors read and approved the final version of this manuscript.

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## Table

Due to technical limitations, table 1 is only available as a download in the supplemental files section

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