“It’s worse with fellow patients... they judge you as evil”: Barriers to access and utilisation of HIV/STIs prevention and care services among trans-women sex workers in the greater Kampala metropolitan area, Uganda.

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Abstract

Background Trans-women sex workers bear the greatest brunt of HIV and other sexually transmitted infections (STI). Trans-women are 49 times more at risk of HIV infections compared to the general population. However, they remain underserved and continue to grapple with challenges in access to and utilisation of HIV/STI prevention services. Our study explored the barriers to access and utilisation of HIV/STI prevention services and associated coping mechanisms. Methodology This exploratory qualitative study was conducted among trans-women sex workers in the Greater Kampala Metropolitan area, Uganda. Twenty-two in-depth interviews, six key informant interviews and nine focus group discussions were conducted to obtain data on barriers to access and utilisation of HIV and other STI prevention and care services, and coping strategies of trans-women sex workers. Data were analysed through thematic analysis under a hybrid of inductive and deductive approaches. Results Barriers to access and utilisation of HIV/STI prevention and care services were classified as individual, community and health system barriers. Individual barriers included internalised stigma and low socio-economic status. Health system barriers included discrimination by some healthcare providers, stigmatisation by fellow patients, stockout of lubricants drugs and other medical supplies, inadequate access to trans-specific STI drugs, and high cost of drugs. Community barriers comprised social exclusion and lack of recognition by other key population groups, and transphobia. The coping strategies included the use of substitutes such as lotions, avocado, egg white or yoghurt to cope with a lack of lubricants. Herbs were used as substitutes for STI drugs, while psychoactive substances were used to cope with stigma and discrimination, and changing the dress code to mimic gender identity. Conclusion Trans-women sex workers grapple with access to HIV/STI prevention and care services. Individual, community and healthcare facility level barriers hindered trans-women sex workers from access and utilisation of HIV/STI prevention and care services. There is a need to create an enabling environment in order to enhance access to and utilisation of HIV/STI prevention and care services for trans-women sex workers through sensitisation of healthcare providers, other key population groups and the community on the transgender identity.

Background

Trans-women are defined as individuals who do not conform to conventional notions of male or female gender but combine or move between the two (1). Global statistics indicate that more than 19.1% of trans-women are living with HIV, and are 49 times more at risk of HIV infection compared to the general population (2). While there is limited data on HIV prevalence among trans-women sex workers in Uganda, available data from other settings indicate a high prevalence of HIV that is linked to the absence of a conducive environment for accessing prevention, care, and treatment services (3, 4).

Trans-women are often victims of social and legal exclusion, extreme economic vulnerability, and are at an increased risk of experiencing violence. Furthermore, low self-esteem, lack of social programs, low education status, limited legal and civil rights (5–7), and lack of empowerment make it difficult for trans-women to negotiate for HIV prevention strategies, such as the correct and consistent use of condoms (3).
Owing to the economic vulnerabilities faced by trans-women, majority engage in sex work as a means of basic survival amidst economic discrimination (8). Of concern however, sex work is characterised by high-risk behaviours such as incorrect and inconsistent condom use, drug and substance use (9), and multiple sexual partners (10). Evidence shows that social, cultural and policy issues surrounding trans-women (such as internalised stigma and violence, limited access to non-stigmatizing health services) and inaccurate perceptions of self and partners’ risk escalate HIV acquisition (11). However, little is known about the barriers to access and utilisation of HIV and other sexually transmitted infections (STIs) prevention and care services among trans-women sex workers in Uganda.

Trans-women, especially those engaged in sex work, remain a socially hidden population in Uganda (11). The majority of key population studies focus on the sexual and reproductive health of female sex workers (12), largely ignoring the public health importance of understanding trans-women sex workers sexual and reproductive health behaviours, and their role in escalating the HIV/AIDS pandemic. Furthermore, trans-women vulnerabilities, frustrations, and insecurities have been historically overlooked by mainstream society (Khan et al., 2009), including among healthcare providers (12). For example, trans-women were (and are still in Uganda) originally misclassified as men who have sex with men (MSM) (2), despite their distinct vulnerabilities (13). Transwomen experience discrimination resulting from many forms of stigma relating to gender identity, gender expression, perceived sexual orientation, and involvement in sex work (Poteat et al., 2015a), trauma, fear and lack of legal recognition of their gender identity (13, 14). Transwomen sex workers for instance, face gender-related stigma, peer, and institutional distrust (7, 13) and remain absent from national HIV surveillance systems and program interventions (10).

Owing to their unique needs, risks, and vulnerabilities to HIV and other STIs, trans-women sex workers require innovative, comprehensive, and effective HIV/STI prevention strategies (2, 11). However, there is limited scientific evidence to support such strategies (11). As a result, structural barriers as well as high-risk behaviours remain persistent (11). Our study used the Andersen and Newman framework to understand the barriers to the utilisation of HIV/STI prevention and care services among trans-women sex workers in the greater Kampala metropolitan region. This framework gives insights into conditions that either facilitate or impede access and utilization, and are categorised as predisposing, enabling factors, and the perceived need for health care services (15). The Andersen and Newman framework of health services utilization has been widely used to understand barriers to access and utilisation of HIV prevention and care services among other high-risk populations (16–18).

Methodology

Study area

This study was conducted in the Greater Kampala metropolitan area (GKMA). The GKMA occupies about 970 km$^2$ of land and geographically encompasses a circle of about 30 km radius from Kampala city centre. The GKMA comprises Kampala capital city, Mukono, and Wakiso districts. This is also the most populated region in Uganda. Wakiso district has the highest population in Uganda, followed by Kampala,
with a population of approximately 2 million and 1.5 million people, respectively, whereas Mukono district is the 7th most populated in Uganda, with 596,804 people (19).

Study population

This study was conducted among trans-women sex workers in Kampala. Trans-women sex workers were defined as women aged 18 and above who were assigned male at birth and had received money or goods in exchange for sexual services in the last one month.

Study design, data collection procedure and tools

A formative qualitative study was conducted. Implementation of the study was spearheaded by researchers from the Makerere University School of Public Health in collaboration with the programs department at Transgender Equality Uganda (TEU). TEU played a central role in linking the study team to trans-women sex workers, and all non-governmental organisations working with transgender persons. At the time of data collection, the study participants were purposively selected through snow bowling.

We conducted 9 focus group discussions (FGDs), each comprising between 7 to 8 participants, 3 per district. The FGDs provided an opportunity to capture views on access and utilization of HIV/STI prevention and care services from the trans-women sex workers community. Specifically, these FGDs were used to explore the Sexual and Reproductive Health (SRH) issues that affect the trans-women sex workers, their health-seeking behaviours, and attitudes towards available healthcare services as well barriers faced. In order to ensure privacy and confidentiality, FGDs were conducted in secluded places where trans-women sex workers usually gathered during their free time. These included entertainment places like restaurants or hotels. The actual time for the interview was agreed on with the selected study participants. Interviews were conducted during the day after 11.00am when most trans-women sex workers were awake and before going for work in the evening. A total of 22 follow-on IDIs (10 for Kampala city, 6 for Mukono and 6 for Wakiso district) were conducted with selected trans-women sex workers to capture the lived experiences, and to gain a deeper understanding of SRH issues identified during FGDs. A total of 6 key informant interviews (KII) were also conducted among policy makers at the Ministry of Health and managers of healthcare facilities (both private and public), where the transwomen usually access SRH services. Study participants were asked about the main SRH problems faced by the transwomen sex workers community, experiences while accessing HIV and STIs prevention and care services, availability of trans-specific SRH services, delivery of SRH services, quality and attitudes towards available SRH services, and barriers to utilisation of SRH services. The total number of IDIs and KII conducted was determined by the principle of theoretical saturation (20).

Data management and analysis

All interviews were digitally recorded with permission from the respondents. These were then transcribed verbatim by two experienced transcribers. Interviews conducted in the local dialect were also transcribed and translated by experienced bilingual personnel without losing meaning. Transcripts were read several
times by two members of the study team, who then developed codes and code book definitions based on the study objectives while integrating emerging themes from the data. The code book was discussed and agreed upon by all members of the core study team. Coding of the transcripts was done using ALTAS-ti software in order to ease analysis. The code reports generated by ALTAS-ti were read and discussed by study investigators who afterwards agreed on themes, organising themes and basic codes. A social ecological model was used in the presentation of findings.

Quality control

Research assistants with a good command of English and the local language (Luganda) were trained to ensure validity and reliability of the study results. The interview guides were back-translated from English to the local language by two experienced translators. The original English version was compared with the version translated from the local languages to ensure consistency of meaning. Furthermore, research assistants were also oriented on the common slangs and terminologies used by the trans-women sex workers community.

Results

The average age of study participants for IDIs was 21.5 (standard deviation = 2.3). The majority, 90% (20/22) of the participants were aged between 18 and 24 years; 50% (11/22) had attained an ordinary level of education, and 72.7% (16/22) had never been married. About 50% (11/22) of the study participants did not have any other source of income other than sex work, and 54.5% (12/22) stayed with a fellow trans-woman. With regard to sex work, 54.5% (12/22) had engaged in sex work for less than 5 years, and the majority, 41.0% (9/22) operated from their residences or homes. Less than half of the study participants, 36.4% (8/22) had ever tested for HIV. (Table 1).
| Variable                          | Category                                                      | Frequency (N = 22) | Percentage (%) |
|----------------------------------|---------------------------------------------------------------|--------------------|----------------|
| Age                              | 18–24 years                                                  | 20                 | 90.9           |
|                                  | 25–27 years                                                  | 2                  | 9.1            |
| Highest level of education       | Primary                                                      | 1                  | 4.5            |
|                                  | O' level                                                      | 11                 | 50.0           |
|                                  | A level                                                       | 8                  | 36.4           |
|                                  | University                                                   | 2                  | 9.1            |
| Marital status                   | Divorced/Separated                                           | 1                  | 4.5            |
|                                  | Single, never married                                        | 16                 | 72.7           |
|                                  | Not Married but in relationship with biologically male born person | 4                  | 18.2           |
|                                  | Widowed                                                      | 1                  | 4.5            |
| Religion                         | Catholic                                                     | 9                  | 40.9           |
|                                  | Muslim                                                       | 5                  | 22.7           |
|                                  | No religion                                                  | 1                  | 4.5            |
|                                  | Pentecostal                                                  | 2                  | 9.1            |
|                                  | Protestant                                                   | 5                  | 22.7           |
| Other sources of income other than sex work | Casual Worker                                           | 3                  | 13.6           |
|                                  | Other Businesses                                             | 4                  | 18.2           |
|                                  | Salaried                                                     | 4                  | 18.2           |
|                                  | No other source of income                                    | 11                 | 50.0           |
| Who do you currently live with?  | Live with fellow trans-woman                                 | 12                 | 54.5           |
|                                  | Live with family members                                     | 6                  | 27.3           |
|                                  | Live alone (no one to stay with)                             | 4                  | 18.2           |
| Type of sex work                 | Street based                                                 | 3                  | 13.6           |
|                                  | Entertainment place based                                    | 7                  | 31.8           |
|                                  | Residence/home-based                                         | 9                  | 41.0           |
| Variable                          | Category               | Frequency (N = 22) | Percentage (%) |
|----------------------------------|------------------------|---------------------|----------------|
|                                  | Online/phone           | 3                   | 13.6           |
| Duration in sex work             | Less than 5 years      | 12                  | 54.5           |
|                                  | More than 5 years      | 10                  | 45.5           |
| Ever tested for HIV              | Yes                    | 8                   | 36.4           |
|                                  | Declined to respond    | 14                  | 63.6           |
| Frequency of testing for HIV (N = 8) | Three or more times per year | 7                   | 87.5           |
|                                  | Twice                  | 1                   | 12.5           |

Emerging themes from our data were classified as barriers to access and utilisation of HIV/STI prevention and care services, and coping strategies. The “barriers theme” encompassed the following organising themes; individual level barriers, community level barriers and health system barriers. The “coping strategy theme” encompassed the following organising themes; coping with lack of hormones, drugs and medical supplies and coping with stigma and discrimination. The findings are presented following these themes. (Table 2).
### Table 2
Barriers to access and utilisation of HIV/STI prevention services and coping strategies among trans-women sex workers in the greater Kampala metropolitan region, Uganda

| Themes           | Organising themes                              | Basic themes                                                                 |
|------------------|------------------------------------------------|------------------------------------------------------------------------------|
| **Barriers**     | Individual barriers                            | Internalised stigma                                                          |
|                  |                                                 | Low socio-economic status                                                    |
|                  | Community barriers                              | Transphobic community                                                        |
|                  | Health system barriers                          | Discrimination by some healthcare providers                                  |
|                  |                                                 | Stockout of hormones, drugs, lubricants and other medical supplies           |
|                  |                                                 | Inadequate availability of well-equipped treatment centres                  |
|                  |                                                 | High cost of drugs                                                           |
| **Coping strategy** | Coping with inadequate availability of hormones, drugs and medical supplies | Use of substitutes such as lotions, avocado, egg white or yoghurt to cope with a lack of lubricants |
|                  |                                                 | Resorting to use of herbs to cope with inadequate access to STI drugs        |
|                  | Coping with stigma and discrimination           | Use psychoactive substances to cope with stigma and discrimination           |
|                  |                                                 | Changing the dress code to mimic their gender identity                      |

Barriers to access and utilisation of HIV/STI prevention and care services

**Individual barriers**

**Internalised stigma**

Internalised stigma among trans-women sex workers was mentioned as a key barrier to access and utilisation of HIV/STI prevention services. According to the study participants, some trans-women felt once they went out to seek health services, they would not be welcomed by healthcare providers, while others felt that the public would accuse and pinpoint at them as those that are pretending to be what they are not. Internalised stigma among trans-women sex workers was portrayed in the following forms.

**Perception of being viewed as abnormal**
This study revealed that some trans-women sex workers suffer from trauma, mainly resulting from the perception of being viewed by the rest of the community as being abnormal. This feeling hindered trans-women from associating with other members of the community, consequently preventing them from accessing information on SRH services.

“When the community around gets to know that you are a transgender, you feel shy to move out of the house; you cannot be bold enough. Whenever you are sick, there is no one you can talk to because of trauma. Now like for my situation, I understand that there are other people who may think that am abnormal and they do not like it. So, I think that is another factor that hinders me from going to those health centres” (IDI participant).

**Low self-esteem**

Trans-women sex workers found it difficult to identify with their gender identity, sex work occupation and health condition while at healthcare facilities, thereby making diagnosis of SRH conditions difficult. It was also evident that some trans-women sex workers were afraid of mentioning that they had sexual feelings for men and associating themselves with sex work.

“It is difficult to express ourselves while at healthcare facilities. I cannot easily say that I am a transwoman or even a sex-worker, and that I am suffering from this condition (STI) or that, yet they do not understand who we are. Again, having a low self-esteem because the trans-women are not well recognized as a key population.” (IDI participant).

“Explaining to somebody that you are a transwoman is not easy. Telling a healthcare provider that “I am a transwoman, I behave like a woman although I am a man, my sexual feelings are for men, I am only attracted to men, so, I have sex with men and I am actually a sex-worker.” If you say it today, you will also need to explain to another healthcare provider next month. It is not easy!” (IDI participant).

**Feeling embarrassed to declare STIs**

Trans-women sex workers reported to have feared healthcare providers, felt embarrassed or did not have the confidence to report the STIs they suffered from, while at the healthcare facility, thereby affecting access to diagnosis and quality healthcare services.

“Most Trans-women lack the confidence to express themselves, and fear healthcare providers. If I know that I have STIs like anal warts, I feel embarrassed to tell the healthcare provider what I am suffering from. Therefore, as the trans, we need that confidence to be able to express ourselves and what we are suffering from to the healthcare providers in order to get the treatment we need.” (IDI participant).

Internalised stigma among trans-women sex workers was also highlighted by one of the key informants who mentioned that:

“Trans-women sex workers also stigmatize themselves. They often think that they will be discriminated against while at healthcare facilities. They also at times believe that they will be referred to as
homosexuals yet they are not” (Key informant).

Low socioeconomic status

It was evident that many trans-women sex workers have a low socioeconomic status and rely solely on sex work as their source of livelihood. A limited source of income implied that many trans-women sex workers failed to access SRH services at healthcare facilities due to lack of money to pay for transport and to buy medicines.

“The first issue is the distance from the healthcare facility. I for example, stay in Buziga [suburb] and the healthcare facility is in Namuwongo [another suburb]. You may think that it is a short distance, but once you’re “broke” [lack of money] you can actually fail to access it. You may also get an STI and fail to get treatment due to lack of money” (FGD).

“Poverty is one of the challenges that hinder trans-women sex workers from accessing HIV/STI services. Some trans-women sex workers claim that they do not have transport to come and access SRH services. So, they would rather sit back and not access the services” (Key informant).

Community level barriers

Transphobic community

Some trans-women sex workers were not able to access healthcare facilities due to fear of community perpetrated violence and gossip. Trans-women sex workers were discriminated against by the community because they defied societal expectations such as dress code and behaviour. As a result, many transwomen sex workers tend to socially exclude themselves and only move out of their homes to visit bars at night.

“Some trans-women sex workers fear that they may be attacked by the community because of the way they dress, and of course the society expectation. If you are a man, you are supposed to dress and walk like a man, yet, you know the trans-women dress as females” (Key informant).

“We fear community gossip and sometimes physical assault. Actually, due to fear and community gossip, most trans-women sex travel at night to visit bars. It is rare to find us visiting friends during the day because even gay men do not welcome us. My husband can’t allow any unknown person to enter our house, they are trans-phobic” (IDI).

Social exclusion and lack of recognition by other key population groups

Trans-women were branded by healthcare providers as “proud” because they did not want to associate, and had a poor relationship with other members of key populations, particularly the lesbians, gays and female sex workers. The poor relationship with other members of the Lesbians, Gay, Bi-sexual, Transgender and Intersex (LGBTI) community mainly stemmed from competition for sex clients and wanting preferential treatment while at healthcare facilities. Wanting special treatment was irrespective
of whether it was a public healthcare facility or an NGO-managed healthcare facility. Failure to get the preferential treatment at the different healthcare facilities stopped some of them from seeking HIV and other STI prevention services.

“They (trans-women sex workers) do not want to associate with the rest of the LGBTI community. They always want special treatment yet the LGBTI community here does not recognize them”. (Key informant).

“Trans-women sex workers always want to be treated in a very special way when they come to the healthcare facility. They always want to be served faster than other key populations. They are proud, very proud, and always want to be handled like princesses. They think they are better than the lesbians, and often despise other genders. That is why, in most cases, they are not always welcomed by other members of the LGBTI community. We always find that challenge. If they find a queue of other patients, for instance patients who may have come in the morning, they always want to bypass and enter the clinical room and tell you “handle me and I go”. When you tell them to wait in the queue they reply; “Musawo (healthcare provider), I have told you I want to go, I have to go and sell sex” so they see the other genders as competitors for sex clients so they always want to be served first”. (Key informant).

Health system barriers

Discrimination while at healthcare facilities

Besides internalised stigma, discrimination by the communities where they live, members of other key population groups such as female sex workers and men who have sex with men, the trans-women sex workers reported being harshly judged by some healthcare providers. Transgender persons also felt that they were not satisfactorily recognized under the key population umbrella by other key population groups and healthcare providers. This was due to this discrimination and lack of recognition that many trans-women sex workers shunned visiting healthcare facilities for SRH services. The forms of discrimination are elaborated in the following subthemes.

Discrimination by some healthcare providers

It was evident that some trans-women sex workers were discriminated by healthcare providers on the basis of their gender identity. Some respondents pointed out that they were made to wait for longer hours as healthcare providers called upon their colleagues to come and see an ‘abomination’ (a trans-woman) at the healthcare facility. It was also mentioned that some healthcare providers shunned providing SRH services to some trans-women sex workers, a problem that the respondents attributed to their dress code and physical appearance, which was not considered by some healthcare providers as being normal. In response to the main challenges that trans-women sex workers faced while at healthcare facilities, some respondents were quoted;

“Some healthcare providers make us appear like tourist attractions. When you get to a healthcare facility, she (healthcare provider) first calls her colleagues saying; “you come and see this abomination (while referring to a trans-woman)” . They make you sit and wait for drugs so that her colleagues can come and
look at your appearance. Sometimes you feel out of place (embarrassed) and just decide to leave the healthcare facility without getting the SRH service you want”. (FGD).

“Some healthcare providers do not want to treat us because we are trans. I may do my makeup and carry a hand bag as I go to the facility. But once you reach the healthcare facility, you may hear her (healthcare provider) call a colleague; “you come and work on this one, am very busy”. Some of them just don’t want to work on us”. (FGD).

Discrimination by other patients

Fellow patients at public healthcare facilities referred trans-women to as homosexuals and evil, thereby limiting their motivation to access SRH services at these healthcare facilities.

“It is worse with fellow patients. Once you meet them, it is like you have met fire. They see you as Satan! They judge us as very evil”. (FGD).

“I was dressed up in my clothes but not sexy. So, when I reached the healthcare facility, other patients started pointing at me while telling their friends, “come and see the homosexuals”, a man who takes himself to be a woman” (FGD).

Stockout of hormones, lubricants, drugs and other medical supplies

The utilisation of a wide range of HIV and other STI prevention services was hindered by stock out of drugs and other medical supplies such as lubricants and hormones (microgynon pills). An inadequate supply of hormones and lubricants dampened the desire of some trans-women sex workers to undergo transitioning. Stockout of STI drugs and other medical supplies at healthcare facilities was attributed to the limited supply of STI drugs from the central medical stores. Additionally, some healthcare facilities failed to conduct STI tests due to limited funding of SRH services.

“There are times you go to a healthcare facility and you don’t find medicine, yet, it is the only place you’re comfortable with. There is a healthcare facility where I get my medication, they know me very well. They usually welcome me, hug me and I feel at home while with healthcare providers. However, there are times I go to the healthcare facility and they tell me that the drugs are out of stock, and this can take like three to four months”. (IDI).

“We have challenges of drug stock outs. Healthcare facilities may not be able to offer some of the tests if there are no kits. Right now, healthcare facility XXX does not have enough funding and is not able to do STI tests”. (Key informant).

Managers of healthcare facilities and ministry of health officials re-emphasized that stock out of STI drugs and other medical supplies was a challenge to most of the healthcare facilities in Uganda. On being asked the biggest challenges faced by healthcare facilities in the delivery of HIV and other STI
prevention services, one of the healthcare facility managers of an NGO-managed key population clinic responded;

“Drugs! Some trans-women want to transition but we have a challenge of hormones. Many people want to start using hormones but we do not always have them. So, if they have money, they will run to Nairobi” (Key informant).

Healthcare managers acknowledged that drug stockouts compromised the treatment of STIs among the transwomen and the general population at large. Whereas it was revealed that STI testing was done every three months, treatment remained a challenge. However, it was pointed out that strides had been made by some stakeholders to equip key population-friendly clinics with essential STI drugs.

“STI treatment has been hmm... a challenge, but it has been routinely offered whenever HIV testing is being done. We have been able to screen for STIs ...as we do HIV tests. Therefore, screening is being done, but the problem is treatment for those who are found with STIs. Most public healthcare facilities do not have enough STI drugs. However, efforts are being made by PEPFAR to stock key population healthcare facilities with STI drugs. Although we still hear that some facilities have stockouts for now, yes.” (Key informant).

Drug stock outs were further validated through a key informant interview with one of the Ministry of Health officials who pointed out that they had obtained similar evidence in a recent validation study for STI and Prevention of Mother to Child Transmission (PMTCT). Furthermore, it was found out that most of the STI drugs in supply were not liked by patients, and that, STIs regimens being supplied by the central medical stores to healthcare facilities were not those recommended by the new STI treatment guidelines. As a result, trans-women sex workers experienced a recurrence of STIs.

“One of the major problems is limited supply of drugs. We recently conducted a validation study for treatment of STI and PMTCT and also discovered that STI drugs are not liked by patients, and are expensive.” (Key informant).

“The National Medical Stores doesn't supply the drugs that were recommended by the 2010 STI treatment guidelines. Even when you are in meetings with the health workers, they tell you that “you are telling us to treat STIs using drugs that are not being supplied”. And, if you are not supplying them, they resort to treat STIs using drugs recommended in the old treatment guidelines, of which research was done and most of those treatments are not helpful to the patient.” (Key informant).

Inadequate availability of well-equipped treatment centres

Trans-women sex workers faced challenges in accessing trans-specific STI drugs from general clinics. This was attributed to the fact that most general clinics serve heterosexual populations which may not suffer from STI in peculiar parts of the body such as anal region. Such infections require proctoscopy for better diagnosis and management, yet, it is not readily available in the general clinics.
“There are times you go to a healthcare facility and the equipment are not available. The infections we suffer from are different from those of straight people, especially infections that are sexually transmitted. You cannot go to general clinics to seek such treatment because they do not have those specific machines. So, you have to go to key population clinics like XXX and YYY for such treatment. You cannot just go to other healthcare facilities because even talking to the healthcare provider will be a problem. You cannot easily open up and tell them, I have this infection on the anal area. They will not understand you.” (IDI).

High cost of STI drugs

Respondents pointed out that, besides unavailability, they found it expensive to buy STI drugs from healthcare facilities. Some argued that they only depended on sex work thus making it difficult for them to save money to drugs.

“The problem we always get is that when you get to the healthcare facility and ask for treatment, they tell you that some of the medicines are not in stock, which means you have to use some of the money the client paid you to go and buy the medicine. In most cases, the medicines are very expensive. So, you end up spending all the money in buying medicine and saving nothing”. (FGD).

“Sometimes our clinics do not have the medicines yet we may be in need of them. You may also find that you do not have money to buy from the pharmacy since these are very expensive. For instance, the cost of treatment for anal warts ranges from UGX 25,000 (equivalent to 7 USD) to UGX 40,000 (equivalent to 11 USD) which I don’t have since I mainly depend on sex work” (IDI).

Coping strategies

Use of substitutes such as lotions, avocado, egg white or yoghurt

Some trans-women sex workers used lotions while others made local lubricants by blending avocado, egg white, margarine, or yoghurt to cope with lack of lubricants. However, the use of lubricants made of yoghurt, margarine and jellies was associated with side effects such as a burning sensation in the anal area, abdominal pain and diarrhoea. When asked how the trans-women sex workers coped with a lack of lubricants, some of the IDI participants said;

“Improvising! It’s actually a funny story. We use eggs! You get an egg; remove the yolk and you remain with albumen. It’s what we use as lubricants. That’s option one. Option two; We use yoghurt; the PH of yoghurt is not really harsh and aggressive to the rectum. If not, yoghurt and avocado, you get the avocado, blend it to get a smooth cream because avocado has an oily part. And the last option would be ‘blue band (brand name for margarine)’ or margarine” (IDI).

“At times we go to meet clients without lubricants due to lack of money to purchase them. Therefore, we decide to use quick items like oils or jelly to lubricate “down” (anal area). These items have chemicals that can even burn the skin. As a result, the anus changes and turns red, and it feels like it is burnt. Some
of these oils reach inside the digestive system and changes the internal system, you start feeling stomach ache, and diarrhoea. You may also realize that the behind is full of wounds to the extent that you can’t do anything by yourself.” (IDI).

Psychoactive substances use

Trans-women sex workers resorted to the use of psychoactive substances such as alcohol in order to cope with discrimination, reduce stigma and depression, and to increase their esteem. Some trans-women sex workers mentioned that the use of psychoactive substances would boost their confidence thereby making it easy to approach healthcare providers for SRH services. When asked how they coped with stigma, one of the IDI participants said;

“As transgender persons, we sometimes use drugs to gain confidence, fight off depression or to relieve ourselves of stigma” (FGD).

This was also reaffirmed by one of the healthcare providers who said;

“Drinking alcohol and the use of drugs; anyway, when I ask them why they drink or use drugs, they say the reason is to cope or survive.” (Key informant).

Use of herbs to treat STIs

Some trans-women sex workers resorted to the use of herbal medicines to treat STIs such as syphilis in order to cope with a high cost, limited access and stockout of STI drugs.

“We have these herbalists who claim to cure STIs, and some of us have used these herbal medicines to cure these infections. Therefore, they (herbalists) are alternatives. Some trans-women sex workers go to these “Sengas” (female herbalists) and take natural herbs or botanical plants that have healing properties for STIs like syphilis.” (IDI).

Changing the dress code to mimic gender identity

Trans-women sex workers in this study pointed out that they often dressed in a way that met the societal expectations. These put-on clothes like trousers for men as opposed to their desired dresses.

Discussion

This qualitative study explored barriers to access and utilisation of HIV/STI prevention and care services among trans-women sex workers. The themes that emerged from this study were classified as individual, community and healthcare facility barriers to access and utilisation of HIV/STI prevention and care services. In this section, we discuss the implications of existing barriers to the future of prevention and treatment of HIV and other section transmitted infections in low resource and transphobic settings. Furthermore, we endeavour to elaborate how trans-women sex workers cope with the existing barriers, in a setting that is unquestionably transphobic (21).
Background characteristics of our study participants for IDIs indicated that only 8 out of the 22 respondents had ever tested for HIV. This may not be surprising, given the limited innovations in increasing access to HIV prevention services to this unique key population subgroup. Trans-women sex workers are known to be a socially excluded population (11), which requires innovative approaches in increasing access to SRH services such as HIV testing and treatment of STIs. This would also require breaking the structural barriers at individual, community and healthcare facility level, thus creating an enabling environment for access and utilisation of existing services.

At individual level, it was evident that a low socio-economic status and internalised stigma greatly impacted on the health seeking behaviours of trans-women sex workers, and consequently access and utilisation of available HIV/STI prevention and care services. Internalised stigma, expressed through a low self-esteem, perception of being viewed as abnormal, feeling embarrassed to identify with the sex work, and feeling embarrassed to declare STIs not only compromises prevention efforts but also the quality of care obtained at the healthcare facilities. Trans-women sex workers in our study feared to declare STIs, especially to private healthcare providers and those working in public healthcare facilities without specialised key population clinics. This is so because trans-women sex workers suffer infections in unique parts of the body such anal warts, which would arouse curiosity from healthcare providers to find out the underlying causes. This could in turn force transgender persons to declare their gender identity and occupation as sex workers, which they may not want due to fear of discrimination, stigmatisation and legal consequences. Our findings reaffirm those by Ganju and Saggurti (22) and Rael, Martinez (23) which indicated that internalised stigma, including a low self-esteem affected access and utilisation of HIV prevention and care services among transgender persons. In addition, Fisher, Fried (24) and Chambers, Rueda (25) pointed out that transgender persons may not discuss their sexual healthcare needs with healthcare providers because they anticipate being stigmatised, and a breach of privacy and confidentiality by healthcare providers. Based on this school of thought, it is not surprising that less than half of our study participants had ever tested for HIV. It is also worth noting that some trans-women sex workers resorted to the use of psychoactive substances such as alcohol and thus increasing their risk to HIV and other STIs.

At individual level, a low socio-economic status, evidenced by half of the study participants not having an alternative source of income was deterrent to access and utilisation of HIV/STI prevention and care services at individual level. The low socio-economic status of trans-women sex workers could be due to the fact that they are denied education and employment opportunities (26). This can limit their ability to reach healthcare facilities. It may not be surprising that trans-women sex workers in close proximity to public healthcare facilities may not bother to attend them due to the fear that they will be requested to buy drugs for STIs, after all most healthcare facilities acknowledged persistent drug stockouts. This coupled with a high cost of STI drugs, forced many trans-women sex workers to resort to the use of traditional medicines such as herbs for the treatment of STIs such as syphilis. The use of herbal treatments for treatment of STIs among transgender persons in Uganda has also been reported by (27).
At community level, transphobia including violence greatly compromises decisions to seek appropriate medical help, reaching an appropriate healthcare facility and receiving adequate care. The fear of violence, expressed in forms of physical assaults and gossip not only affects the social life but also health seeking behaviours of transgender persons. Issues of violence toward transgender persons in Uganda are widely documented (28–32). Due to fear of violence, trans-women sex workers in our study coped by changing the dress code to the one that meets societal expectations in order to access HIV/STI prevention and care services, despite not being in conformity with their gender identity. The use of dress code to mask the gender identity of transgender persons has been reported in Malaysia and the United States (33, 34). Our study also reveals that trans-women sex workers did not access services due to the lack of recognition by other key population groups such as female sex workers and MSMs. This could be due to the fact that trans-women sex workers are seen as competitors for sexual partners and clients. Besides being competitors for sexual clients and partners, lack of recognition and discrimination by other key population groups might have arisen due transgender behavioural dynamics, gender identity and physical appearance (35).

At health system level, trans-women sex workers were discriminated by some healthcare providers and lacked recognition from members of other key population groups such as MSMs and female sex workers, thereby forcing them into social exclusion. It could be due to social exclusion that some healthcare providers failed to declare their sexually transmitted disease status to healthcare providers. The discrimination reported in our study could be due to the fact that trans-women sex workers do not behaviourally conform to the expected gender norms and roles, and thus prone to transphobia from healthcare providers. To put this into context, some trans-women sex workers visit healthcare facilities dressed in a way that is against the expectation of healthcare providers and other patients in these healthcare facilities. Therefore, it is important to break all forms of discrimination by healthcare providers and other patients in order to improve disclosure and confidence in the healthcare system, and consequently access to quality sexual and reproductive healthcare services. Our findings are not different from those of Ganju and Saggurti (22), Poteat, Reisner (26) and Bradford, Reisner (36) which indicated that trans-women sex workers face widespread discrimination in healthcare. Additionally, this study re-echoes the importance of non-discriminatory and inclusive SRH services for trans-women sex workers (37).

Stockout of lubricants, drugs and other medical supplies and inadequate access to trans-specific STI drugs was pronounced in healthcare facilities. In order to cope with limited access to lubricants, transwomen sex workers used substitutes such as lotions, margarine, avocado, egg white or yoghurt. The use of eggs, lotions, margarine as a lubricant among transgender persons is documented (32, 38). However, these may have health effects to the users. It was also reported that some trans-women sex workers resorted to the use of traditional medicines such as herbs for the treatment of STIs. The use of herbal medicines for treatment of STIs including HIV is not novel in Uganda and is widely documented (39–41). However, there is need to understand the efficacy and health effects of using herbs in the treatment of STIs. The inadequate access to trans-specific STI drugs and drug stockouts reported in our study have also been found in high-income countries, where it was attributed to failure of drug authorities
to provide an adequate supply of medical supplies to healthcare facilities working with transgender persons (42). In Uganda’s context, however, a limited supply of essential drugs, lubricants, and hormones could also be associated with limited funding for SRH interventions, and transphobia not only among healthcare managers but also policy makers. Due to inadequate access to STI drugs, healthcare managers and policy makers pointed out that healthcare providers had resorted to the use of regimens that were not being recommended by the current STI treatment guidelines. This could exacerbate antimicrobial resistance thereby making the treatment of these conditions more expensive.

Strengths and limitations

This is one of the few studies that has so far examined barriers to access and utilisation of HIV/STI prevention and care services among trans-women sex workers in a low resource setting. However, our participants for FGDs were not a homogenous group as per social demographic characteristics in terms of age group, education level, tribe, and religious background. Our intention was to capture the commonalities of lived experiences of trans-women sex workers who live in Greater Kampala and not differences in social demographics. In addition, findings from FGDs were triangulated with findings from IDIs and key informants, thus increasing credibility of findings. According to the Ugandan culture a topic on sex is considered very sensitive issue. Besides sex work is illegal in Uganda. This could have led some participants not to fully share some lived experiences, although there was trust build between our research assistants and study participants. For this study we only interviewed participants from the Greater Kampala metropolitan area, which is an urban setting. This limits the generalizability of the findings to trans-women sex workers in other districts in Uganda.

Conclusion

This study revealed that trans-women sex workers face challenges with access and utilisation of HIV/STI prevention and care services. At individual level, access to HIV/STI prevention and care services was hindered by self-enacted stigma and a low socio-economic status. At community level, trans-women sex workers failed to access services due to fear of community perpetrated violence, and faced social exclusion and lack of recognition by other key population groups. The most predominant healthcare facility barriers were discrimination by healthcare providers, stockout of hormones, lubricants, drugs and other medical supplies, high cost of drugs, and inadequate access to trans-specific STI drugs. There is need for the different stakeholders to break these barriers through training healthcare providers on trans-friendly services, sensitisation of the community on who the transgender persons are, and increased funding of SRH programs.

List Of Abbreviations

AIDS Acquired immunodeficiency syndrome

HIV Human immunodeficiency virus
Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Makerere University School of Public Health Research and Ethics Committee (MakSPH-HDREC). The study was also registered by the Uganda National Council of Science and Technology (UNCST) (Ref. No. SS 4868). Informed written consent was obtained from all the study participants. Prior to data collection, the research assistants explained to the study participants the objectives, benefits and risks that could have been associated with participating in the study. Study participants were paid UGX 10,000 (an equivalent of USD 3.0) as compensation for their time. All the data gathered from the study participants was treated as confidential, and anonymous identifiers were used. Data were only accessible to the study team.

Consent for publication:

Not applicable

Availability of data and materials:

Not applicable

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

TS, JBI, MN and JNB obtained the funding for this work, conceptualised the study, drafted and reviewed study tools, participated in data collection and analysis, and participated in drafting the manuscript. EB, RKM and RKW participated in the analysis and drafting of the manuscript. All authors reviewed and approved the final manuscript.
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References

1. Khan SI, Hussain MI, Parveen S, Bhuiyan MI, Gourab G, Sarker GF, et al. Living on the Extreme Margin: Social Exclusion of the Transgender Population (Hijra) in Bangladesh. Journal of Health Population Nutrition. 2009;27(4):441–51.

2. Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. The Lancet infectious diseases. 2013;13(3):214–22.

3. UNAIDS. The gap report. Joint United Nations Programme on HIV/AIDS; 2014.

4. Reisner SL, Perez-Brumer AG, McLean SA, Lama JR, Silva-Santisteban A, Huerta L, et al. Perceived Barriers and Facilitators to Integrating HIV Prevention and Treatment with Cross-Sex Hormone Therapy for Transgender Women in Lima, Peru. AIDS Behav. 2017;21(12):3299–311.

5. Coleman E, Bockting W, Botzer M, Cohen-Kettenis P, DeCuypere G, Feldman J, et al. Standards of care for the health of transsexual, transgender, and gender-nonconforming people, version 7. International journal of transgenderism. 2012;13(4):165–232.

6. Aristegui I, Vazquez M, Dorigo A, Lucas M. Percepciones y experiencias sobre estigma y discriminación en poblaciones trans, HSH y usuarios de drogas. Buenos Aires: Fundación Huésped; 2012.

7. Scheim AI, Travers R. Barriers and facilitators to HIV and sexually transmitted infections testing for gay, bisexual, and other transgender men who have sex with men. AIDS Care. 2017;29(8):990–5.

8. Hwang SJ, Nuttbrock L. Sex, Workers, Fem Queens, and Cross-Dressers: Differential Marginalizations and HIV Vulnerabilities Among Three Ethnocultural Male-to-Female Transgender Communities in New York City. Sexuality research & social policy: journal of NSRC : SR & SP. 2007;4(4):36–59.

9. Arayasirikul S, Pomart WA, Raymond HF, Wilson EC. Unevenness in Health at the Intersection of Gender and Sexuality: Sexual minority disparities in alcohol and drug use among transwomen in the San Francisco Bay Area. Journal of homosexuality. 2018;65(1):66–79.

10. Poteat T, Wirtz AL, Radix A, Borquez A, Silva-Santisteban A, Deutsch MB, et al. HIV risk and preventive interventions in transgender women sex workers. Lancet. 2015;385(9964):274–86.
11. The Crane survey. Bio-Behavioral Surveys among Groups at Increased Risk for HIV in Kampala-Uganda 2017.
12. Bianchi FT, Reisen CA, Zea MC, Vidal-Ortiz S, Gonzales FA, Betancourt F, et al. Sex Work among Men Who Have Sex with Men and Transgender Women in Bogotá. Arch Sex Behav. 2014;43(8):1637–50.
13. Wilson EC, Arayasirikul S, Johnson K. Access to HIV care and support services for African American transwomen living with HIV. International Journal of Transgenderism. 2013;14(4):182–95.
14. Poteat T, Wirtz AL, Radix A, Borquez A, Silva-Santisteban A, Deutsch MB, et al. HIV risk and preventive interventions in transgender women sex workers. The Lancet. 2015;385(9964):274–86.
15. Andersen R, Newman J. Andersen and Newman framework of health services utilization. J Health Soc Behav. 1995;36:1–10.
16. Upadhyay P. Sexual and reproductive health services: utilization pattern of adolescents in Nepal. 2018.
17. Kerridge BT, Mauro PM, Chou SP, Saha TD, Pickering RP, Fan AZ, et al. Predictors of treatment utilization and barriers to treatment utilization among individuals with lifetime cannabis use disorder in the United States. Drug Alcohol Depend. 2017;181:223–8.
18. Nowotny KM. Health care needs and service use among male prison inmates in the United States: A multi-level behavioral model of prison health service utilization. Health justice. 2017;5(1):9.
19. UBOS. The National Population and Housing Census. In: (UBOS), U. B. O. S, editor Main Report. Kampala, Uganda. Kampala, Uganda.: Uganda Bureau of Statistics 2016.
20. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Quality quantity. 2018;52(4):1893–907.
21. Thapa SJ. LGBT Uganda today: Continuing danger despite nullification of Anti-Homosexuality Act. Global Spotlight. 2015.
22. Ganju D, Saggurti N. Stigma, violence and HIV vulnerability among transgender persons in sex work in Maharashtra, India. Cult Health Sex. 2017;19(8):903–17.
23. Rael CT, Martinez M, Giguere R, Bockting W, MacCrate C, Mellman W, et al. Barriers and Facilitators to Oral PrEP Use Among Transgender Women in New York City. AIDS Behav. 2018;22(11):3627–36.
24. Fisher CB, Fried AL, Desmond M, Macapagal K, Mustanski B. Perceived Barriers to HIV Prevention Services for Transgender Youth. LGBT Health. 2018;5(6):350–8.
25. Chambers LA, Rueda S, Baker DN, Wilson MG, Deutsch R, Raeifar E, et al. Stigma, HIV and health: a qualitative synthesis. BMC Public Health. 2015;15(1):848.
26. Poteat T, Reisner SL, Radix A. HIV epidemics among transgender women. Current Opinion in HIV AIDS. 2014;9(2):168.
27. Minor Peters M. ‘They wrote “gay” on her file’: transgender Ugandans in HIV prevention and treatment. Culture Health Sexuality. 2016;18(1):84–98.
28. Smith A, Clark M, Bourne A, Kabuti R, Babu H, Weatherburn P, et al. ‘How come you are a refugee, yet in Uganda there is no war?’: Social, sexual and psychological wellbeing of East African MSM and transgender (MSM/TG) migrants in Nairobi. 2019.

29. McQuaid K. 'There is violence across, in all arenas': listening to stories of violence amongst sexual minority refugees in Uganda. The international journal of human rights. 2017:1–22.

30. Jjuuko A, Mutesi F. The multifaceted struggle against the Anti-Homosexuality Act in Uganda. Downloaded from the Humanities Digital Library. 2018:269.

31. Anna B-J, Oppegaard SMN, Berntsen Øl, Flatås MD, Rindal E, Sarpong SP, et al. Forms of Discrimination of LGBT People in Ghana, Uganda, Russia and Norway. A report by ISFiT Research Group 1/2017. 2017.

32. Naughton JLGBTQ, Ugandans Balance Hope And Fear. Four years after an anti-gay bill attracted global notoriety, queer Ugandans are cautiously coming out from the shadows. World Policy Journal. 2018;35(1):70–83.

33. Sa’dan A, Awang J, Nur Farhana A, editors. A Preliminary Study on Transgender Issues: A Case Study on Justice for Sister (JFS) as a New Social Movement in Malaysia. 3rd International Seminar on Islamic Thought PROCEEDINGS; 2018.

34. Valentine SE, Shipherd JC. A systematic review of social stress and mental health among transgender and gender non-conforming people in the United States. Clin Psychol Rev. 2018;66:24–38.

35. Rodriguez A, Agardh A, Asamoah BO. Self-Reported Discrimination in Health-Care Settings Based on Recognizability as Transgender: A Cross-Sectional Study Among Transgender U.S. Citizens. Arch Sex Behav. 2018;47(4):973–85.

36. Bradford J, Reisner SL, Honnold JA, Xavier J. Experiences of transgender-related discrimination and implications for health: results from the Virginia Transgender Health Initiative Study. American journal of public health. 2013;103(10):1820–9.

37. Seelman KL, Colón-Diaz MJP, LeCroix RH, Xavier-Brier M, Kattari L. Transgender Noninclusive Healthcare and Delaying Care Because of Fear: Connections to General Health and Mental Health Among Transgender Adults. Transgend Health. 2017;2(1):17–28.

38. Lee M, Sandfort T, Collier K, Lane T, Reddy V. Breakage is the norm: Use of condoms and lubrication in anal sex among black South African men who have sex with men. Cult Health Sex. 2017;19(4):501–14.

39. Anywar G, Kakudidi E, Byamukama R, Mukonzo J, Schubert A, Oryem-Origa H. Indigenous traditional knowledge of medicinal plants used by herbalists in treating opportunistic infections among people living with HIV/AIDS in Uganda. J Ethnopharmacol. 2020;246:112205.

40. Francis SC, Looker C, Vandepitte J, Bukenya J, Mayanja Y, Nakubulwa S, et al. Bacterial vaginosis among women at high risk for HIV in Uganda: high rate of recurrent diagnosis despite treatment. Sex Transm Infect. 2016;92(2):142–8.
41. Nakanwagi S, Matovu JK, Kintu BN, Kaharuza F, Wanyenze RK. Facilitators and barriers to linkage to hiv care among female sex workers receiving hiv testing services at a community-based organization in Periurban Uganda: A Qualitative Study. Journal of sexually transmitted diseases. 2016;2016.

42. Geffen S, Horn T, Smith KJ, Cahill S. Advocacy for Gender Affirming Care: Learning from the Injectable Estrogen Shortage. Transgend Health. 2018;3(1):42–4.