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Acceptability and perceptions of HIV oral self-testing across settings: A comparative qualitative study among Dominican and Tanzanian female sex workers

Sam Wilson Beckham ^a, Tahilin S. Karver ^a, Andrea Mantsios ^b, Catherine Shembilu^c, Yeycy Donastorg ^d, Martha Perez^d, Hoisex Gomez^d, Clare Barrington ^e, Ardi Mwampashi^c, Wendy Davis^f, Samuel Likindikoki^c, Jessie K. Mbwambo^c and Deanna Kerrigan ^f

^aDepartment of Health, Behavior and Society, Johns Hopkins School of Public Health, Baltimore, MD, USA; ^bPublic Health Innovation & Action, New York, NY, USA; ^cDepartment of Psychiatry, Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania; ^dInstituto Dominicano de Dermatología y Cirugía de Piel, Santo Domingo, Dominican Republic; ^eDepartment of Health Behavior, Gillings School of Global Public Health, University of North Carolina, Chapel Hill, NC, USA; ^fDepartment of Prevention and Community Health, Milken Institute School of Public Health, George Washington University, Washington, DC, USA

ABSTRACT

Rapid oral HIV self-tests (HIVST) have potential to increase the proportion of people who know their HIV status, especially among stigmatised populations. This study was embedded in two cohorts of female sex workers (FSW) in the Dominican Republic (DR) and Tanzania. Qualitative interviews with 40 FSW were conducted to explore perceived acceptability of HIVST. Interviews were analysed using inductive and deductive thematic coding. Emergent themes were organised by socio-ecological framework levels. FSW in both settings responded positively to the ease of use of HIVST but questioned test accuracy due to the use of saliva rather than blood. FSW in the DR had a more cautious response, while women in Tanzania had favourable perceptions expressing eagerness to use it. At the individual level, themes shaping participants' interest included autonomy, HIV risk perception, and emotional well-being for those with reactive test results, and self-efficacy. At the interpersonal level, privacy, confidentiality, sex work and HIV stigma and social support were salient. Structural level themes focused on health systems including linkages to HIV treatment, provider roles, and access (cost, travel, distribution). Understanding FSW's perceptions and acceptability of HIVST is essential to its integration into health systems and programmes using a community-driven approach.

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HIV; self-testing; female sex workers; Dominican Republic; Tanzania

Introduction

Knowing one's HIV status is the first step in the HIV care continuum (diagnosis, linkage to care, initiating medication, retention in care, sustained viral suppression) (Long-Acting HIV Prevention Tools, 2019). Significant barriers to HIV testing exist across settings and populations including low risk perception (Deblonde et al., 2010; Hamilton et al., 2020; Schwarcz et al., 2011), fear of stigma and discrimination (Deblonde et al., 2010; Fakoya et al., 2008; Hamilton et al., 2020; Jürgensen et al., 2012; Li et al., 2012; Schwarcz et al., 2011), access to testing and care (Deblonde et al., 2010; Fakoya et al., 2008; Hamilton et al., 2020), and inability to afford treatment (Spielberg et al., 2003). There are

also barriers associated with counselling and testing strategies, such as concerns about confidentiality (Hamilton et al., 2020), anxiety while waiting for results, and venipuncture (Spielberg et al., 2003). These barriers are exacerbated for high-risk, stigmatised populations such as people who sell sex.

HIV self-testing (HIVST) using rapid oral fluid-based self-testing kits is one strategy to expand testing coverage and allow people to test more frequently, while potentially overcoming barriers related to access, confidentiality, wait time, and venipuncture. The World Health Organization issued guidance in 2016 recommending HIV self-testing as an additional testing strategy to help reach the UN 90-90-90 goals (UNAIDS, 2014), specifically the first goal of diagnosing 90% of all people with HIV (World Health Organization, 2016). HIVST has the potential to increase the proportion of people who know their HIV status (Qin et al., 2018), showing particular promise among vulnerable and stigmatised populations (Figueroa et al., 2015; Witzel & Rodger, 2017). Furthermore, self-testing may be cost effective, particularly if targeted to high-risk groups (Indravudh et al., 2018) such as female sex workers (FSW).

FSW are at heightened risk of HIV acquisition and bear a disproportionate burden of living with HIV, particularly in sub-Saharan Africa (S. Baral et al., 2012; Pruss-Ustun et al., 2013). Previous research has shown that even in generalised epidemics, FSW have 12 times higher odds of being HIV infected (S. Baral et al., 2012), and that targeting services to FSW has great potential for reducing incidence among FSW as well as HIV transmission within the general population (Pruss-Ustun et al., 2013). Worldwide, FSW face multi-level and multi-faceted stigma and discrimination, including from health care workers, further constraining their access to care, including HIV testing (Scambler & Paoli, 2008; Scorgie et al., 2013; Shannon, 2018). Understanding FSW's willingness to use HIV self-testing can aid in appropriately tailoring programmes that meet their needs and preferences.

Research conducted with key populations, including FSW, on perceived acceptability of HIVST highlights both the appeal and the concerns around this testing option. Benefits of HIVST identified by potential users in previous studies include increased confidentiality and privacy (Burke et al., 2017; Figueroa et al., 2015; Harichund & Moshabela, 2018; Njau et al., 2019), convenience (Burke et al., 2017; Figueroa et al., 2015; Njau et al., 2019), the opportunity to test before sex (Burke et al., 2017), to test as couples (Njau et al., 2019), and decreased stigma and discrimination (Harichund & Moshabela, 2018). Concerns raised include lack of face-to-face counselling (Figueroa et al., 2015; Harichund & Moshabela, 2018; Njau et al., 2019), poor linkage to care (Burke et al., 2017; Harichund & Moshabela, 2018; Njau et al., 2019), cost (Burke et al., 2017; Njau et al., 2019), perceived unreliability (Figueroa et al., 2015; Njau et al., 2019), fear and anxiety of a positive (reactive) test result, and quality of kits (Njau et al., 2019). Despite significant drawbacks, prior research indicates potential users, including FSW, feel that the benefits of HIVST outweigh the disadvantages (Burke et al., 2017). While some studies with actual users have documented their preference for the oral-fluid test (Martin et al., 2018; Njau et al., 2019) because it was seen as easy, painless, and less invasive (Njau et al., 2019), others have found more concerns for oral fluid-based than blood-based HIV tests (Figueroa et al., 2015).

Prior studies among FSW reveal varying perspectives around perceived acceptability, willingness, and preferences of this population for HIVST. A study of FSW in Malawi found that women felt favourable about HIVST given that they had a high risk self-perception and a desire to self-monitor their HIV negative status (Lora et al., 2020). This echoes findings from Botswana where FSW also expressed awareness of their high risk sexual behaviours along with a desire to stay healthy, and honed in on the perceived autonomy over one's healthcare decisions that could be afforded by HIVST (Shava et al., 2020). In Cambodia, a study of FSW found a tension between the benefit of being able to conduct a self-test without a physician and the drawback of not receiving pre- and post-test counselling that would be provided in a healthcare facility (Pal et al., 2016). On the other hand, a different study of FSW in Botswana revealed women did not feel that HIVST would add any value to their health care because they felt they already had easy access to health services and were concerned with both the lack of assisted testing and inadequate post-testing

counselling specifically due to fear of strong emotional reactions (Oduetse et al., 2019). A preferences study in Tanzania found that female bar workers were less likely to prefer home testing, more concerned about disclosure issues, and were comfortable with travelling distances to test compared to other high-risk groups (Ostermann et al., 2015).

The existing literature demonstrates the need to explore contextual, cultural, and population-specific factors and dynamics in assessing how to effectively introduce HIVST to FSW. It can be useful to utilise a socio-ecological framework that includes individual, interpersonal, and structural levels of influence. This can aid in organising various facilitators and barriers into respective levels and then target intervention approaches at the different levels, while also considering the HIV epidemic stage in the local contexts (Baral et al., 2013).

This study was conducted among female sex workers in two different geographic and epidemiologic settings – Santo Domingo, Dominican Republic, and Iringa Region, Tanzania. HIV prevalence among the adult general population in the DR was low (0.7%), but higher among FSW (4.4%) (Kerrigan et al., 2016). In the DR, USAID reports 91% the sex workers knew their HIV status, while a study conducted in Santo Domingo found that only 71% knew where to go for HIV testing and only 31% got an HIV test (Johnston et al., 2017). In contrast, at the time of data collection, HIV prevalence was 6.2% in the general adult population in Tanzania (National Bureau of Statistics et al., 2013), and 41% among FSW in Iringa Region (Kerrigan et al., 2017). Although 92% of the Tanzanian participants reported having been tested for HIV, only 48% had done so in the past 6 months (Kerrigan et al., 2017).

The context of sex work in each country differs. While sex work itself is not punitively regulated nor criminalised in the DR, (MODEMU, 2017; UNAIDS, 2018), people who sell sex still experience stigma and discrimination, including from police and other authorities (Carrasco et al., 2017; MODEMU, 2017). In the DR, sex workers work in diverse environments, including venue-based settings (bars, clubs), and non-venue-based settings (street, operating through cell phones). Uniquely, the DR had a relatively large proportion of female sex workers compared to country population size (Baral et al., 2012; Kerrigan et al., 2016). In Tanzania, sex work is criminalised but largely tolerated by authorities; nevertheless, FSW face stigma and discrimination, and operate largely in secret. Sex work in the Iringa Region is mostly establishment-based in entertainment venues, such as bars, guesthouses, clubs, etc. Iringa is on a major trucking route and home to many large agricultural operations that rely on seasonal migrant labour. Combined, these create a high demand for sex work in the area, and the region has one of the highest HIV prevalence in the country (National Bureau of Statistics, et al., 2013).

While the settings have vastly different HIV prevalence, it is useful to examine the two cohorts to compare and contrast the experiences of FSW in epidemics with both low and high prevalence of HIV. At the time of data collection, there was no self-testing policy in the DR (UNITAID & World Health Organization, 2018), though the tests were available privately, for purchase (Kramer et al., 2016). In Tanzania, there was a written, but not yet implemented, self-testing policy (UNITAID & World Health Organization, 2018), and the tests were not yet available but access was being planned (Kramer et al., 2016).

A greater understanding of perceived acceptability and appropriateness of self-testing among FSW is essential to tailoring rollout in specific contexts to maximise feasibility, uptake, and proper use among this key population. The aim of this paper is to qualitatively explore FSW's initial awareness, perceptions, and acceptability of oral self-testing across two different cultural and epidemic contexts to inform future implementation and maximise uptake in these and other similar settings and key population groups.

Methods

Study sites

This study was embedded in two ongoing cohorts of female sex workers in each study location. In the Dominican Republic, FSW ($n = 20$) were referred to the study by participants

and peer navigators from Abriendo Puertas (Opening Doors), an intervention targeting FSW in Santo Domingo, Dominican Republic. It is a multi-level intervention that utilises an integrated approach to promote HIV prevention and care through individual counselling and education; peer navigation; clinical care provider training; and community mobilisation (Donastorg et al., 2014; Kerrigan et al., 2016). Findings from this intervention revealed that higher level of engagement with Abriendo Puertas resulted in increased ART adherence (AOR 2.42; 95% CI: 1.23–4.51) and protected sex (AOR: 1.76; 95% CI: 1.09–2.84) (Kerrigan et al., 2016).

In Tanzanian, the study was embedded in Project Shikamana (Stick Together), an ongoing cohort of a community empowerment-based HIV prevention and treatment model for FSW in Iringa, Tanzania. The Shikamana intervention included a drop-in-centre as a safe space for FSW to meet as a community and access HIV testing services; venue-based HIV testing and peer educational outreach; provider and police sensitivity trainings; text message reminders to promote engagement and adherence; and peer navigation to support FSW living with HIV in accessing and sustaining care. Results and further details have been previously published (Kerrigan et al., 2017, 2019; Leddy et al., 2019). The Shikamana baseline survey revealed a high HIV prevalence of 40.9% among the FSW, but low HIV testing rates (47.7% in the past 6 months) (Kerrigan et al., 2017).

Data collection

We conducted qualitative, in-depth interviews with 40 HIV-negative FSW. Self-testing modules were added to qualitative sub-studies exploring HIV prevention and sex work-related stigma. Half ($n = 20$) were purposively sampled (Sandelowski, 1995) from the Shikamana cohort in Tanzania, and half ($n = 20$) were referred by Abriendo Puertas peer navigators in the DR. Tanzania participants were recruited to achieve variety in location and age. DR participants were recruited to gain a variety in number of years in sex work and sex work location. Using a semi-structured guide, we assessed participants' awareness of HIV self-tests, explained the concept of oral fluid-based self-tests, and asked about their perceptions of the advantages, disadvantages, anticipated challenges, and willingness to use. Participants were shown an image of a self-test to assist with their comprehension of self-testing kits. Interviews were conducted in the local language (Swahili or Spanish) by trained research staff.

Data analysis

All interviews were audio recorded with permission and transcribed verbatim. In Tanzania, transcripts were translated into English by SWB (20 years of experience speaking Swahili) and checked by CS (native speaker). In the DR, transcripts were analysed directly in Spanish by TK, a native speaker; and quotes were translated to English as needed. We conducted thematic coding (Charmaz, 2006) in Atlas.ti of *a priori* themes based on the interview guide, while also allowing for emergent themes from the data, and then compared findings across settings. During analysis, the results were organised by emergent themes within a framework based on a socio-ecological model, with individual, interpersonal, and structural levels. The functionality of the test itself was also an important theme in the interviews and is placed within the centre of the model.

All participants gave informed oral consent before the interviews. This research was approved by ethical review boards at the Johns Hopkins Bloomberg School of Public Health (USA), the Muhimbili University of Health and Allied Sciences (Tanzania), the National Institute of Medical Research (Tanzania), and the Instituto Dermatologico Y Cirugia De Piel 'Dr. Huberto Bogaert Diaz' (IDCP) (DR).

Results

Of the 40 participants interviewed, none had either heard of or used an oral fluid-based HIV self-test, though they were aware of blood-based HIV tests at health facilities. Despite not having heard of these tests previously, participants offered a variety of anticipated advantages and disadvantages compared to traditional clinic-based testing. They also highlighted some concerns that were not unique to self-testing, but more generally to receiving an HIV diagnosis. Some themes that arose were common across the DR and Tanzanian, while others were unique to one setting or the other.

We have organised results into major themes and placed them within a socio-ecological model with individual, interpersonal, and structural levels (Figure 1). At the centre of the model is functionality, referring to the operation of the test itself. Functionality themes included usability, body fluids (saliva vs. blood), and test accuracy. At the individual level, the emergent themes were related to autonomy; knowledge of HIV; HIV risk perception; emotional well-being for those whose tests are reactive; and self-efficacy for self-testing. At the interpersonal level, participants discussed emotional support; relations with partners and clients, health care providers, and the broader community; and revolved around themes of privacy, confidentiality, and FSW- and HIV-related stigmas. At the structural level of the model, themes are related to the health system, including referrals and linkages to HIV care and treatment, the roles of providers, and issues of accessibility (cost, travel, distribution). Table 1 details major themes across the levels of the socio-ecological model and by setting and provides further details on each of those themes. These are elaborated on below, with differences and similarities by setting also discussed. Illustrative quotes for each theme by SEM level can be found in Table 2.

Functionality

In both settings, participants perceived the HIVST would be convenient and simple, and liked the possibility of getting their results quickly. A Tanzanian participant said, ‘I would use it! I would be the first! Because I love how easy it is!’ (FSW, Tanzania), and a Dominican participant stated, ‘It’s good, it’s good. That way at least you can go to the pharmacy and say, “Give me this test”’ (FSW,

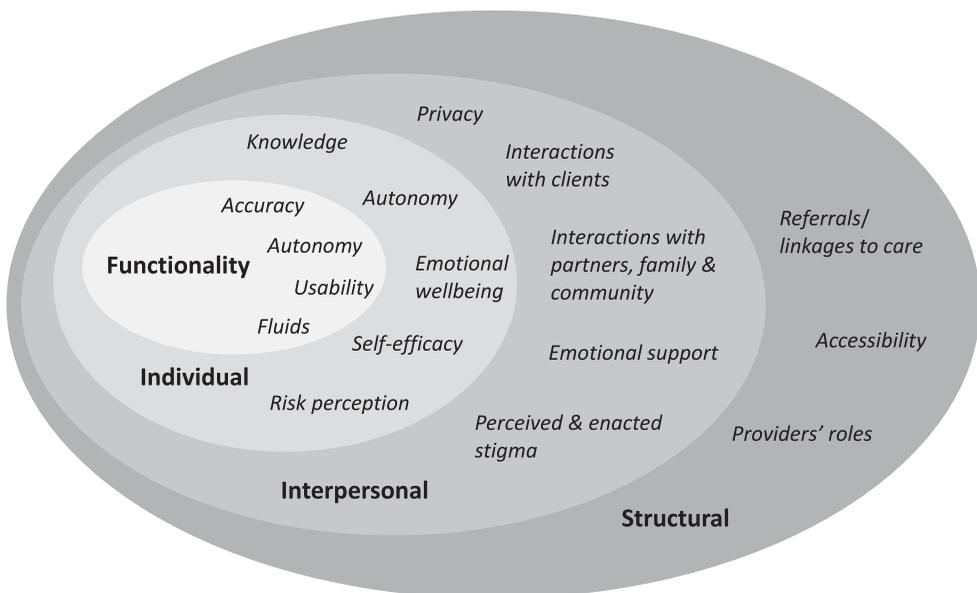


Figure 1. Socio-ecological model of themes related to HIVST for FSW in the Dominican Republic and Tanzania.

Table 1. Key themes by SEM level and setting.

		Findings Common to Both settings	
Level	Benefits/Advantages	Disadvantages/Challenges/Concerns	
Functionality	<i>Usability</i> Convenient; get results quickly; simple	<i>Accuracy</i> Distrust, disbelief of results	
Individual	<i>Risk Perception</i> Good idea, given occupation; FSW are perceived to be at high risk <i>Autonomy</i> Time & space to process on her own	<i>Emotional Wellbeing</i> Strong emotional reaction if test is reactive <i>Knowledge</i> Misunderstandings about antibodies & window period	
Interpersonal	<i>Community-level Stigma</i> Confidentiality, secrecy from others & from providers Decrease gossip; decrease discrimination	<i>Emotional Support (non-provider)</i> Lack of emotional support if test is reactive; not good to be alone when learning results	
Structural	–	<i>Referrals/Linkages</i> No pre- & post-test counselling; counselling is essential No linkage/referral if test is reactive Need for trained, educated, knowledgeable provider to conduct test	
		Additional Findings Unique to the Dominican Republic	
Level	Benefits/Advantages	Disadvantages/Challenges/Concerns	
Functionality	–	–	
Individual	<i>Risk Perception</i> Sense of security of being able to test, should a client's condom break <i>Autonomy</i> Allows her to take better care of her health	<i>Emotional Wellbeing</i> Depression, suicidality if test is reactive & she is alone Silent suffering at home, if reactive Person needs the emotional capacity to handle a reactive result <i>Self-efficacy</i> May not understand how to use and interpret the test; needs training	
Interpersonal	<i>Community-level Stigma</i> No 'witch hunt' and outing of each other to clients Prevents feelings of shame of others' knowing Prevents being made fun of No being seen at an HIV centre	<i>Emotional Support (non-provider)</i> Treatment supporter system not in place Need a person there to help, to prevent suicidality <i>Interactions with Clients</i> Can stay silent about positive status, have condomless sex with clients and transmit HIV to them	
Structural	–	<i>Providers' Roles</i> Better follow-up care if test at centre High level of trust in providers; gives helpful, clear information Provider would provide mental preparation for results Provider gives reassurance about HIV treatments; 'AIDS does not kill'	
		Additional Findings Unique to Tanzania	
Level	Benefits/Advantages	Disadvantages/Challenges/Concerns	
Functionality	<i>Usability</i> Similarity to already-familiar pregnancy test Small, easy to carry & hide in a purse Easier to test frequently <i>Fluids</i> Non-invasive; saliva only No needles, no puncture, no pain Does not cause harm (removing blood seen as harmful)	<i>Accuracy</i> Concerns about validity; needs to perform well Distrust of saliva for HIV results	
Individual	<i>Self-efficacy</i> Gives confidence to be able to test oneself <i>Autonomy</i> Can test alone, privately Can decide when to use it Good to know one's status, whether infected or not Can control who knows <i>Emotional Wellbeing</i> Gives time to process results and build courage to go to HIV treatment services	<i>Self-efficacy</i> Lack of testing self-efficacy Difficulty interpreting results (what if the line is not clear/not strong) <i>Knowledge</i> Distrust of saliva for HIV testing <i>Emotional Wellbeing</i> Might lose consciousness Might take the test but throw it away without seeing result Might want to try to purposely infect others if infected <i>Risk Perception</i> Fear of results, knowing she has risky behaviours	

(Continued)

Interpersonal	<i>Community-level Stigma</i> Eliminates fear of testing at facility, where others can see and gossip	<i>Community-level Stigma</i> Fear of being seen obtaining test
	<i>Interactions with Partners & Clients</i> Use to 'screen' clients, self, partners Potential distribution to clients	<i>Interactions with Partners & Clients</i> Potential violence from partners & clients if used together
Structural	<i>Provider's Role</i> No provider involvement, & thus decreases potential gossip Distrust of providers telling her she is uninfected	–
	<i>Accessibility</i> No need to go a health facility, travel Can buy from pharmacy as needed	

DR). However, participants also expressed concern about the accuracy of the test. In Tanzania, some participants expressed distrust particularly of a saliva-based test, unsure of its validity, and in the DR, participants expressed stronger belief in the accuracy of a blood-based test. (Table 2, Quote 1–2)

Yet many Tanzania participants expressed a strong preference for the self-test over traditional HIV testing due to the non-invasiveness of a saliva-based test. They felt that using saliva seemed much easier, and they liked that they would be able to avoid needles. There was a common perception among participants that blood draws are very painful, and women described that many of their peers were deterred from HIV testing by a dislike or fear of needles and blood draws. Some considered removing blood from the body a major disadvantage, even harmful to health, so saliva-based testing was appealing. Participants believed that the non-invasiveness of self-testing would motivate more FSW to test more frequently and would make it easier for them to follow the recommendation to test every three months. (Table 2, Quote 3)

Upon seeing a picture of a self-test, some Tanzanian participants compared it to at-home, over-the-counter pregnancy tests, with which they were familiar. They liked that the HIVST was small, easy to carry and hide in a purse, and could be taken when needed. These qualities would make it easier to test frequently, they felt.

Individual level

At the individual level, themes were related to personal risk perception, autonomy, self-efficacy for self-testing, and emotional wellbeing. In both settings, participants shared that FSW have a high risk perception for HIV acquisition and so the increased testing accessibility through self-testing was considered a good idea for them, given their occupation. (Table 2, Quote 4) One woman described the potential for the self-test to instil a sense of security stating, '[She will think to herself,] "my health is safe." So, it means that it will give her a sense of being careful' (FSW, Tanzania). Conversely, another participant suggested that women might fear the result, perceiving themselves at high risk, and throw out the test without reading the result.

Women across settings also felt the autonomy that self-testing provided was beneficial; this could allow them to process their results by themselves, in their own time, before deciding about treatment. (Quote 5) However, participants in both countries also worried about low self-efficacy for taking the test correctly and interpreting the results correctly and emphasised the need for proper training on use. (Quotes 6–7)

In both settings, participants were particularly concerned for test-takers' emotional wellbeing while testing alone, particularly for those who may have strong emotional reactions after receiving positive results. (Quote 8–9) They preferred that people test with the appropriate counselling and support. Participants in the DR mentioned the possibility of depression and even suicidality, should a woman test alone and receive a reactive result. They worried that some may suffer at home in

Table 2. Quotes by Level of Socio-Ecological Model.

Level	Representative Quotes
Functionality	<p>Accuracy – Distrust, disbelief of results</p> <p>Quote 1: In the saliva, how does it work with saliva? Saliva and blood, me, I see that those are different things. Saliva and blood, aren't they different? Blood is in the veins, that is, it's in your whole body. This is just saliva, it comes from the belly, no? That's why I don't believe that it's true that saliva can say that I am such-and-such [HIV-positive], no. With what reason? In the past, they said that if a person swaps saliva, jeez, you can't get AIDS, isn't it so? Wasn't it like that? But me, like that, I don't believe it. Saliva, me, I wouldn't use it to see if I am pregnant, [nor if] I have whatchamacallit, or I don't have whatchamacallit, AIDS. No, I don't trust saliva. (FSW, Tanzania)</p> <p>Quote 2: Even if [the self-test] says it is [positive] or not, I don't believe in that. I believe it when I do it in a hospital. You understand me? That is the same as the pregnancy test, I just think when I go to a hospital, 'let me go do the test,' but [I need to see] it in a tube [blood for lab tests]. (FSW, DR)</p> <p>Usability – Convenient, easy, get results quickly</p> <p>Quote 3: A lot will use it because it's not a piercing method. You know, many are afraid of having blood taken through piercing the vein. You'll hear, 'Oh! Give my finger to be pricked? Oh, me, no!' Or, 'Me, give my arm to have blood taken from my vein? Oh, ha, me, no!' But if you tell her, 'Man, yeah, this test you hold yourself, just put it in your mouth, and then you watch and read it,' she will agree. A lot will use it, I mean, a lot of working women [FSW] will use this test. It's an easy method. (FSW, Tanzania)</p>
Individual	<p>Risk Perception – Good idea given occupation; FSW have high risk self-perception</p> <p>Quote 4: 'Of course, [the self-test] would be advantageous because that way you have security, because you do not know [who has HIV]. And sometimes you put the condom on the men and sometimes they break, and there is a lot of risk.' (FSW, DR)</p> <p>Autonomy – Time & space to process on one's own</p> <p>Quote 5: Everyone likes to know her status. And again, especially to test yourself, I feel many people will use it. Because a person thinks, 'I just go buy that test, I test myself, and I know what my health status is.' So, the person goes to buy it. She tests herself. (FSW, Tanzania)</p> <p>Knowledge – Misunderstandings about antibodies & window period</p> <p>Quote 6: I would test at the hospital. There, there's more certainty. I don't read [the results] myself. Me, I will test myself just me, as me? It's different for me who has no education. The doctor has education. (FSW, Tanzania)</p> <p>Quote 7: Oh, it is good, because that way, you realize what you have, at least, you know? But that is when you have knowledge of how, um, the test that you see is: when you have it, when you don't you have it, do you understand me? To do it, well, you have to have an example to know how to read the result. (FSW, DR)</p> <p>Emotional Wellbeing – Strong emotional reaction if test is reactive</p> <p>Quote 8: When I was tested, even if I didn't do anything, even if I had relationships with people with a condom, that is scary, I was scared and until—if for example I get a positive [result], you even think about killing yourself. (FSW, DR)</p> <p>Quote 9: For this test, oh, maybe, some people have high blood pressure, and can look like this. She says, 'Oh, already [I'm infected]!' It means, now some people, you know, they feel bad, she can tell you 'fine' but [she's really thinking] 'me, now, I'm already dead! Whoa, I have AIDS? I didn't know I had the AIDS infection! Humph!' She starts to give up that very day. (FSW, Tanzania)</p> <p>Quote 10: If you realize that you have [HIV], if you realize that you have that alone, one is even able to kill oneself. But if someone else tells you, talks to you there at the moment, you try to not do a bad thing. But if you are alone you are capable of doing anything.' (FSW, DR)</p> <p>Quote 11: There's one disadvantage, maybe. Someone can test and get a shock, she herself. Meaning, if you go to the hospital, aren't you counselled, yeah? And then you are tested and given your results. (FSW, Tanzania)</p>
Interpersonal	<p>Community-level stigma – Confidentiality/privacy from others & from providers, decreased gossip, and discrimination</p> <p>Quote 12: I have supported that idea because you find that others are afraid to go to the hospital. They say, 'Dah! If I go to the hospital to test [...] the other people who I will meet there will also know that I am doing this test somewhere,' right? ... Others are ... scared, they are filled with fear. If such a test is available, one is not afraid because she knows that she will shut herself inside and I will test on my own to check and see how I am. (FSW, Tanzania)</p> <p>Quote 13: Just in case if I go and have HIV – I hope to God that doesn't happen – I will be the only one to know. Even if I die right there and I have a [heart attack], but at least only I will know, and so nobody will make fun of me. (FSW, DR)</p> <p>Quote 14: If there is a colleague who [gets a positive test], immediately [she] will change [her] face and you will realize, 'Damn, this girl came out looking weird from this [the test].' They will know that you have that [HIV] and the witch hunt begins, and they begin to make comments to the clients and those things. But if you do it [the HIV self-test] only you [know], nobody is going to see you. You are going to take your [own body] and [you] will react and nobody is going to be watching you and you are going to do it in your house.' (FSW, DR)</p> <p>Quote 15: There will be stigma for that person, I mean, from that person who doesn't know what it's used for ... who doesn't have education about it. If a person comes and asks you, 'What's this thing?' And you tell her, 'It's an HIV test.' 'Oh, now you walk around with it in your bag? Does that mean you already have it [HIV], or?' I mean, isn't that how it is for someone who doesn't know? You tell her 'This thing, no, but it's for testing.' 'Oh, for testing, and you walk around with it in your bag? You are – it is possible that you are already infected, but you are just hiding it from us!' (FSW, Tanzania)</p>

(Continued)

Table 2. Continued.

Level	Representative Quotes
	<p>As a screening tool</p> <p>Quote 16: Perhaps she might tell her lover to go and get tested. She could just say that there are some tests that are using saliva, that are sold. She can just buy them, and they can test themselves there instantly. (FSW, Tanzania)</p> <p>Quote 17: Some will do it themselves at first secretly, because some people have a husband and are going outside the marriage. Now you totally know that ‘Now, I have gone outside the marriage, I have it [HIV] now.’ Now you know this man [husband] is harsh ... I know he’ll come and beat me and murder me for nothing. Because if I tell him, ‘Man, I already tested and we are infected,’ he will kill me. Just wait, I’ll test myself alone, and if I see I am infected, I’ll take the medicine alone, until I come to advise him carefully, while I have already started the meds. (FSW, Tanzania)</p>
	<p>Structural</p> <p>Referrals/Linkages – Pre- & post-test counselling is essential, no linkage/referral if test is reactive</p> <p>Quote 18: The disadvantage is that someone might test and find out that she is infected and not go to enrol in a clinic and get medicine.[...] It is different from the one which you go to the hospital and get tested there. If you have the infection, you get counselling. You start straightaway in the service [HIV care and treatment]. You start [antiretroviral] therapy.’ (FSW, Tanzania)</p> <p>Quote 19: Of course [I prefer going to the doctor’s], if necessary, if you get [HIV], God forbid, [I would] follow my normal life; because [HIV] doesn’t kill, there is treatment and things. Doctors have told me when I have been tested: ‘AIDS does not kill,’ because there is treatment, do you understand me? (FSW, DR)</p> <p>Providers’ roles – Need for trained, educated, knowledgeable provider to conduct test</p> <p>Quote 20: I do not see what the advantage is, because if you go to a doctor and the doctor will tell you ... God forbid [you are positive] ... the doctor will follow up ... But you do your test in your house and you see [you’re positive], you are going to remain silent. [You are going] to die of the suffering and say, ‘I have AIDS!’ and go crazy and shut up. Because that is what happens to most.’ (FSW, DR)</p> <p>Quote 21: No, I don’t see an advantage [...] because I want to go to a [health] centre, to a centre that prepares you mentally. (FSW, DR)</p> <p>Quote 22: It’s different from that to go in to test, you can go test and then you meet the doctor herself isn’t trustworthy, and she tells you, ‘Hey, that person, that person knows how to make herself look good, but I met her as a patient that one day! [...] That person is sick, she is!’ It’s not true. It’s just better if you can test yourself. (FSW, Tanzania)</p>

silence, rather than seek help or treatment. Similarly, Tanzanian participants expressed concerns about emotional reactions citing depression, thoughts of death, and giving up. Given strong emotional reactions, many thought self-testing alone would be detrimental and preferred the idea of having someone there with them, to talk them through any negative reactions.

Interpersonal level

At the interpersonal level, participants in both settings described the appeal of the potential for confidentiality presented by self-tests, highlighting that self-testing could decrease stigma, gossip, and discrimination they might encounter when testing in a healthcare setting. Some women were afraid of other people at a hospital knowing that they were testing for HIV and other expressed concerns about their test results being shared with others. For these reasons, several participants said they would feel less afraid to self-test than to go to a health centre for testing. One Tanzanian participant captured this sentiment in the following quote: ‘She is obtaining her test and going home to test herself. She finds she has the infection, there, it remains her secret, in her heart’ (FSW, Tanzania). (Quotes 12–13)

Participants spoke about implications of the HIVST for community-level stigma. On the one hand, some participants noted how providing one with the ability to obtain results privately could protect women who test positive from gossip, unfair treatment, or feelings of shame. In the DR, some women saw the privacy of the HIVST as an opportunity to protect themselves from reactions from other FSW or members of the community, specifically in the case of testing positive at a healthcare facility and having an emotional reaction that would lead others to assume she was HIV positive. One participant described the potential consequence of such an incident as a ‘witch hunt’, with other FSW informing clients about each other’s status. (Quote 14) In Tanzania on the other hand, a couple of participants

saw a disadvantage in community-level stigma around self-testing. Participants were afraid that people might see them buying a self-test or they could be found carrying a self-test. They were worried that this could cause stigma given the somewhat common belief in their community that if someone is testing for HIV, they are likely HIV-positive. (Quotes 13)

In both settings, some participants discussed how having self-tests might impact their interactions with clients, either positively or negatively. Some participants in Tanzania talked about a desire to use HIVST as a screening tool, either before intercourse with a client or partner to attempt to confirm they are both uninfected, or immediately after intercourse with a client of unknown status. (Quote 16–17) A Tanzanian participant described it as follows: ‘I will be testing every time I go sleep with someone I don’t know personally. I have left there [sleeping with him], I come test, I’ll grab it, and test’ (FSW, Tanzania). Women described how they could buy and keep self-tests for clients and partners to use and immediately know their results.

In both settings, participants worried about the potential impacts of self-testing on clients and partners. Participants were worried about their partners’ negative and potentially violent reactions to a reactive test result. A Tanzanian participant explained that self-testing would give her the privacy to test and begin treatment on her own, allowing her to have more flexibility in deciding how and when to tell her partner(s) about her status. This use of the test did not appear in the DR data; rather, participants felt the self-test would be a disadvantage to clients, because women could keep their positive status a secret, ‘remain silent and spread the disease’ (FSW, DR).

Structural level

At the structural level, participants discussed the importance of linkages to care for those whose tests are reactive, the important roles of providers in HIV testing, and accessibility of self-tests in terms of cost and availability. Participants in both countries were worried that some women who test using self-testing may be in denial of their status and may choose not to seek treatment. They believed that linkage to care would be easier and more immediate when testing at a health centre than with self-testing, in part because the post-test counselling that is provided at health centres includes referrals to care. (Quotes 18–19) Testing at a clinic was thought of as including direct referrals and linkages to treatment, making this the preferred model for many of the Dominican participants. Participants were concerned that without post-test counselling, some women may not know how or where to access treatment. In Tanzania, though, many participants trusted that FSW whose tests were reactive would link themselves to care, as soon as they were ready. Many expressed sentiments similar to the following participant’s quote: ‘So, the person goes to buy it, she tests herself, if she finds she has the virus, it means it stays her secret ... that she should go and find her services to start the dose [ART]’ (FSW, Tanzania). In fact, participants valued the autonomy it would enable them to have throughout the process of testing and subsequently seeking treatment on their own terms, when they were ready.

In the DR particularly, participants felt that HIV testing is best done by trained, educated providers, and not left to the women to test themselves. (Quotes 20–21) Dominican participants had a certain level of trust in providers and the information they give and felt that their involvement in the process could prevent suffering for women with reactive test results. In contrast, many Tanzanian participants expressed a strong distrust of health care providers, describing that they believed health care providers often gossiped and shared confidential results. As one participant shared, ‘Those service providers, don’t they just tell people’s secrets?’ (FSW, Tanzania). Participants were also worried that a health care provider might stigmatise them for receiving an HIV-positive result. (Quote 22) Tanzanian women said they liked the fact that health care providers would not need to be involved in HIVST; the fact that they would not be worried about provider stigma when self-testing was a benefit.

In Tanzania, participants talked about how self-testing could increase accessibility, such as being able to obtain an HIVST at a neighbourhood pharmacy, without having to travel to a health centre.

One woman stated, ‘It is easy for that person to use it and she can use it any time that she wants to ... Currently, you need to travel all the way there’ (FSW, Tanzania). While several Tanzanian participants talked of readily buying the test, some participants were worried about cost as a potential barrier to accessing the self-tests and felt that the tests should be given out for free rather than being sold. ‘I would prefer they are not sold, they should just be given to people who, maybe, feel like testing, to check their health [HIV] status’ (FSW, Tanzania).

Discussion

No participants in this study had heard of HIV self-testing using oral fluid. Overall, FSW in the DR had a cautious response, characterised by scepticism of the HIVST while women in Tanzania had more favourable perceptions expressing they were eager to use the self-test, even frequently, and noting that they would much prefer not to use a blood-based test (with some reservations about accuracy of saliva).

Study findings highlight some of the unique considerations around HIVST for FSW. Women in both the DR and Tanzania conveyed high risk perception which made the accessibility of the self-test appealing to them. This echoes findings from prior research (Lora et al., 2020; Shava et al., 2020) and suggests the possibility that self-tests could provide FSW with a sense of security and control within the high-risk context of their work as well as a perceived sense of autonomy over their healthcare decisions (Shava et al., 2020). Findings also highlight a key tension identified by FSW in both settings between wanting the autonomy to test on their own and feeling that a health care professional needs to be part of the testing process – both to support women’s emotional well-being if they are receiving an HIV diagnosis and for ensuring linkages to care. Prior studies with FSW have documented similar concerns about the lack of counselling and support if receiving a reactive result when using HIVST (Burke et al., 2017; Shava et al., 2020). Another important consideration for FSW is the real risk of interpersonal violence, should they use HIVST to test clients or intimate partners. Formative studies in several sub-Saharan African countries that worked with FSW to develop implementation strategies did indeed find some cases of harm to peer navigators and FSW in testing distribution and use (Napierala et al., 2019). In Zambia, an intervention study gave multiple HIVST to FSW with instructions to distribute them to partners at their discretion. A qualitative sub-study found that FSW used their agency to carefully decide who to share tests with, and a variety of strategies to avoid and de-escalate violence (Maman et al., 2017). Such possibilities must be weighed and addressed; see recommendations below.

Women in our sample had some concerns around accuracy, specifically in thinking that blood-based tests were more effective than saliva-based ones, as was found with FSW in Cambodia (Pal et al., 2016). At the same time, the ease and appeal of a non-invasive testing modality (for those with a fear of needles), and usability of a saliva-based test allowing for testing outside of a health facility were all seen as desirable aspects of the self-test. Women across both settings in this study also expressed concern about low self-efficacy for taking the test correctly and interpreting the results correctly. The issue of low literacy among FSW has been raised in prior work, pointing to how it could affect comprehension of testing instructions, and competency to perform testing and interpret results (Njau et al., 2019; Shava et al., 2020). Importantly, a study in China in which FSW were provided with HIVST documented concerns among the women around perceived unreliable results and the study ultimately concluded that operation errors could present challenges to the feasibility of HIVST with this population (Marley et al., 2014).

Some of the differences in perceptions of HIVST in the two settings were associated with differing attitudes towards healthcare providers and facilities in the DR and Tanzania. In the DR, participants conveyed a sense of trust in providers and healthcare, including the comfort of being able to rely on an expert rather than having to take the test alone. In contrast, the narratives from Tanzanian participants convey the dominating attitude towards the healthcare community was one of distrust. Given these distinctively different dynamics and relationships with healthcare providers and

settings, it is clear why the removal of clinical staff and settings from the HIV self-testing process would be seen as an advantage for one group of women and a drawback for the other. This finding underscores the importance of designing culturally and contextually appropriate implementation projects when introducing HIVST to FSW populations.

These findings have several implications which inform our recommendations for the introduction and roll-out of HIV self-testing to FSW and other high-risk populations. Appropriate and tailored educational and communication materials should be developed for FSW populations focusing on self-efficacy training on correct use and interpretation, specifically clarifying the meaning of the window period, and explaining why saliva is used in the self-test while it does not spread HIV. To appropriately tailor roll-out of self-testing to high risk groups like FSW, it should be integrated into community-empowerment based programmes such as Abriendo Puertas and Shikamana. Additionally, alternative and innovative distribution strategies should be explored for high-risk groups like FSW including venue-based and safe-space self-testing as well as through and facilitated by peer navigators and social networks (other FSW, clients). Involving social networks including clients will require formative research and careful and thoughtful implementation to avoid unintended consequences such as partner/client violence as well as the possibility of screening clients during the window period (Leu et al., 2012; Ventuneac et al., 2009). Finally, both a low and no cost option for self-testing should be provided to high-risk groups (Indravudh et al., 2018).

This study has several limitations including the cross-sectional nature of the study design and the fact that questions pertaining to self-testing were secondary to the primary purpose of data collection. Additionally, participants' perspectives were based solely on the hypothetical of a self-test described to them by the interviewer, they did not have a chance to see, hold, or try the tests which could have elicited more depth in their responses. There was also no clear understanding that a reactive result on the self-test should be considered a screening only, to be followed up with clinic-based testing, rather than a positive diagnosis itself. Finally, we developed the model during and after analysis as findings suggested mapping onto such a multi-level framework might be useful and thus we did not embark on the study giving thought to exploring, for example, structural level advantages and disadvantages of HIVST with FSW.

Conclusions

Study findings reveal multi-level factors influencing FSW's perspectives on HIVST and reflect how these perspectives can vary across settings. Understanding FSW's perceptions and acceptability of HIVST in distinct geographic and epidemic contexts is essential to effectively integrating self-testing into health systems and programmes in a manner that reaffirms their rights, dignity, and choice and is responsive to their needs.

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Data availability statement

Data cannot be shared publicly because of potentially sensitive information from a vulnerable population. Data are available by contacting the IRB of the Johns Hopkins Bloomberg School of Public Health for researchers who meet the criteria for access to confidential data at irb@jhsp.edu.

ORCID

S. Wilson Beckham  <http://orcid.org/0000-0002-9694-3091>

Tahilin S. Karver  <http://orcid.org/0000-0001-7362-9377>

Andrea Mantsios  <http://orcid.org/0000-0002-3314-9173>

Yeycy Donastorg  <http://orcid.org/0000-0002-0556-0133>

Clare Barrington  <http://orcid.org/0000-0001-7802-4051>

Deanna Kerrigan  <http://orcid.org/0000-0001-7401-9159>

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