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Barriers to Free Antiretroviral Treatment Access for Female Sex Workers in Chennai, India

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Acronyms and Abbreviations

- AIDS** – Acquired immunodeficiency syndrome
- ARV** – Antiretrovirals
- ART** – Antiretroviral treatment or therapy
- CBO** – Community-based organization
- FGD** – Focus Group Discussion
- FSW** – Female Sex Workers
- HIV** – Human Immunodeficiency Virus
- ICTC** – Integrated Counseling and Testing Centres
- INP** – Indian Network for People living with HIV
- KII** – Key informant in-depth Interview
- MSJE** – Ministry of Social Justice and Empowerment
- NACO** – National AIDS Control Organization
- NGO** – Nongovernmental organization
- PLHIV** – People living with HIV
- TNSACS** – Tamil Nadu State AIDS Control Society
- VCTC** – Voluntary Counseling and Testing Centre

ABSTRACT

National AIDS Control Organization (NACO), India, has been providing free first-line antiretroviral treatment (ART) for eligible people living with HIV (PLHIV) since 2004. To assist in developing policies and programs to ensure equity in ART access, we explored the various factors that hinder free ART access for female sex workers (FSWs) living with HIV in Chennai, India. Three focus group discussions among FSWs (n=19 participants) and 2 key-informant interviews were conducted, audio-taped, transcribed and translated. Focus group and interview data were explored using framework analysis to identify categories and derive themes. Findings revealed barriers at the individual, healthcare system, and programmatic and social levels. Barriers need to be addressed by: creating effective stigma reduction measures at the society and healthcare system levels; strengthening linkages between HIV prevention and treatment programs; providing sufficient information to FSWs on ART, including ART eligibility, irrespective of their HIV status; addressing unmet basic needs; and having a national action plan to ensure equitable ART access to all marginalized groups.

I. INTRODUCTION

Availability of antiretroviral treatment (ART) has significantly improved the prognosis of people living with HIV (PLHIV) by controlling viral replication, restoring immune system function, extending life, and thus enhancing the quality of life of PLHIV.

In 2004, the government of India began providing free first-line ART in government ART centers. India's National AIDS Control Organisation (NACO) has explicitly stated that "Under NACP-III [third phase of the National AIDS Control Programme], first-line ART drugs will be provided to all those who need it." Furthermore, NACO maintains that public health facilities need to ensure that ART is provided to PLHIV referred from interventions targeted toward sex workers, men who have sex with men (MSM) and injecting drug users (IDUs) (NACO, 2006a – p.114).

NACO estimates that among the 2,376,140 adults living with HIV in India in 2006 about 25% required ART (603,125). In December 2007, twenty percent (118,052) of these adults were receiving free ART from government ART centers (NACO, 2008). Clearly, most persons who require ART are not yet receiving it, and a major challenge for government ART centers is to expand access to free ART.

Female sex workers (FSWs) have been recognized by NACO as one of three 'core high risk groups' that are worst affected by the HIV epidemic in India (NACO, 2006a). The estimated size of the FSW population in India is 0.8 to 1.24 million (NACO, 2006a, p-14). HIV prevalence among FSWs is estimated to vary from less than 1% in some districts of Kerala to more than 30% in some districts of Maharashtra and Karnataka (Claeson and Alexander, 2008).

There is no information available from NACO about the number of FSWs taking ART through its national program (NACO official, e-mail communication). However, positive people networks and community organizations working with FSWs report that FSWs living with HIV have limited access to free first-line ART from government ART centers. This has been documented in a series of reports from the International Treatment Preparedness Coalition (ITPC) that recommended creation and implementation of a policy and action plan on equity in ART access for marginalized groups living with HIV (Abraham et al., 2006a, 2006b, 2007a, 2007b; Chakrapani, 2005). One ITPC report quotes a doctor from a government ART centre in Chennai as having said: "Where are the sex workers [coming to our ART centre]? We only see clients of sex workers." (Chakrapani, 2005)

Chennai has an FSW population of about 19,000 (TNSACS, 2007), with an estimated HIV prevalence of 3.6% (NACO, 2006b, p-108). To address inequities in ART access for marginalized groups such as FSWs, it is crucial to identify their different needs and constraints when accessing ART (i.e., 'why' some groups are excluded) and to design interventions accordingly (Braveman & Gruskin, 2003; Kalanda et al., 2007).

This study aimed to identify and understand barriers to accessing free ART provided by government ART centers faced by FSW living with HIV. Identifying and understanding these barriers will inform development of suitable strategies to enhance access to ART of FSWs living with HIV.

II. METHODS

In this article, ART access refers to the free first-line ART regimens available in the government ART centers supported by NACO. The first-line regimens available at the time of this study were a combination of zidovudine, lamivudine, and nevirapine or a combination of stavudine, lamivudine, and nevirapine. For patients on treatment for tuberculosis, nevirapine is substituted with efavirenz. The three government ART centers that provide ART to adults in Chennai are located within the major government hospitals.

We conducted three focus group discussions (FGDs) (about 6 participants per focus group) and 2 key informant interviews among FSWs recruited through non-governmental organizations (NGOs) that provide services to FSWs in Chennai, India. Focus group participants were recruited using purposive sampling to reflect diversity in terms of area of residence, living situation (with family members or alone) and duration of contact with service agency. Recruitment was conducted by volunteers from NGOs by word-of-mouth only in order to avoid potential risks to participants through being identified as FSWs. Participants were also selected based on ability to articulate their own and their peers' perspectives in relation to accessing free ART from government ART centers. Sex work was reported as the main occupation by all participants.

One key informant was an FSW community leader and the other a trained peer counselor, a former sex worker with several years of experience in providing counseling to FSWs. Key informant interviews focused on exploring their perspectives and experiences in relation to free ART access for FSWs as well as to elicit their insights on how to remove barriers to ART access.

All focus groups were conducted in a private room at agencies that work with FSWs. Written informed consent was obtained from all participants, including consent for audio-taping of the interview. The study received approval from the ethics review committee constituted by the Indian Network for People Living with HIV (INP+).

Focus groups and key informant interviews were conducted using a semi-structured in-depth interview guide in Tamil with scripted probes. Questions were modified or added over the course of the study in an iterative process to explore and reflect on emerging findings, a technique called progressive focusing (Schutt, 2004). Focus group facilitators and interviewers were native Tamil language speakers who received extensive training in interviewing and research ethics. All interviews and communications with participants were conducted in Tamil.

The duration of focus groups ranged from 60 to 90 minutes; key informant interviews lasted approximately 60 minutes. An honorarium of 250 Indian rupees (about 7 US dollars) was given to focus group participants. Key informants did not receive an honorarium. Interviews were tape-recorded and transcribed verbatim in Tamil and translated into English for data analysis.

Data analysis

Focus group and interview data were explored using framework analysis (Ritchie & Spencer, 1994) to identify categories and derive themes. In accordance with framework analysis, we developed a hierarchical thematic framework and used the framework to classify and organise data according to key themes, concepts and emergent categories. Framework analysis is particularly appropriate for applied qualitative research when a study is oriented towards policy outcomes (Green, 2005; Pope et al., 2000). Based on Aday and Andersen's (1974) framework of access to health services and our previous research experience in studying barriers to HIV testing (Chakrapani et al., 2008a) and sexual health services

(Chakrapani et al., 2008b), we hypothesized that barriers to ART access might occur at several levels: individual, health system, programmatic, policy and social. Accordingly, we developed a framework structure to allow detailed analysis of emerging themes and concepts raised during the focus groups and interviews (Pope & Mays, 2000). Our aim was to identify themes that could elucidate factors that influence sex workers' access to free ART from government health care centers.

Using the framework approach, we devised an *a priori* coding scheme that could identify themes at different levels (i.e., individual, health care system, etc.). Three data analysts coded one focus group and one interview together and then coded additional transcripts separately once it was clear that the coding system was being used consistently. Any uncertainties in coding were discussed with at least one other member of the research team to ensure consistency and revisions to the coding scheme were made as necessary. We used open coding and in vivo coding to derive new codes that emerged in addition to the pre-determined coding categories and a constant comparative method within and across cases (Charmaz, 2006; Strauss & Corbin, 1998) to test provisional hypothesis. Theoretical coding was undertaken to identify higher-level codes and relationships among categories (Charmaz, 2006; Glaser, 1978). In presenting the themes and subthemes, we incorporated both commonalities and differences in viewpoints and experiences that emerged along with illustrative quotations.

We used peer debriefing and member checking to enhance validity of the findings. Peer debriefing (Lincoln and Guba, 1985) was conducted by discussing interpretations of the data with community experts on FSWs. Member checking (respondent validation) was implemented by re-engaging key informants to discuss and clarify their interview data and reflect on emerging findings (Lincoln and Guba, 1985). Researcher triangulation between investigators in India, and the USA who independently reviewed and analysed the data, and data source triangulation between participants and key informant service providers increase the trustworthiness of the findings (Lincoln & Guba, 1985).

III. FINDINGS

FGD participants (n=19) ranged in age from 21 to 48 years (mean = 33 years). Thirty-seven percent (n=7) had completed high school; 42 percent (n=8) were currently married and living with their spouse; and 21 percent (n=4) were on ART. All reported sex work as their main occupation.

For convenience, the findings are grouped under three major sub-headings: individual level barriers, healthcare system barriers, and family and social barriers. However, we found substantial interlinkages among the barriers at all levels.

A. INDIVIDUAL LEVEL BARRIERS

Fear of adverse consequences of disclosure of HIV status

FGD participants were a mix of 'home-based' or 'secret' sex workers, whose family members do not know that they engage in sex work, and 'street-based' sex workers, who mainly obtain clients from the streets or in public places (NACO, 2007). 'Secret' sex workers mainly contact their clients on the phone, through word of mouth, or through middlemen, but sometimes even on the streets (though done discreetly). Given the stigma associated with sex work, these FSWs do not disclose that they engage in sex work, the purpose of which is to earn money to support their family. Thus, FGD participants and key informants stated that home-based FSWs found to be HIV-positive face several problems: domestic violence from the husband; eviction from the home by the husband and in-laws; and rejection by family members including their own children. To avoid these negative consequences, HIV-positive, home-based FSWs often do not disclose their HIV status because such disclosure might also suggest that they became infected through sex work. In the absence of symptoms of HIV illness, the fear of being exposed as HIV-positive and an FSW to family members prevents many FSWs from seeking ART:

“We [peers] indirectly tell them [other FSWs] to take ART but they are afraid of what if their family comes to know [about their HIV-positive status] and hesitate to take it. If the family comes to know about that then for sure there will be problems. They are not taking [ART] for these reasons.” (FSW participant)

Participants pointed out that often people who are known to be HIV-positive are looked down upon by society as “immoral” or “bad in character”. Thus, some FSWs living with HIV do not seek health care because they fear being isolated:

“[Some FSW] think that, 'If other people come to know that we are HIV-positive then they might isolate us from the society' and they are reluctant to visit the hospital.” (FSW participant)

Some participants expressed fear of isolation from their support circle of FSW friends. In addition to losing social support, some feared that referral of clients from other FSWs would stop if their HIV-positive status became known, with the consequent loss of income:

“If [they] come to know that I am like this [HIV-positive], my friends [peers] might think about me differently. Then, they will not even refer their clients to me. They don't invite me if there is some function.” (FSW participant)

In addition, some participants stated that due to competition for clients, some FSWs disclose or threaten to disclose to clients the HIV status of their HIV-positive FSW colleagues.

Thus, fear of adverse consequences is a main barrier that prevents FSWs from accessing proper health care, including free ART. This individual-level barrier (fear) is bound up with the family and social level barriers of stigma and discrimination related to HIV and sex work.

Lack of adequate knowledge about ART

Key informants and FGD participants reported that most FSWs had inadequate knowledge about ART, including ART initiation and side-effects. A key informant expressed the importance of positive people networks for information about ART:

“There are some networks for [HIV-] positive people in some places. People who don’t know about [networks] or who do not go there also don’t know that, ‘we shall have a healthy life with this [ART].’”

PLHIV with CD4 counts less than 200 cells/microlitre are eligible for free ART from government centers (NACO, 2007). But some FSWs are not even aware of their CD4 count. As expressed by a key informant: “If we ask what your CD4 count is, some [FSWs] will just say ‘I don’t know.’” Consequently, some FSWs who might have initiated ART had their CD4 count been known seek medical care only when they have a severe opportunistic infection. As expressed by a key informant: “Since they are fine, they don’t think about this [ART]. Only when they become ill, they think about it.”

FSWs who have understood the benefits of taking ART do initiate ART. One participant said, “The fact that we can live well and healthy for many years if we take ART [facilitates] taking it.” Also, some HIV-positive FSWs who take ART motivate others to take ART. A key informant FSW narrated how referrals among FSW help in ART initiation: “While seeing [peer] in the field [sex work site], I refer her [to ART center]. She refers others. We both referred four other people.”

Fatalism and fear of side-effects

FGD participants related that some FSWs are reluctant to initiate ART, in spite of the recommendation of peers and health care providers, because they believe ART only briefly extends life and they face premature death whether or not they take ART. These FSWs do not want to burden themselves by taking ART that requires medication adherence and monthly visits to an ART center and may result in unpleasant side-effects. One participant said:

“There are a lot of people affected by HIV/AIDS but when we tell the people, some accept while some say like, ‘Whatever it is we are going to die anyway; till then let us enjoy and die’ and refuse to accept.”

A key informant told us, “She [FSW] says, ‘I am going to live for only a few days. Why do I need to take medicines for that? It can make my life miserable.’” Thus, both a fatalistic attitude and misinformation about side-effects of ART led this FSW to not take ART.

A key informant said about side effects: “They [FSWs] are afraid that some side-effects may come. That is a problem.”

Participants mentioned that patients who register for ART are strictly advised not to consume alcohol to ensure adherence and to reduce side-effects. Some FSWs are reluctant to initiate ART because they do not want to stop consuming alcohol. According to a key informant, “While taking drinks [alcohol] and medicine [ART] together, it brings side-effects. Yes, just for that [reason], they don’t start [taking ART].”

FGD participants and key informants related that some FSWs, although skeptical about the benefits of ART, are motivated to take ART by their commitment to family members. One

FDG participant said, “I have a three-year-old baby. My husband is a drunkard. If not for me I have to live for my baby. That is why now I am on ART.” A key informant shared a similar view: “They [FSWs] are not going to achieve anything by taking ART. It is only for their family they take [ART]. Since, they have to take care of their children they take [ART].”

Unmet basic needs

Most FGD participants reported that they engage in sex work in an attempt to meet their day-to-day needs. Often, they lack basic needs for survival such as proper food for themselves and their family. This lack of adequate food, in the face of counselors’ emphasis on the importance of proper nutrition for PLHIV on ART, makes some FSWs reluctant to initiate ART. As expressed by a key informant:

“If they have to take ART, then they need to have adequate *strength* [English term]... Since some people don’t have [regular access to] food, they are not taking that medicine [ART]. Some people say, ‘If I have to take ART, then I have to take proper food. It is very difficult for us to get proper food. So, I am not taking that.’”

Loss of wages while visiting an ART center discourages such visits. According to one FGD participant:

“[Some FSWs say] ‘If I have good income I can eat something depending on my hunger or else drink one tumbler of milk’. Without income what can we do? We feel like, ‘Should we go for treatment?’...We will not earn anything when we go to hospitals.”

Practical constraints in taking ART during sex work hours

ART, if initiated, needs to be taken regularly, even during sex work hours. Thus, some FSW do not initiate ART because taking ART during sex work hours would expose that they are ‘diseased,’ with possible loss of clients and income. As a FDG participant mentioned:

“Are we standing there [sex work site] to earn money or to come back empty-handed? As such there is a demand for getting ‘customers’ [English term]. And if we are known to be positive – that’s all – we have to close our shops [stop doing sex work]. We don’t want to be seen having those pills [ART].”

Another participant said:

“Most sex workers on ART have this fear like, ‘What will happen? For four days in a week we are going for business [sex work]. These four days we cannot take this [ART]. So for those four days, tablets will be wasted and [can create] a lot of problems’.” Hearing about problems of taking ART in the ‘field’ motivates other HIV-positive FSWs not to initiate ART. Others are concerned they would forget to take ART during sex work. A key informant said, “We do not take ART while going to sex work. We will forget to take it. Due to this, most of us do not take [initiate] it.”

Belief in alternative medicines and expectations of cure

Fear of eventual failure of first-line ART combined with a belief in potential cure by alternative medicines prevents some FSWs from initiating free ART. According to a FSW participant:

“Someone told me that first-line ART will work only for two years. After that there will be some side-effects [referring to drug resistance in this context]. Country medicines don’t have such side-effects. We heard that diseases not cured by ‘English’ [allopathic] medicine can be cured by country medicines.”

These kinds of messages prompt some FSWs to reject allopathic medicine and to not initiate ART. Participants reported that some FSWs embrace the belief that AIDS can be cured by alternative medicine and visit alternative medicine practitioners. As a key informant agreed: “Some people say that, this [HIV] will get cured by country medicines. ...Two or three members [FSWs] went to some hospital in [a place in Chennai] thinking that they can get cured.”

B. HEALTHCARE SYSTEM AND PROGRAMMATIC BARRIERS

Negative experiences of FSWs with healthcare providers

Having had prior negative experiences and having heard about negative experiences of others in the government healthcare system discourage some FSWs from attending ART centers.

Some FSWs pointed out the unfriendly attitude of staff in the government hospitals, who view FSWs as “promiscuous” and use insensitive language. As narrated by a FGD participant:

“Honestly speaking. I don’t have *strength* [English term as mentioned. In this context refers to lack of motivation] to go the hospitals or somewhere else. Fortunately, by god’s grace there are NGOs to take care us. In case of absence of [these NGOs], ‘I will live simply as long as I can and die’ because I don’t like going there [government hospital]. Once, they [staff in government hospital] shouted at a person: ‘Since you don’t live with one person and go to many [persons], you get not only this [HIV infection] but also all [many diseases] together.’ If I am going to be in a condition to take tablets [ART], I will not go there because they denigrate us [FSWs].”

According to a key informant:

“[Some FSWs] are already afraid that they might be seen by others [in the society] when going to an ART center for the first time. [In this situation,] they [health care providers] say, ‘Do you have HIV? Don’t sit here, Go and sit there. Don’t touch this, don’t touch that’... they [FSW] become scared. Mainly due to this, [some people] say, ‘I don’t want any medicine’ and run away.”

These negative attitudes extend to doctors, which may lead to substandard or biased treatment. According to one FGD participant, “[Some doctors say], ‘you have gone [had sex with] with many [men] and got the disease [HIV]. Even doing this much [providing treatment] is a big thing.’ And it seems to me, given a choice, they would not like to treat us. It is as though ‘Why should we [doctors] give treatment to people like you?’...They look at us with disrespect.”

Lack of comprehensive and adequate counseling services at government centers

The key informants reported that FSW rights to privacy during counseling were not protected in some government hospitals. According to one key informant, “They [counselors] have learnt how to give counseling but they don’t practice it properly. [Counseling] has to be given one-to-one in a separate room. There is nothing like that.” The key informants believed the lack of privacy was a systemic problem, stemming from inadequate infrastructure and high patient volume.

Key informants suggested that high patient load was also responsible for counselors providing cursory information within the short time available for counseling each patient. For example, a FGD participant complained about the lack of detailed counseling about CD4

counts: “[The] counselor would say only, ‘your CD4 [count] is low. Get the health *tonic*.’ They [counselors] are very slack and do not explain things in detail.”

Post-test counseling for persons testing HIV-positive in government centers should include information about ART (NACO, 2007). However, according to a key informant, FSWs are often counseled about ART in a way that prevents them from accepting the message.

“Proper counseling is not given to them after knowing that [HIV status]. What they are doing in counseling is - they are simply threatening them. They are threatening like: ‘you have to take care of your health, you have to take tablets correctly, only then it is good for your health’. They [FSWs] are afraid when they talk like this [in a strict manner]. The person who is a counselor should speak politely.”

Some FSWs did report that they received adequate information about ART and its benefits during post-test HIV counseling, which motivated them to go to an ART center to check their eligibility for ART. According to one FGD participant:

“After confirming our [HIV-] positive status they [counselors] give us counseling during which they talk about condom use, sexually transmitted diseases and safer sex. Depending on the duration of our infection they [counselor] also talk about ART and how to use it. Only because of this did we start to take this medicine.”

Perceived biased treatment of FSWs who are not referred by NGOs

FGD participants related that people who come to ART centers accompanied by an NGO (or PLHIV network) staff-person or with a referral note from an NGO are registered immediately if medical eligibility is satisfied. Key informants clarified that staff in ART centers tend to give priority to people referred by NGOs because NGOs have established good rapport with the government hospitals and because those referred by NGOs are usually followed-up by NGO staff to ensure adherence. According to a key informant:

“If we visit through NGOs, with staff or a peer educator and letter pad [referral note from NGOs], for sure they will get ART. It is very difficult to get ART without referral. They are saying, ‘no medicine for you, go and come next week’.”

Similar concern was shared by a FGD participant: “If we go to the hospital, some will treat us well but some do not. It is good to get treated while a person from a [positive people] network sits nearby. Why it is? ... If I don’t know anyone there, they will not treat me well.”

Practical difficulties in getting admitted for observation during ART initiation

Some ART centers in Chennai recommend a two-week hospital admission for PLHIV who are initiating ART to monitor for serious side-effects (such as a life-threatening allergic reaction to nevirapine), which are more common during the first few weeks. Some FGD participants reported this admission to be a barrier to ART because they would not be able to explain a two-week admission to their family members, who do not know their HIV-positive status, and because they would not be able to engage in sex work or other work to earn money to feed their family during their hospital stay. Thus, some FSWs postpone initiating ART until they become symptomatic even though their current CD4 count may be less than 200 cells/microlitre, which makes them eligible for ART initiation. One FGD participant said:

“If I have to be started on ART, I need to get admitted in the hospital for 15 days. How can I do this when I have four children? My in-laws will question me about my health. I cannot say to them that my CD4 is low and leave my four kids and come [to the hospital]. They don’t know that I am involved in this [sex] work and I am [HIV-] positive.”

In spite of these practical difficulties, some FSWs prioritize their health over sex work and thus initiate ART. As expressed by a participant:

"[Some sex workers might say] 'we must take care of our health first, that is more important for us. Sex work is only next. No problem if we have no earnings for a week. Let us take care of our health.' Sometimes we think like this and go to the hospital [ART center]."

Another participant said, "If we take care of ourselves we can take care of our family. Hence, I regularly go for my health check-up to [name of the ART centre]. They asked me to come back later as my CD4 is okay now."

Inadequate knowledge about ART among outreach staff

HIV interventions among FSWs mainly focus on HIV prevention education and condom promotion and distribution (NACO, 2008). FGD participants complained that outreach workers – most of whom are FSWs themselves – do not provide detailed information about ART to their peers. A key informant agreed: "Even though they [outreach workers and peer educators] have knowledge up to the level of saying 'Take ART when your CD4 becomes low,' they still require some more training."

C. FAMILY AND SOCIAL BARRIERS

Lack of family support

As seen earlier, most FSWs do not reveal their profession and HIV-positive status to their family members. Hence, fear of rejection by their family members deters them from ART initiation, which might reveal their HIV-positive status. As expressed by a participant: "Since my [family] is not aware of my activities [sex work], taking this medicine will be a big problem for me."

Furthermore, some FSWs feel they need family support for ART adherence. According to one participant, "I need to take this medicine [ART] on time but no one [in family] will take care of me. It will be difficult to take this tablet [ART] without their support." This puts FSW in a bind: they want family support for adherence but fear that disclosure of their HIV status would undermine family support.

Most FSW participants were married women who, like other married women in India, take care of all the household chores, their husband and their children, but do not receive family support to take care of themselves (Joseph & Bhatti, 2004). As a participant said, "I have to do all the housework to send my children [to school] and husband [to work]. By the time, it would become around 10 to 10.30 [am] and then once back in the evening I need to work until late night. Where will I find time to take the medicine?"

Stigma and discrimination associated with HIV/AIDS and sex work

Participants noted that PLHIV may be ostracized because they are viewed to be immoral and "bad in character," and that FSWs are denied alternative work. One FGD participant related how her friend was disowned by her family and isolated by society after her HIV-positive status and profession were revealed to them:

"After she [a FSW] had been to the ART center, her father-in-law went and inquired. Confidentiality should have been maintained, but the lady counselor over there told everything to him. This family is a high-class family. Now, they have isolated her - without house and job. The entire area has isolated her. She is not even able to get a job of carrying sand [daily-wage labor]. Wherever she goes, the father-in-law comes

and tells about her [positive status]. When this is the situation taking ART is a big problem.”

In the absence of family and broad societal support, support from NGOs helps some FSWs initiate ART. As a participant said:

“Only through NGOs did we come to know about this [ART]. Otherwise we do not speak or interact with others ... Only after coming to NGOs, they ask us like, ‘take this test, take that test, go here, go there.’ We also go forward and stand in the queue [in government hospitals]. Is it not? ... they counsel us like, ‘don’t be afraid, be bold’.”

IV. DISCUSSION & RECOMMENDATIONS

FSWs in Chennai face interrelated individual, healthcare system, and family and social barriers to accessing ART. Most FGD participants reported secretly entering into sex work to earn money to meet basic needs of themselves and their families. Their strong motivation to keep their sex worker and HIV status secret was intimately bound with HIV/AIDS stigma and practices of discrimination prevalent in their families and the larger society. Adverse consequences of disclosure could include rejection by family, domestic violence, eviction from home, social isolation, and loss of work. Participants were even reluctant to disclose their HIV status to their FSW colleagues for fear of losing client referrals or having their HIV status disclosed to clients by other FSWs. To the extent that FSWs feared that taking ART presented risk of disclosure, their fear of disclosure translated into fear of initiating ART. Consequently, FSWs tend to postpone initiating ART as long as possible, until they become symptomatic.

While most FSWs in Chennai might have adequate knowledge about some aspects of HIV (APAC, 2007; NACO, 2006c) the current study indicated that they have limited knowledge about ART and treatment-related issues. Lack of such knowledge was also found in a multi-state study conducted among various subgroups of PLHIV including FSWs (Chakrapani et al., 2007). Systemic steps that could be taken to improve FSW knowledge about ART include incorporating information about ART into targeted interventions among FSWs (Report of the Commission of AIDS in Asia, 2008; WHO, 2004), which currently focus on HIV prevention education, and condom promotion and distribution, but not ART; training outreach workers on treatment issues; improvement of infrastructure and staffing levels at government centers to allow adequate time and privacy for counseling; training of counselors to counter HIV/AIDS stigma and stigma associated with sex workers; and government mass media campaigns on ART availability. Another systemic step that could help increase FSW access to ART would be flexibility around the two-week hospital admission for PLHIV who are initiating ART.

Lack of adequate knowledge could also explain excessive fear of ART side effects, which, along with skepticism about allopathic medicine, might have motivated some to seek alternative medicines in place of ART. There is a common belief among wide segments of the population that alternative medicines with virtually no side effects can cure chronic diseases that are not cured by allopathic medicine (Chandrashekara et al., 2002; Gogtay et al., 2002; Mehrotra et al., 2004). Thus, education about ART should include accurate and unbiased information about what alternative medicines can and cannot do.

Staff and health care providers at government ART centers share with the broader society negative attitudes toward FSWs and conceptions about sexual morality that could lead to inadequate care for FSWs. Entrenched attitudes about sexuality and sex work are difficult to modify. While the current training programs for health care providers and staff do include sections on stigma and discrimination, the adequacy of these modules has been recently questioned (Pinagapani & Shanmugam, 2008). For example, there are no interactions with FSWs or people from other marginalized groups during these training programs.

Changing the negative attitudes of the general public in relation to sexuality will also be challenging. To start, public education campaigns to counter HIV/AIDS stigma and discrimination and to promote acceptance of PLHIV, including those from marginalized groups such as FSWs, need to be implemented (UNAIDS, 2007).

Proper training for health care providers and staff is important, but not sufficient – the Indian health care system is faced with a crisis of ever increasing patient volume that has a strong tendency to overwhelm the available human resources and infrastructure (Satpathy &

Venkatesh, 2006). Thus, policymakers should ensure that trained human resources and infrastructure are appropriately proportionate to the client load in the public health systems in general and the government ART centers in particular.

We found that some FSWs are reluctant to initiate ART because they do not want to stop consuming alcohol, which is highly recommended at government ART centers for those taking ART. This points to the need for treatment of alcohol dependence among FSWs.

There are few other studies that focused specifically on barriers to ART access among FSWs in India. However, one report showed that FSWs living with HIV in Mumbai faced discrimination from health care providers, were evicted from brothels once their HIV-positive status was known, and faced delays in being referred to government hospitals for treatment when they were in custody in remand homes (Gaikwad, 2007), which tends to corroborate some of the barriers reported in the current study.

WHO states that there is a need to “to monitor the coverage [ART] of marginalized populations, such as intravenous drug users and sex workers” (WHO, 2004) and recommends collecting disaggregated data from treatment sites on the number of people being treated from various segments of the population, including those from marginalized groups such as sex workers, men who have sex with men, and injecting drug users. However, at the time of publication of this report, NACO was not collecting these data, which is needed to determine whether FSWs and members of other marginalized groups have equitable access to ART from government centers.

WHO also states that specialized interventions are necessary to meet the specific needs of members of marginalized groups living with HIV. For FSWs, MSM, and IDUs, these interventions should address legal status, social isolation, police abuse, and discrimination in health services (WHO, 2004).

This study had some limitations. Being a qualitative study, our intention was not to generalize the study findings across the various subpopulations of FSWs in Chennai. Since recruitment of the study participants was done through NGOs working with FSWs, the knowledge level and community support for the study participants were likely relatively high and hence different from those FSWs who are not associated with NGOs. Furthermore, our study participants were almost exclusively ‘home-based’ or ‘secret’ FSWs who are otherwise ‘housewives’ and do not work in brothels. Thus, transferability of our findings to other urban settings with brothel-based or other typologies of FSWs may be limited. Future studies need to include other subgroups of FSWs in other localities with systematic comparisons by age, marital and living status, substance abuse, incarceration, and other variables, to help determine specific solutions for removing context-specific barriers.

In spite of these limitations, our study captured the perspectives and experiences of FSWs in Chennai with respect to accessing free ART at government centers, which will be useful for informing policies and programs to meet their needs. This should help NACO meet its commitment to ensure availability of ART to “all those who need it.”

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