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ORIGINAL PAPER

Autonomy and Care in Context: The Paradox of Sex Workers' Acceptability of HIV Self-Tests in São Paulo, Brazil

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Abstract

Cisgender female sex workers (CFSW) continue to face structural barriers to HIV prevention. We analyzed the acceptability of the oral HIV self-test (HIV-ST) among CFSW as part of a pragmatic trial on HIV prevention in Brazil. Data from in-depth interviews conducted with 12 women from diverse sex worker contexts and participant observation were analyzed using thematic analysis. CFSW valued autonomy in their workplaces and saw the HIV-ST as a possibility for self-care. Some feared clients' reactions, manager reprimands, and a positive result. HIV and sex work stigma largely drove self-care practices and perceived acceptability of the self-test. We argue that the autonomy offered by the self-test presents a paradox: increasing autonomy on the one hand while risking sidestepping structural dimensions of HIV vulnerability on the other. These nuances must be considered in interventions promoting the HIV-ST by considering the specificities of sex worker contexts, addressing stigma, and effectively involving CFSW and their organizations in intervention development.

Keywords Sex work · Brazil · HIV self-test · Autonomy · Stigma

Introduction

HIV continues to be a major health issue among cisgender female sex workers. Globally, their HIV prevalence is estimated at 10.4% (Shannon et al., 2018), with this group having a 30-times greater risk of acquiring HIV than the general population (Joint United Nations Programme on HIV/AIDS, 2020). Research has also found significant relationships between sex workers' vulnerability to HIV and the criminalization of sex work (Lyons et al., 2020; Platt et al., 2018; Reeves et al., 2017; Ryan et al., 2019) as well as with other structural factors exacerbated in large urban environments, such as poverty and residential instability (Reed et al., 2011; Shannon et al., 2018). Studies have also consistently highlighted occupational stigma as a barrier to sex workers' access to health care and a factor in increasing their vulnerability to violence and HIV in diverse contexts (Benoit et al., 2018; Lazarus et al., 2012; McCausland et al., 2020). Despite such research, structural responses to HIV among sex workers have been slow coming (Shannon et al., 2018).

Indeed, the importance of a response to HIV that recognizes the social and rights dimensions of the epidemic has been central since the epidemic emerged (Mann et al., 1993). As antiretroviral based prevention technologies advanced in the mid-2000s, researchers and practitioners endorsed what came to be known as combination prevention (Piot et al., 2008; UNAIDS, 2010). Combination prevention stemmed from an idea that it was necessary to combine scientific knowledge with diverse contexts of the epidemic, considering its behavioural, programmatic, macroeconomic and political dimensions (Piot et al., 2008). By offering a diverse range of prevention options directed at each of these dimensions, individuals could choose those most responsive to their needs while broader interventions also addressed structural dimensions of the epidemic (Grangeiro et al., 2015). In recent years, however, researchers have raised concerns that biomedical

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technologies, such as Pre-Exposure Prophylaxis (PrEP), have come to side-line structural and rights-based interventions, thereby compromising the approach's potential (Aggleton & Parker, 2015; Monteiro et al., 2019). In the case of sex workers, Bekker et al. (2015) consider that new biomedical technologies should not substitute methods that previously dominated prevention outreach—such as the male condom used with lubricant—but rather form an additional layer of protection.

The HIV self-test is included in combination prevention programs as an option that offers autonomy in knowing one's serological status. Research on the self-test with sex workers has found high levels of acceptability (Chanda et al., 2017; Ortblad et al., 2017), largely due to the privacy they perceive it as offering. Burke et al. (2017) found that privacy was seen as especially advantageous as it allowed sex workers to avoid stigma and discomfort at health centers. Although less frequent, studies have also found occurrences of physical and sexual violence after sex workers offer the test to clients (Maman et al., 2017; Thirumurthy et al., 2016). In a study conducted in Malawi, sex workers reported being coerced to be tested and/or reveal the results to intimate partners, family members and/or peers (Napierala et al., 2019).

While there is a growing body of literature focused on sex work and the self-test, it is primarily epidemiological and from African countries; at the time of writing, there were no published studies focused on Latin America. The majority of studies has also focused on access, with little attention given to the way in which contextual dimensions shape the self-test's acceptability and the effects of risk compensation (Johnson et al., 2017). Furthermore, issues specific to the large urban environments where much sex work takes place, such as the differences between diverse work contexts, distances from health centers and health services provided (or even required) by bosses, are not analyzed. Finally, the two concepts arguably at the core of the self-test—autonomy and care—have not been problematized within contexts of high levels of stigmatization, such as sex work, where the line between autonomy and isolation is often more nuanced than would appear.

In this study we analyzed cisgender female sex workers' acceptability of using the oral HIV-ST in São Paulo (SP), Brazil, paying particular attention to the role of stigma in defining the fluid line between autonomy and isolation. Erving Goffman's (1963) foundational work on stigma is often associated with conceptualizations of stigma as a mark or, as he himself defines it, "an attribute that is deeply discrediting" (p. 3) managed by individuals through their personal and social identities. Yet throughout his seminal work, Goffman also highlights the relational nature of stigma, defining it as "a special kind of relationship between attribute and stereotype" (p. 4), and particularly in the context of prostitution, notes its spatial dimensions and the "morality we employ to keep people in their places" (p. 83).

Ramos (2019) notes that the spatial segregation of prostitution in Brazil has led to the stigmatization of entire areas of cities and often their abandonment by government officials, unless it is to violently intervene. For example, in the 1940s and 1950s, sex work was confined to a specific area in downtown SP, making it a place of frequent police abuse and repression up through the 1980s (Rago, 1991; Rechtman, 2015). In Brazil, the sale of sex is legal, though not regulated, and a number of activities surrounding sex work are criminalized, such as brothels and pimping; an ambiguity that police departments have taken advantage of to control prostitution according to current moral, political and economic interests (Blanchette et al., 2017; Olívar, 2013; Ramos, 2019).

Recent research has highlighted the spatialized dimensions of sex work stigma and its effects on sex workers' health and vulnerability to violence (Orchard et al., 2019; Sanders, 2016). Orchard et al. for example, found that sex workers' spatial navigation of social and health services was crosscut by deep social inequalities and heavily influenced by their desire to avoid stigmatizing encounters. Theoretical work on stigma and health over the past two decades has emphasized similar connections between stigma, power, risk and the reproduction of inequalities (Link & Phelan, 2001; Parker & Aggleton, 2003; Phelan et al., 2008). Drawing on the work of these scholars, Stangl et al. (2019) developed the Health Stigma and Discrimination Framework (HSDF) as a way to move away from thinking about stigma as something individuals impose on others and rather emphasize the broader forces that structure it, paying particular attention to the fluid and complex connections between power and vulnerability. The framework is organized into a series of domains including drivers (i.e. blame, prejudice), facilitators (i.e. gender norms, laws), stigma "marking" (health-conditions, race, class, etc.) and manifestations in terms of stigma experiences and practices. In the framework, all of these domains then influence a range of outcomes and ultimately impact health.

In our analysis of sex workers' narratives, we drew on the HSDF paying particular attention to the drivers and manifestations of stigma and how sex workers' management of them influenced their acceptability of the self-test and the perceived effects of its use. In looking at the acceptability of the self-test through this lens, we aim to situate it within the structural dimensions of HIV vulnerability that crosscut sex work environments while also examining the spatial dimensions of the self-test's acceptability (i.e. perceiving it as acceptable in some spaces while not in others). In doing so, we seek to problematize the concepts of autonomy and self-care and contribute to the planning and organization of self-test strategies for sex workers, particularly in large, cosmopolitan and diverse cities such as São Paulo.

Method

Participants

The research presented here is part of the Combina! Study—an ongoing pragmatic trial that began in 2014 and seeks to analyze the effectiveness of HIV preventive methods in six healthcare services located in five Brazilian cities, including São Paulo (Grangeiro et al., 2015). The results presented come from a qualitative component of the project that included 32 interviews with cisgender female sex workers to understand their access, perceptions and experiences with various HIV prevention methods and linkage to care in São Paulo. Below, we present results from a sub-study of 12 of these qualitative interviews that focused on the acceptability of the HIV self-test. The sub-study was conducted with the goal of subsidizing the distribution of the HIV-ST to sex workers at a time when this method was not yet available in public health facilities in SP. As potential barriers to service access were of interest to the self-test sub-study, we decided not to interview Combina! trial participants as they already had routine visits and testing at public healthcare facilities as part of the project.

The fourth author, a cisgender woman who has been working on HIV/AIDS studies in the downtown area of SP since 2016, recruited participants at a public healthcare facility in downtown SP specialized in HIV prevention, diagnosis and treatment (referred to as a SAE—acronym for Specialized Healthcare Service in Portuguese) that also includes peer outreach activities. From October 2018 to February 2019, the researcher participated in SAE activities at the healthcare facility and at sex work establishments during peer outreach. Along with SAE staff, she recruited five participants that had sought out the SAE for sexual health services, and seven during peer outreach activities. The recruitment at workplaces contributed to diversifying the participants' profiles in terms of access to healthcare facilities and sex work contexts.

When a potential participant was identified, the researcher or SAE staff briefly presented the study to them. Those interested in participating were contacted again two days later by the researcher, who then further explained the study over the phone. If they confirmed their interest in participating, an interview was scheduled.

Participants defined the date, time and place of their preference to be interviewed, being oriented by the researcher that they should choose somewhere private and where they would be comfortable to talk about their work and HIV. Five chose to be interviewed at their workplaces; four in a private room at the SAE; two in private areas of cafes; and one in the participant's house. After the interviews, participants were offered five self-test kits.

Measures and Procedure

Interviews were semi-structured, conducted in Portuguese, lasted between 40 and 90 min and were recorded on audio with the permission of the interviewees. The interview script explored: (1) sociodemographic characteristics and sex work contexts; (2) HIV prevention; (3) sexual and reproductive health; (4) vulnerability to HIV; (5) perception of health services; (6) perception of SAE's outreach activities; (7) perception and knowledge about HIV-ST; (8) perception of possible consequences of using the HIV-ST; and (9) possible effects of HIV-ST on access to health services. In this analysis, we focused specifically on sociodemographic characteristics and sex work contexts, sex workers' perceptions of health services and all interview questions specifically related to the self-test (numbers 7–9 above).

The interviews were transcribed verbatim. The researcher who did the interviews assessed the accuracy of the transcripts by comparing them to the audios. Quotes presented in this paper were translated into English by a professional translator and were reviewed by all authors.

From October 2018 to March 2019, the interviewer also conducted participant observations in the SAE and in the area covered by the peer outreach workers. She recorded her observations along with information about the context of each interview in a fieldwork diary.

Data Analysis

Thematic analysis (Braun & Clarke, 2014; Minayo, 2013) was carried out with the support of the ATLAS.ti software. It covered the following stages: reading of the transcripts in detail; preliminary definition of themes based on our research questions focused on acceptability, work contexts and sex workers' relationship with public health services; a new round of reading; definition of codes considering the previous themes and the topics that emerged most frequently in the narratives; coding of all of the interviews; definition of code groups with the entire research team; and a preliminary interpretation of results based on the theoretical frameworks adopted in the study.

For this first deductive stage of our analysis, we defined acceptability as: "a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention" (Sekhon et al., 2017, p. 4). In this case, we looked at prospective acceptability, given that none of the interviewees had previous experience of using the HIV-ST.

Acceptability as a framework, however, fell short of describing the complexities we observed in data, and we shifted to an inductive approach for the second stage of

Table 1 Sociodemographic characteristics of sex workers interviewed

Pseudonym	Work context	Age	Education	Self described skin color	Children	Had heard of the Self-Test
Cristiana	Nightclub	37	College degree	Light brown	Yes	Yes
Amanda	Day club	26	High school degree	Black	No	No
Taís	Day club	29	High school degree	Black	No	More or less
Flavia	Day club	38	Primary school	Brown	Yes	Not sure
Jacqueline	Apartment building	20	High school degree	Black	Yes	No
Tatiana	Nightclub	38	College degree	White	No	No
Betania	Apartment building	34	In college	Brown	Yes	No
Deisy	Massage parlor	21	In college	Brown	No	No
Marta	Apartment building	29	High school degree	Black	Yes	No
Patricia	Massage parlor	34	In college	Brown	Yes	No
Aline	Street	21	In college	Black	No	Yes
Diana	Street	24	High school incomplete	White	Yes	No

N = 12

analysis (Minayo, 2013). In this phase, autonomy and stigma emerged as transversal themes and we applied the Health Stigma and Discrimination Framework (HSDF) (Stangl et al., 2019) as a lens to guide our third and final stage of analysis and interpretation. As part of this process, we created new code groups around the themes of autonomy and stigma, focusing specifically on the "stigma experiences" category of the HSDF. Within stigma experiences, we looked at experienced discrimination (i.e. suffering stigmatizing behaviors at a health facility or at work); perceived stigma (i.e. perceptions about how sex workers are treated in society); and anticipated stigma (i.e. expectations of being stigmatized by others if their identity as a sex worker is disclosed). We then examined how sex workers' management of these experiences impacted on their acceptability of the self-test, relationship with health care, self-care strategies and attitudes towards their work environments.

Results

Characteristics of Participants

Table 1 presents basic demographic information of the study participants and their pseudonym names. Their ages ranged from 21 to 38, three had completed college degrees, four were currently in college, three finished high school, one did not finish high school and one did not finish primary school. The majority was originally from outside São Paulo, reported their skin color as black or brown and seven had children. Apart from one, all the women had been tested for HIV and three had heard of the HIV-ST before the interview. No one had previously done a self-test, yet all said that they would be interested in using it. Six worked in downtown São Paulo and six in other areas of the city, and all used the services offered by the SAE.

Work Contexts: Prioritizing Autonomy and Managing Conditions

Participants worked in four different kinds of sex work environments: apartment buildings, clubs, a massage parlour and on the street. Although they worked in diverse settings, in general they valued similar characteristics in terms of their work environments: freedom to come and go and make their own agendas, cleanliness, safety and mutual respect with clients, colleagues and owners. These work related values strongly influenced their decisions about where to work and their perceptions of the HIV-ST.

Marta, Betania, and Jaqueline worked in the same large apartment building where each floor was organized into a series of apartments that functioned like small brothels. Each floor had a different manager and workers shared bathrooms, showers and bed linen. Some lived full-time in the building. The women negotiated their daily shifts during the 9am–9 pm operating hours with owners and the timed sexual services usually lasted 15 min, costing around R$30 (~ US$6) each. A daily fee of R$120 (~ US$24) was taken out of their earnings for the floor managers and everything they made after this went to them. The building structure was precarious, and in general the apartments had poor hygiene conditions that were a frequent matter of complaint. As Marta shared:

> A girl there [at the building] complained, she said – 'come on tia,[1] everyone pays a fee to you daily and you don't fix the fan in the rooms?' Because you have to pay

[1] Emic expression used to denote women who manage the establishments.

> her a daily fee of R$120, everyone pays it. She didn't like it. Two days later she fixed the fan, but she didn't like it. Another thing that I don't agree with: on other floors, some [managers] pay for packed lunches for the girls, and some at least give water, they buy 2-liter bottles of water and give it to the girls. There [where I work] they don't…or she [the owner] just takes water from the tap or the bathroom sink and puts it in the fridge to make it cold.

Despite the precarious conditions and occasional conflicts with owners over what was provided considering what they paid, those interviewed emphasized having more autonomy in this arrangement when compared to other establishments. Jacqueline for example had worked in "high class" prostitution, yet, like other women interviewed, was critical of the establishments for having too many rules and valuing clients over the workers.

> That's why I don't like high class houses, because here, as disorganized as it is, here you make your own rules. Here you chose what you are doing to do or not, if you will have anal sex or not…in those other houses, like in day clubs, you don't choose. They choose.

Autonomy to come and go was highly valued. As Betania stated, "I think that I might not have the same freedom I have here in another house."

Amanda, Taís and Flavia worked at day brothels with similar working and hygiene conditions as those observed in the apartment buildings. The main difference was that services were organized by appointment and with higher prices, ranging from R$ 50 to R$100 (˜US$10-$20), of which a percentage went to the owner. As the appointments were controlled by the brothels' owners, the women did not have complete autonomy and saw the owners as more controlling.

Diana and Aline, the youngest women interviewed (aged 24 and 21, respectively), worked on a street a few kilometers away from downtown São Paulo. They charged up to R$150 (˜US$30) for an hour service, which took place either in hidden areas of the street, motels or parking lots. The women paid a daily fee to men they identified as pimps,[2] which, according to the interviewees, was for their security. They did not complain about pimps being controlling with regards to their work hours.

Cristiana and Tatiana worked at nightclubs in upper middle-class neighborhoods. These clubs only opened at night and the sex workers could come and go as they pleased, although those who maintained a certain loyalty to a club often had privileges, such as receiving more of the cut from clients' beverages and/or referrals from clients. The hour-long service cost between R$250 and R$500 (~ US$44 to US$88), and the sex workers kept the entire payment. The houses made a profit by renting the rooms, for which clients paid separately, and by selling alcohol, for which sex workers occasionally also received a commission. Hygiene conditions varied among nightclubs, but were usually better than those found in the buildings and day clubs. Cristiana and Tatiana highly valued the autonomy of their work environment. As Cristiana stated:

> We have a lot of freedom there [at the club]. We can arrive at ten, eleven at night, it is very flexible. But I only leave when the house closes. If you don't have any clients, you can grab your things and leave, whenever you want. We aren't obliged to anything there. Nothing, absolutely nothing. I am treated very well by all of the employees and was always treated well by my clients.

Finally, the massage clinic where Deisy and Patricia worked was self-managed by a group of four women. In this system, the women worked by appointment. Services cost between R$150 and R$250 (~ US$26–US$35) and the house had an explicit policy against alcohol or drug consumption. With a horizontal management system and a clean, organized environment, Deisy and Patricia expressed great satisfaction with their work conditions. Even though they paid 50% of all their earnings to the house, they found the division fair due to what the house offered and the solidarity among the workers. As Patricia said, "We give each other massages, we cut one another's hair, we help each other out to save money (…). We bring our food from home and eat here, we take showers here."

All participants highly valued and sought autonomy, preferring locations that did not demand long hours of work, and where they felt safe and respected by the owners. Situations in which owners expected rigid commitments to work schedules and did not provide the essentials for the women to work were the subject of harsh critiques. When asked specifically about the self-test, some concerns about using it in their work environments emerged. Below we explore these directly in relation to stigma in their work contexts, followed by the self-test in relationship to self-care and as a stigma management tool.

[2] The term *cafetão* in Portuguese (equivalent to *pimp* in English), has a morally loaded and complex history in Brazil like many international contexts. We use it here as it was the term used by our interviewees and refer readers to an article by anthropologists' Thaddeus Blanchette and Ana Paula da Silva on third party involvement in sexual economies in Brazil for a broader discussion of the term and its usage (Blanchette & Silva, 2017).

The HIV Self-Test at Work: Between Its Potential to Improve Self-Care and the Risks of Isolation

All the women expressed interest in the self-test and saw benefits to its use and flexibility. They felt they would be able to do the test alone and did not express concerns about the reliability of the result. While most did not envision their bosses making the test obligatory, they did fear that offering the test to clients might scare them away. A concern shared by several of the women interviewed was that it would be seen as a reminder that HIV (which remained a highly stigmatized disease in the women's narratives) exists.

Betania, for example, thought that it might lead clients to think that something was wrong, stating: "they would think, 'she's sick, she's got something'." While Tatiana and several others thought that steady clients would understand, they thought that new clients might take offense. As Tatiana said, "Steady clients wouldn't take offense. Just those that I am meeting just now, those that don't even know me, they might say: 'But why?'"

Several expressed concerns about the owners' reactions. Marta for example feared that the owners would suspect that sex workers had the test because they were HIV-positive, or even require them to show their results. Another concern was that owners wouldn't accept the test in the club because the test's presence might be associated with HIV, which they imagined owners as seeing as harmful to business. Tatiana said,

> Because the owners, they are like this: 'Oh, we don't even want to talk about HIV. It doesn't exist. All we want to know about is business.' They wouldn't even want the clients to imagine the hypothesis that a girl might have HIV. Because it would ruin them, right?... So the owner might say: 'No. I don't want this self-test here because it is bad for business. So if you want [you can] do it, but not in here.'

When asked about the possibility of using the test with clients, several thought it was likely that negative test results would be used to justify having sex without condoms. This possibility was seen with enthusiasm by Aline, Amanda and Jacqueline due to the chance of earning more money. As Amanda said, "If I had the self-test here, can you imagine? The clients would offer more money to have sex without condoms, and I would have sex with everyone. I would use it with them and make a lot of money." While others, like Cristiana, who were not willing to have condomless sex with clients, saw this as a problem:

I don't think it would work very well for clients. Only if it was a client, like, very steady. And it could also be a bit bad because they might think that they could take liberties, like, 'Ah, you just saw that I don't have AIDS, so let's have sex without a condom.'

Patricia emphasized that a negative result wouldn't mean feeling safe to be intimate without protection, and feared that a client could, "end up forcing me to do it, like, 'I don't have anything, aren't you seeing that I don't have anything? I'm paying you.'

Possible positive test results were also a source of concern. As Taís stated:

> I'd do the self-test without any problem. But, like, confronting the result could be difficult. That's very complicated. I'm not going to lie to you and say it's not.

In this sense, the perceived benefit offered by the self-test was contrasted with a concern about how to handle a positive result, both in terms of negotiating condom use with a client and being isolated without support to handle what was largely seen as unfavorable news. Fear of a positive result meant that many women preferred to think about using it alone, rather than with clients. In these scenarios, Cristiana emphasized that those doing the test would need to be aware about what the result would mean, and where they could go for help. As she stated:

> Now, the person needs to be aware of how she's going to handle the result. Is she going to throw herself in front of a car or is she going to have the wisdom to seek out medical attention?

Medical attention and care were referred to as spaces for orientation and support in situations of need, such as a positive test result. Returning to Tatiana, who expressed concern about how the owners would react to the self-test, she thought that "a relationship between the girls and the health service" would be the best way for sex workers to access the test and therefore avoid any possible conflicts with the establishment owners. Yet as we explore more below, the relationship with the health service, like the relationships at work, were also nuanced and heavily influenced by perceived and anticipated stigma.

HIV Services: Choosing Silence and Avoidance to Manage Stigma

The women referred to public health clinics as spaces where they could receive information and supplies to care for themselves, but not as spaces where they felt comfortable talking about their work. Feelings of embarrassment at sharing their profession in health consultations were common across all interviews, and several mentioned past experiences of discrimination in healthcare facilities, especially when requesting condoms (it's common for public health services in Brazil to provide more condoms if the person discloses that they are a sex worker).

Deisy mentioned attendants at health services loudly asking questions about why she needed so many condoms.

Aline, the youngest sex worker interviewed who worked on the street, mentioned feeling stared at and uncomfortable having to share the information required to access larger numbers of condoms and shared that her colleagues had similar experiences:

> [at the health center] the girls feel really ashamed. They die of embarrassment, they run out of there blushing after having to explain so much. The guys keep asking things about our age, all sorts of things. We show them our IDs and they still keep asking us a bunch of things.

Betania, who was in nursing school and interned in several public health centers, mentioned "dying of embarrassment" and fear at the idea of someone recognizing her as a sex worker when requesting a self-test: "I'm very afraid of running into someone, I have a lot of friends who are nurses, doctors—can you imagine if someone saw me there [hospital specialized in HIV/AIDS]? What would I say?"

Jacqueline mentioned hiding all information about her work when she goes to the doctor, leaving her without any options if she has any work-related concerns.

> [At the health service] I don't talk about my life here, issues about work, I just talk about my private life. So they don't know that I'm a sex worker, how much I have sex, they don't know any of that.

The interviewer followed up, asking Jacqueline where she goes when she has a work-related health issue, and she responded: "I don't go anywhere."

Across the board, hiding the information about their profession appeared as way of protecting themselves from prejudice and stigmatizing attitudes, while also isolating them from care. In this way, perceived, anticipated and experienced sex work-related stigma shaped access to health services and interaction with health providers and contributed to their positive perception of the HIV-ST. As Amanda stated:

> I think that for you to go to the hospital, talk about your life [as a sex worker] ...ok, he's a doctor, I understand that, but it is very difficult, at least for me. Not just for me, my friends [at work] also say the same thing, it is for a lot of people...So if we [sex workers] had that thing that you mentioned [the self-test] for us to do it at our own house, it would be easier.

The self-test was seen as "easier" by many precisely because it meant avoiding having to share personal and professional information that often led to them feeling ashamed and/or embarrassed at health centers. It thus emerged as a potentially effective stigma management tool for being viewed as a way to by-pass stigmatizing lines of questioning related to sex work that made the women uncomfortable at health services.

Access to the HIV Self-Test: Stigma as Mediating Spatial Dimensions of Autonomy and Care

Perceived and anticipated sex work stigma also heavily influenced sex workers' access preferences. Three options of spaces to access the test were offered—peer educators at their workplace, pharmacies (after filling out an online form) or directly at the health facility. Privacy, convenience and the least exposure to the risk of being discriminated against structured sex workers' preferences. Their interpretation of which option would be best according to these criteria, however, varied. Many, for example, said that they would not have the "courage" necessary to request it at healthcare facilities.

> The disadvantage of [getting it at the health care service] is that the majority of the sex workers don't have the balls to go there. Not even to [ask for] condoms, some sex workers [ask others] – 'ah, go and get some for me, I don't have the courage to ask for condoms there.' – Aline, street
> How am I going to go to a health center and ask for an HIV test? They're going to think I'm doing something, that I don't know who I'm going out with it, right? -Patricia, massage clinic

Jacqueline saw the peer educator who regularly visited her workplace as ideal because this would mean she could avoid going to the health clinic:

> People might be ashamed to go to these places and ask for or do the exam. So I think that it would be a lot more comfortable for us to have it here, right? It would be much more comfortable. The exposure would be less too, right?

While others, like Tatiana, thought that some of the women at her workplace might not feel comfortable requesting the self-test from a peer educator due to fear of what other colleagues might think: "Because others would be ashamed… afraid of what the others would think, if she might have something or not."

For similar reasons in terms of privacy and convenience, Marta and Diana preferred receiving the test at the pharmacy, which for Marta, also had the advantage of being a place where she could ask questions and receive guidance. The convenience aspect was also seen as advantageous by Taís. She said she would prefer to get it herself at the health clinic as the peer educator visits were irregular. As she stated:

> I don't like to wait for anything from anyone [laughs]. So, let's imagine, someone is going to bring it here. Ok, she's already coming, she always brings condoms and lube, asks questions, advises us about various things. But I'm not even talking about her specifically.

It's because if I could go and get it [myself], I would definitely go.

Taís' perspective on preferring to take care of herself and resolve things independently was recurrent throughout the interviews. Across the board women reinforced self-care as a central part of their work, taking on both normative and constructed dimensions of care. As Deisy stated, "We have to take care of ourselves, because if we don't, we don't work."

Self-care was a structural part of their work and being tested for HIV was part of their care. Prior to knowing about the self-test, being tested for HIV had often meant confronting perceived, anticipated and experienced stigma at healthcare centers. The positive reception to the self-test revolved around the autonomy to procure and administer the test independently, by-passing this uncomfortableness while also largely keeping the self-test hidden from owners and clients to avoid possible negative reactions.

Discussion

Autonomy emerged in our findings as something sex workers valued in their work environment and when it came to taking care of their health. The self-test was positively viewed as something that would expand their autonomy for self-care in the sense that women felt capable of using it and saw it as filling a gap in their access to prevention supplies and services. On the other hand, access and use preferences were heavily structured by perceived, anticipated and experienced stigma at health clinics, making the autonomy offered by the HIV self-test as much about stigma management as self-care. Furthermore, insecurities about handling a positive result by themselves and potentially negative reactions from clients and/or bosses led to the women imagining that they would restrict its use to an exclusively private domain; a finding we associate with their being fully responsible for the costs and benefits of its use in their work environments. In this sense, sex workers' autonomy and self-care were heavily mediated by spatial dimensions of stigma in their immediate work and healthcare contexts.

Our results are similar to studies conducted with sex workers in Sub-Saharan African countries that found high levels of acceptability and feasibility (Chanda et al., 2017; Ortblad et al., 2017), especially motivated by the advantage of avoiding discomfort at health care services (Burke et al., 2017). Our findings, however, found more benefits for the women's own use of the test, as opposed to their offering it to their clients and intimate partners (Thirumurthy et al., 2016), highlighting the need to comprehend differences and particularities of sex work contexts. Similar to other contexts, we also found a possible risk compensation related to earning more money for condomless sex, not using condoms with stable partners (clients and otherwise) and possible situations of violence and/or coercion at work (Burke et al., 2017; Thirumurthy et al., 2016). All of which require close and careful attention in future research and interventions.

The diversity of motivations, possibilities and consequences of using the self-test shared by the women leads us to problematize the predominant vision of individual autonomy in bioethics that assumes an ability to make decisions independently and as guided by reason and self-interest (Kasoka, 2020). According to a socio-relational perspective of autonomy, possibilities for self-care should instead be located within a constantly evolving social context shaped by emotions, need for social validation and goal of protecting and promoting collective well-being and survival (Kasoka, 2020). Such an approach to autonomy also aligns with Hoy et al.'s (2007) definition of self-care as "a set of action capabilities for health directed towards universal needs, goals and health problems and, on the other hand, as a set of action processes directed towards meaningful connectedness to the context and building and integration of the self in daily life" (p. 463). Such action capabilities and processes mutually reinforce one another and build on experience, ideally resulting in good health, well-being, greater autonomy and empowerment (Mailhot et al., 2013; Matarese et al., 2018).

The intrinsic dimension of intentionality of using the self-test as a self-care strategy should thus be understood within the context of intra and intersubjective relationships, such as sex workers' preference for accessing the self-test at the pharmacy or health center due to the irregularity of prevention actions and lack of privacy at their places of work. As Kasoka (2020) argues in their work looking at the self-test in the context of Sub-Saharan Africa, the concept of individual autonomy is not compatible as an ethical base for thinking about HIV testing from an ontological perspective that situates human beings as intrinsically connected and interdependent to their broader world. This perspective is also consistent with the relational perspective dominant in Brazilian anthropological studies of health that emphasize the moral and social dimensions of health and sickness, and urge avoiding the reduction of both to their biomedical and even political dimensions (Duarte, 2003; Sarti, 2010).

In looking at these relational, moral and social dimensions in our results, a strong tension between autonomy and individual responsibility emerges, illuminating what we refer to in our title as a paradox of sex workers' acceptability of the test: on the one hand it increases autonomy, while on the other it sidesteps the larger structural and work environment related issues that would expand their rights as workers and reduce their vulnerability to HIV. We found stigma, be it related to HIV or prostitution, as materializing in this illusion of rational independence and driving self-care practices and the perceived acceptability of the self-test. Sex workers' comprehension of their work contexts and broader

prejudices surrounding prostitution strongly informed their preference to access care through the means that required the least amount of social interaction. Perceptions of stigma combined with the structural characteristics of their work contexts restricted the use and potential impact of the self-test, further isolating sex workers from public health services, their colleagues and their bosses.

The self-test thus emerged in our results as a sex work-stigma management tool. Drawing on Goffman's (1963) discussion of managing stigmatized identities, Benoit et al. (2018) highlight how information management—or deciding who or who not to tell about one's stigmatized trait or behavior—is one of the most common strategies used by sex workers in studies conducted across diverse contexts. Our results regarding sex workers' decision not to disclose their profession in doctors' visits and other work contexts are examples of such information management techniques.

In addition, spatial divisions—such as resistance to going to health clinics where they might know someone and the clear lines that sex workers placed between their work and private contexts–pervaded our results as stigma management techniques directly related to the acceptability of the self-test. In this sense, our results echo research on the spatial dimensions of stigma and its management as factors that impede access to care and prevention methods for sex workers (Orchard et al., 2019; Sanders, 2016). They also point towards the need for future research to look more critically at HIV prevention technologies as stigma management tools, and the potential consequences of this for vulnerable populations like sex workers.

In light of our findings, we conclude by emphasizing that one strategy for offering the self-test will not be enough and that as stigma continues to operate as a driver of the HIV epidemic among sex workers (Dourado et al., 2019; Lyons et al., 2020), the success of any intervention will depend on addressing this structural determinant of the epidemic. First, there is a need to invest permanently in assuring non-discriminatory practices in all health facilities, as well as investing in societal debates around sex workers' rights. Second, our findings highlight the need for interventions that strengthen sex workers' autonomy in their workplaces. The fact that sex workers do not have any kind of labor protection in Brazil means that they are much more vulnerable to arbitrariness from their employers, which partially explains their fears surrounding the possible negative effects of having the self-test in their work environment, or even losing their jobs if they tested positive. This type of threat has long been addressed by the labor legislation in Brazil for other types of work: since 1992 federal regulation has prohibited mandatory HIV testing for work purposes, as well as firing workers due to HIV status (Brasil. Programa Nacional de DST e Aids, 2004).

Regulating sex work in Brazil, however, is an increasing challenge in a scenario of growing neoliberalization of labor relations, weakening of democratic institutions and growing power of far-right conservative politicians (Reis Brandão & Cabral, 2019). Indeed, much of the state-funded solidarity and mobilization based interventions with sex workers that brought international recognition to Brazil are no longer possible on a broader scale due to this context (Murray et al., 2019; Parker, 2020). However, if interventions promoting the self-test are not developed with sex workers, their organizations and their workplaces, our findings suggest they risk further isolating them from vital health and social services. Furthermore, the State must ultimately be responsible for supporting such interventions as part of comprehensive, public sexual and reproductive health services if we are to truly work towards the kinds of structural changes that are needed to reduce HIV vulnerability (Ghose et al., 2008; Kuhlmann et al., 2014; NSWP, 2018).

To our knowledge, this is the first study to assess HIV self-test acceptability among sex workers in Brazil, and we are sadly aware that the possibility of implementing our recommendations in our own context is unlikely as we finalize this paper in August 2021 amidst continued political and public health turmoil. At the same time, sex worker mobilizations in the face of extreme adversity and marginalization during the Covid-19 crisis in Brazil (Santos et al., 2020) and elsewhere (Global Network of Sex Work Projects., n.d.; Jozaghi & Bird, 2020; Lam, 2020; SWAN; ICRSE, 2020) provide motivation and evidence of collective, sex worker led action as the most viable and effective path forward.

In terms of our limitations, the relatively small number of interviews restricted our analysis to specific sex work contexts and cisgender female sex workers included in this study. Participant observation complemented the in-depth interviews to enrich our data, yet the inclusion of other sex work contexts and the inclusion of other social actors from these contexts such as transgender sex workers, peer educators, clients and owners would likely bring different elements to the analysis not considered here. In addition, the women had very low levels of knowledge of the self-test and more experience with it might shift their interpretations and meanings attached to it.

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authors contributed to the Introduction and Discussion, and read and approved the final submitted article.

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Data Availability Given the sensitive nature of the interview content the transcripts are not publicly available to fully protect those interviewed.

Declarations

Conflicts of interest The researchers declare no conflict of interest.

Ethics Approval The research was approved by Institutional Review Board of the University of São Paulo School of Medicine (number 2.733.520). All participants were informed of the research aims and signed an informed consent form.

Code Availability The authors are happy to provide codebooks upon request to the corresponding author.

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