

Barriers to Free Antiretroviral Treatment Access for Injecting Drug Users 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
- HBC** – Hepatitis C Virus
- HBV** – Hepatitis B Virus
- HIV** – Human Immunodeficiency Virus
- ICTC** – Integrated Counseling and Testing Centres
- IDU** – Injecting Drug User
- INP** – Indian Network for People living with HIV
- KII** – Key informant in-depth Interview
- MSJE** – Ministry of Social Justice and Empowerment
- NA** – Narcotic Anonymous
- 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

Background: National AIDS Control Organization (NACO), India, provides 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 to IDUs, we explored the various factors that hinder free ART access for IDUs living with HIV in Chennai, India.

Methods: Three focus groups (n=19 IDUs) and 4 key-informant interviews were conducted, audiotaped, transcribed and translated. Data were explored using framework analysis to identify categories and derive themes.

Results: Barriers at several levels were identified. Individual-level barriers: lack of concern about health while on drugs; lack of correct knowledge of ART; misconceptions such as 'ART does not suit IDUs'; fear of need to stop taking drugs/alcohol if started on ART; fear of rejection by drug-using peers since taking ART would reveal their HIV-positive status; and belief that they would not adhere to ART regimen. Health system barriers: lack of local residence proof (for homeless IDUs) to get enrolled in government ART program; perceived and actual discrimination from health care providers; lack of screening for Hepatitis-B/C viruses (HBV/HCV) before starting ART; lack of free treatment for HIV and HCV/HBV co-infected people; and dilemma among doctors whether to start ARVs for current users and for those on sublingual buprenorphine substitution treatment. Social, Policy and Programmatic barriers: Stigma and discrimination against IDUs living with HIV; and lack of effective linkages between needle syringe programs and drug dependence treatment programs (including opioid substitution programs) as well as government ART centers.

Conclusions: Barriers to ART access for IDUs need to be addressed by: assisting current users living with HIV to take rational decisions about their health by linking them with harm reduction and drug dependence treatment programs including opioid substitution; providing correct information on interactions between ART and street drugs; offering screening and treatment for HBV/HCV co-infections; educating/sensitizing health care providers; and having a national policy and action plan on equity in ART access to 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 India, an estimated number of 2.47 million people are living with HIV at the end of 2006, the third highest number in the world by country (IIPS, 2007). In 2004, the government of India began providing free first-line ART in government ART centers. 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, only twenty percent (118,052 out of 603,125) of adults who required ART were receiving free ART from government ART centers (NACO, 2008). A major challenge for the government is to expand access to free ART and an additional challenge is to ensure equity in ART access.

Marginalized communities – female sex workers (FSWs), injecting drug users (IDUs), and men who have sex with men (MSM) and Hijras [transgender women] – have been recognized by NACO as 'core high risk groups' that are worst affected by HIV epidemic in India (NACO, 2006). 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." NACO maintains that public health facilities need to ensure that ART is provided to PLHIV referred from interventions targeted toward these marginalized communities (NACO, 2006 – p.114). However, there is no information available from NACO on the number of FSWs, IDUs, and MSM taking ART through its national program (NACO, e-mail communication).

Positive people networks and community organizations have reported that marginalized groups living with HIV have limited access to free first-line ART from government 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). In Manipur in 2006, where 49% of reported AIDS cases were categorized as having acquired HIV through injection drug use, fewer than 5% of persons accessing ART from government centers were current IDUs (Sharma et al., 2007). That was despite IDUs making up the single largest category affected by HIV in Manipur - 49% of the reported AIDS cases were categorized as having contracted HIV through injection drug use (in 2006). Similarly, studies from various international settings have demonstrated that, even in settings where ART (even if free) is widely available, IDUs have lower uptake of ART than other HIV-infected populations (Celentano et al., 1998 & 2001; Cunningham et al., 2000; Gebo et al., 2005; Molitor et al., 2002; Wood et al., 2000, 2003 & 2008).

To address inequities in ART access for marginalized groups such as IDUs, 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, 2003; Kalanda et al., 2007).

The study **purpose** was to identify and understand barriers to accessing free ART provided by government ART centers faced by IDUs living with HIV. Identifying and understanding these barriers will inform development of suitable strategies to enhance ART access to IDUs.

IDUs in Chennai

In 2005, Tamil Nadu government's HIV sentinel surveillance has shown a HIV prevalence of 18% among IDUs, not showing any significant downward trend from 1999 (Government of Tamil Nadu, 2006). A study among IDUs in Tamil Nadu has documented HBV (HBsAg carrier status) infection rate of 23.8% and HCV infection (anti-HCV positivity) rate of 76.2% in 1999 (Panchatchar et al., 2000). No published data is available on co-infections rates (i.e., HBV and HCV infection rates) among IDUs living with HIV in Chennai.

II. METHODOLOGY

In this report, 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.

Qualitative research methodology was used with focus groups and key informant interviews. This study was conducted with assistance from the community-based organizations and non-governmental organizations working with IDUs in Chennai. All the FGD participants were recruited using purposive sampling method. The recruitment was conducted only by word of mouth in order to avoid potential risks to participants. Sociodemographic questions were asked of all focus group participants. These included questions about age, level of education, occupation, and marital status.

A total of three focus groups among IDUs living with HIV (n=19 participants) and 4 key informant interviews were conducted. The key informants were health care providers and community leaders of agencies that work with IDUs in Chennai, Tamil Nadu. All the focus groups were conducted in a private room of the INP+ office. No focus groups were conducted in field sites, owing to risks to participants and staff. Written informed consent was obtained from all participants, including consent for audiotaping of the interview. This study received approval from the ethics review committee constituted by INP+.

Focus groups and key informant interviews were conducted using a semistructured 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 groups 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 and key informants interviews approximately 60 minutes. An honorarium of 250 Indian rupees (7 American dollars) was given to the study participants who attended focus groups. Key informants did not receive any 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. Framework analysis is particularly suited to policy-relevant qualitative research (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., 2008b) and sexual health services (Chakrapani et al., 2008a), 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 et al., 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 and 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 & 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 & Guba, 1985). Researcher triangulation between three investigators 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).

Characteristics of the FGD participants

FGD participants (n=19), ranged in age from 26 to 48 years (mean = 35 years). Thirty-seven percent (n=7) had completed high school; 74% (n=14) were married; and 21% (n=4) were on ART. Of those who were employed (n = 17/19), about one-third (n = 6/17; 35%) were staff of voluntary organizations. Six (n=35%) participants were current users.

III. KEY FINDINGS

A. INDIVIDUAL LEVEL BARRIERS

1. Active drug use
2. Unmet basic needs
3. Lack of self-efficacy and low motivation
4. Inadequate and incorrect knowledge about ART

1. Active drug use: Need for de-addiction treatment and relapse prevention

Active drug use prevents IDUs from taking care of their health

When peer outreach workers talk about HIV and ART to IDUs on the drug using sites, those messages do not reach IDUs as they are under the influence of drugs and not in a position to comprehend and act on the messages received. Hence, participants and key informants suggested that the IDUs need to be 'stabilized' first by linking them to Opioid Substitution Therapy (OST)¹ and then to drug-dependence treatment program. Participants and key informants emphasized the importance of continuous reinforcement of HIV prevention and treatment messages to IDUs in various forms and through a range of people (peer outreach workers, doctors, and counselors). They felt that such repeated messages will at least then lead some to go for HIV testing and if tested HIV-positive, help them in getting enrolled in the government ART program.

¹ 'OST' using Sublingual Buprenorphine tablets. In India, methadone substitution treatment is not available.

Lack of concern about health while on drugs

'The reason why they [IDUs] are unaware of HIV is - their main focus is *drug*. Due to the addiction they don't care about HIV - in spite of the awareness given to them. They [messages] do not reach the person who is under the control of drugs. Drug is the most important thing for him. He [IDU] can take care of him only if he gets rid of them.'

(A former user in a FGD)

Awareness about ART does not necessarily means accessing ART

'It [Information about ART] reaches only fifty percent of them [IDUs]. Though he is aware of ART, he would prefer going after drugs and not care about ART. He would think [of ART] only when he starts getting symptoms [becomes ill]. "Oh! They said about ART" - He would [say]. [Thus, he thinks] of ART only when he lands up in a serious situation.'

(A former user in a FGD)

Need for de-addiction treatment before beginning ART?

Key informants as well as some FGD participants had a strong opinion that current users should be first linked with de-addiction treatment center and only after they become 'clean' (out of drug dependence) they can be started on ART. They gave many reasons for what led them to say so:

- In a 'high' state, IDUs are not in a position to receive/comprehend information given to them – including any information about HIV testing or ART.
- Doctors hesitate to give ART to IDUs who are current users
- Adherence might be good if one is 'clean'

Need for relapse prevention support

Participants mentioned that though some IDUs may be clean when ART is started, some relapse into drug use while they are on ART and this can lead to problems due to drug interactions and problem with ART adherence. Hence they emphasized the need to ensure steps are taken for relapse prevention and take actions if relapse occurs.

Start ART after one gets 'clean'

'He should get rid of drug addiction. Once he comes out of it, ART should be commenced. There must be follow-up. ART should commence only after referring him to a de-addiction centre.'

(An IDU in a FGD – emphatically stating the need for de-addiction before initiating ART)

Convincing IDUs to take ART would be easy if they come out 'clean' first

'They [drug users] wouldn't come forward. They would be careless. They mainly need de-addiction centre to come out of drug addiction. They can be easily convinced to take ART if they come out of drug addiction.'

(A key informant who is a service provider for IDUs)

2. Unmet basic needs (Unstable social circumstances: Food & Shelter)

Key informants as well as many FGD participants said that many homeless IDUs rejected by their family members do not have access to adequate food to satiate their hunger let alone nutritious food. Hence they opined that since the counselors in the ART centers as well as the peer outreach workers tell IDUs that they should take adequate and nutritious food if they are going to be on ART, IDUs are afraid to start taking ART. Also, if IDUs are focused on getting only drugs then they will not have adequate nutritious food. Thus, there is a need to focus on both linking IDUs to de-addiction treatment as well as finding ways to provide nutritious food for both IDUs who need to be started on ART or who are on ART.

Homelessness, No food, and Continued drug use

Lack of access to adequate/nutritious food prevents IDUs from start taking ART

'They [IDUs] become afraid as they [counselor/doctor] say that there would be *side-effects*. And we are asked to take good food but we don't even have food at times. [They will say] 'You can take medicine only if you have food on the right time'. We are afraid that something might happen if we take [ART] without taking food.' (A current drug user in a FGD)

For homeless IDU getting food (and drugs) would be a priority – not taking ART

'He is on the roads [homeless IDU]. What will he do if he is given ART? He doesn't have food to eat... For him [getting] food is more important than ART. Also how will ART work if taken without proper food?' (A former drug user in a FGD)

Food menu offered by counselors is "Only for rich"

'[Only] the rich can take such food [mentioned by counselors]. Can the one on platform [homeless] drink hot water? Can he take nutritious food such as nuts, dates, dal? He would just nod his head to the counselor while all these questions keep flashing in his mind. He doesn't get admitted - neither does he get ART. He thinks, "Oh! There is so much in this [taking ART]. So let me continue doing whatever I am doing now and die when I am going to".' (An IDU in a FGD)

3. Lack of self-efficacy and low motivation***Belief that IDUs would not adhere to ART regimen***

Though some health care providers hesitate to start ART for IDUs because of concerns about adherence, even some FGD participants (current or former drug users) felt that it might not be possible for IDUs to adhere to ART. Such lack of self-confidence in adhering to ART could be due to the internalized negative attitude of others - especially health care providers and that of their own peers. Hence it is important to address and challenge this belief that may hinder IDUs to access ART. Though adhering to ART may be challenging for some IDUs, it does not justify denying ART to drug users but points out the need for proper and adequate support in initiation and adherence to ART.

Low motivation: Fatalism and Pessimism

Some participants have heard from other IDUs that 'What is the point in living for a long time? Who respects us?' Thus, the lack of desire to live and the associated fatalism need to be explicitly addressed. This fatalism possibly stems from the discrimination they face from the society. Also, the need to take ART for lifelong and lack of cure make it difficult for IDUs to commit to start ART.

Lack of self-efficacy in adherence (Afraid to make 'commitment')

'Apart from that, as it [ART] has to be taken for the entire lifetime, we are afraid that we might not be able to [do so].'

4. Inadequate and incorrect knowledge about ART

In addition to the lack of accurate information about ART, there were several misconceptions and false beliefs among IDUs that prevented them from taking ART. Some participants mentioned that they have 'seen IDUs who died of ART' and when asked to explain in detail it was found that those IDUs also had co-existing HBV/HCV infections and they were started on ART at an advanced stage, and later they died. Thus, their perspectives that 'IDUs have died of ART', 'ART does not suit IDUs', and 'ART will not work for IDUs' are based on such anecdotal experiences, with no accurate information about the benefits of ART, and interactions of ART with street drugs and alcohol.

Lack of correct knowledge about HIV and ART (Connected to drug influence)

'Only those [IDUs] who are HIV-positive have gained understanding about HIV and its treatment. The awareness is comparatively less among drug users [who do not know their HIV status].'

Some IDUs don't know even basic information about HIV [let alone ART]

'Though people are well aware of HIV, there are some [IDUs] who are still unaware of it – without understanding what is meant by HIV, And [even if they come to know that they have HIV] they live without confidence since they do not know the details [about HIV and ART].'

Fear-mongering or spreading wrong information about ART

'There are people who are addicted to smoking and alcohol. When they are instructed not to consume them when under medication, they hesitate and think whether or not to take this medicine. They think of smoking and consuming alcohol along with this medicine. And when something happens they blame ART for the effect. Without consulting doctor they say others that vision has diminished and they have itching and things like that. They thus spread a wrong opinion about ART and threaten others.'

Some IDUs (in different FGDs) postulated that some IDUs could not stop taking drugs and alcohol when they are on ART and thus experience side-effects. They then spread misinformation to other IDUs that ART produces side-effects and 'does not suit IDUs'.

Some participants who are now on ART once believed that if one has to be started on ART then they should not touch drugs or alcohol. Thus they did not want to be started on ART since they were not sure whether they could ever stop taking alcohol/drugs and they were afraid of the possible interactions between ART and alcohol/drugs.

B. HEALTHCARE SYSTEM BARRIERS

1. Perceived unfriendly hospital environment and procedures
2. Barriers in knowing one's CD4 count
3. Lack of screening and treatment for HBV/HCV
4. Provider-perceived nonadherence
5. Need for address/identity proof to get enrolled in free ART program
6. Negative experiences with health care providers
7. Lack of former drug users as ART counselors
8. Lack of effective linkages with de-addiction programs and NGOs working with IDUs

1. Perceived unfriendly hospital environment and procedures

High patient overload and lack of efficient patient flow

IDUs, just like other people, find it very inconvenient to wait for a whole day in the hospital to see the doctor or counselor. However, they have some specific reasons: if an active drug user needs to stay for a relatively longer duration in the government hospital then they might develop withdrawal symptoms – which they try to avoid by not staying back; and also for daily-wage laborers a day-long stay in hospital is loss of that day's wages. Furthermore, because of the bad reputation gained by the public health facilities in general, the very thought of going to a government hospital means there would be a long wait deters IDUs from going to government ART centers. Other reasons include: not wanting to be seen by people from their locality that they are in a government ART center (or TB hospital where a government ART center is located); not wanting to be identified as HIV-positive and as a result face further stigma and discrimination.

Problems with navigation and lack of availability of facilities in one roof

Though located within the government hospital campus, ART centers are virtually stand-alone centers since for blood tests, and medicines, patients need to go to as many as three to four different places. Thus, patients find it very taxing that prevent some from coming back to collect test results. These 'stories' of the need to run 'from pillar to post' are then shared with other patients that prevent them from even visiting government ART centers. Thus, key informants reported that even those who are from lower middle class background but who could not afford to buy ART, may not want to come to government hospitals because of the bad image and the reputation of how patients are treated there.

Run from pillar to post

'In spite of so many problems – poor physical condition, money paid for bus – he [IDU living with HIV] comes to the government hospital. There he is made to run from pillar to post. When he is asked to go to first floor, then to the eighth, then to room number 106 or the like, he finds it difficult to walk around. There's no one to take care, give him hope, motivate and make him sit at the right place. So they develop fear the moment they are asked to go to Government hospital. – They would say 'Aiaiyo [Oh No!] – they would make us to run from here and there'. Even the one-day experience there becomes a hell for him. So, some of them are afraid to go there even for treatment.'

(A former user in a FGD)

Lack of privacy and confidentiality

Although participants mentioned that many patients coming to government ART centers receive individual face-to-face counseling, high patient load sometimes compel counselors to conduct group risk-reduction counseling and treatment education sessions. Sexual risk reduction messages are thus provided in a generic manner and no tailored sexual risk reduction counseling would then be possible under those circumstances. Similarly, in 'group counseling', some men are not comfortable in sitting with "small boys" (referring to adolescents/young men) since others also come to know that they have HIV disease.

Group counseling means lack of privacy and confidentiality

'We [IDUs] feel shy. We couldn't listen to the counseling they give. But in counseling given by NGO, they make the wife and husband sit separately and give counseling. They patiently ask, "How many times do you have sex in a month and how?" We are able to answer. But ...in a group, we are not able to undergo counseling. They ask whether we have sex in front of ten people. We have to look at each others' face and the ladies had to sit with their heads down.' (An IDU in a FGD)

2. Barriers in knowing one's CD4 count

For enrolling in government's free ART program, the CD4 count needs to be less than 200 per microlitre or the patient should have had at least one AIDS-defining illness. But often, emphasis is given on CD4 count alone. However, many IDUs living with HIV do not know about their medical eligibility for ART since they do not know their CD4 status. Key informants mentioned that some reasons could be lack of information about CD4 test availability, and lack of proper mechanisms in the government's hospital in deciding when to conduct CD4 testing for a person living with HIV to determine his/her eligibility for enrolling in ART program. Thus, often only when a person living with HIV comes with severe symptoms or AIDS-defining illness, CD4 testing is done.

3. Lack of screening and treatment for Hepatitis-B/C viruses (HBV/HCV) before starting ART

Key informants reported that proper protocols are not being followed in government ART centers before they start ART from IDUs. They said that though it is necessary to find out whether an IDU has HBV and HCV before initiating ART, often these tests are not done because of lack of screening test kits for HBV and HCV. If an IDU has HIV as well as HBV and/or HCV, then the presence and severity of co-infections have implications on starting ART. Hence, if ART is started in an IDU living with HIV in absence of knowledge about the HBV and HCV status, then there might be some untoward complications – especially liver damage. So when IDUs come to know about the lack of screening tests for HBV and HCV as well as lack of treatment for those who are HCV-positive, then they do not want to take ART since they believe that could impair their health if their liver is already damaged by HBV and/or HCV. Key informants also felt that there is lack of expertise among doctors in government ART centers to treat IDUs co-infected with HIV and HBV/HCV though it could be well because of lack of free treatment for HCV².

Getting blood tests done is difficult

'In those two weeks [admitted for 'observing' for any side-effects of ART], the patient may be affected by common diseases like fever, loose motion [diarrhea], etc. even before ART is started...Observation means monitoring a person immediately after ART is started and from then on. They [Doctors] admit and treat any common diseases but don't take any [blood] tests. They should test for sugar level, hepatitis B and C, vision, etc. But they don't. Instead they start giving ART immediately if the test [result] shows that CD4 count is less than 200. There's no value when no [other] tests are taken – whether ART is taken or not.'

(A key informant who provides services to IDUs)

'...But basically no test is taken. Mainly, the drug addicts would have a virus called hepatitis B which causes jaundice. No test is done for that.'

(A peer outreach worker – former drug user - in a FGD)

Not everyone gets tested for HBV and HCV

'Yes, they take tests [for hepatitis viruses]. But not everyone is given that opportunity.'

(Doctor, who worked in a government ART center)

(Discussion with doctors showed that frequent shortage or lack of Hepatitis B/C test kits was the main reason behind not offering HBV/HCV tests routinely to all PLHIV.)

4. Provider-perceived nonadherence

Doctors hesitant to start ART for IDUs

Participants as well as key informants reported that doctors in ART centers are hesitant in starting ART for IDUs since they are not sure whether IDUs – former or current - would adhere to ART. Also, since IDUs do not wish to stay in the hospital for two weeks when they start ART, doctors seem to have concerns about not able to observe them for any side-effects (especially that of nevirapine).

A doctor who worked in a government ART center told that in general, a history of drug use means doctors would be wary of starting ART even if the CD4 count is less than 200 per microlitre. He admitted that though national guidelines do not specify that drug users should not be started on ART, he justified doctors' stance of not starting ART to drug users by stating "What if he [drug user] does not take drugs properly and develops [drug] resistance [to antiretrovirals]? Other [read non-drug using PLHIV] would suffer [if drug-resistant HIV spreads]. We [doctors] do not want to take that risk". He clarified that in the ART center he once worked, "Doctors do not

² Treatment for hepatitis C is not available free of cost in the government hospitals. However, private gastroenterologists in Chennai provide treatment for Hepatitis C infection.

distinguish whether the IDUs are current or ex[-users]. How can you tell whether someone is current or ex[-user]? You would never know – there is no way you can find out. And even ‘ex-users’ might be taking alcohol or other [non-injectable] drugs.” Thus, irrespective of whether someone is an active or former drug user, some doctors are hesitant to initiate ART even if IDUs satisfy the medical criteria (CD4 count less than 200 or having had an AIDS-defining illness).

Thus, as advised by some non-governmental agencies, some HIV-positive drug users conceal their drug use history and get their ART started on the usual triple-drug regimen that contains nevirapine. (The mode of acquisition of HIV is noted in the clinical records as ‘sexual’). This means, if their liver is already damaged (due to Hepatitis B, C, or alcohol) there is a high chance of further damage due to hepato-toxic side-effects of the antiretrovirals – especially nevirapine. Though some of the drug users who are on OST (buprenorphine) are also on ART, not all of them have revealed it to their ART center doctors or counselors. A participant in a FGD mentioned that “We don’t tell that [we are on OST] because we are afraid that we would not be given ART. Doctors and counselors don’t even understand the basic things about IDUs.” A key informant mentioned that even those agencies that provide OST to drug users sometimes advise their clients not to mention they are on OST because of limited knowledge about OST among the government health care providers.

5. Need for address/identity proof to get enrolled in the free ART program

Until recently, no identity/address proof was required for getting enrolled in government ART program in Chennai. However, many ART centers in Chennai have now made it mandatory to have at least one identity/address proof in order to follow up with the patients if they do not come back to get ART. Key informants suggested that this new requirement was introduced because many people living with HIV including IDUs living with HIV used to give wrong address and thus they could not be traced back if they do not come for follow-up. However, some IDUs are afraid that if they are going to give a (correct) address proof then hospital workers may come to their home and inform other family members and neighbors that they are HIV-positive. This fear prevented some IDUs from getting enrolled in government ART programs. Also, for those IDUs who are homeless (whom participants referred to as “care of platform”), that posed a major hurdle and many of them could not get enrolled in ART program even if they satisfy medical criteria.

Fear of breach of confidentiality prevent giving address proof and thus getting enrolled
 ‘Some [IDUs] are afraid even to come ...to Government Hospitals. Apart from that, half of them run away from there when they ask for ID [identity proof], address, photo, phone number, etc. Some think that they can take care of their health all through their life by just taking good food and not to go for ART- and so walk away.’
 (An IDU in a FGD)

Address proof requirement excludes homeless IDUs from getting ART
 ‘When they are infected by HIV and their CD4 level comes down, they are compelled to take ART. When they are started on ART, it gives rise to many obstacles. Mainly, they are asked for ration card, address proof, photo, etc. He [IDU] had already been sent away by the family for taking drugs. Then how could he get all those things?’
 (A key informant who is a service provider to IDUs)

6. Negative experiences with health care providers

Discrimination faced by IDUs living with HIV is on the basis of both their HIV status as well as being an active or former drug user. Sometimes we cannot definitely attribute whether the discriminatory incidents narrated by the participants were because of their HIV-positive status or their drug use.

Participants narrated several incidents in which the words, actions, and non-verbal cues of the health care providers suggested that they are not comfortable in counseling HIV-positive drug users – which IDUs interpreted as fear of getting HIV from them by some way and not competent to provide counseling to drug users. Perceived or actual discrimination in the health care settings lead drug users living with HIV to conceal their drug use status in the ART treatment centers and consequently affect getting relevant information and referral services. Also, stories about discriminatory incidents discussed in the informal networks (drug use networks, and NGOs) also prevent IDUs from accessing ART centers, since they do not want to face discrimination.

Discrimination from health care providers

(Quotes from FGDs)

Sending the message 'across the table'

'The treatment in the hospital is very worse. They don't give right counseling to us. If there is someone who has understood us, they can give us the right treatment. Others can't give us right treatment. They behave as though it's just part of their duty and so give advices like – 'Hello! Take carrot, beetroot, greens, vegetables, etc'. If we are weak, they move back [from the table] as if it [HIV] would spread to them and make us also suspect whether that is so. We went there with the thought that they will give us some good information.'

IDUs feel they are not welcome and counselors have undue fear

'While counseling...their chair would be in front [near the table in-between the two] and ours at the back [away from the table]. If we try to move it to front [near the table], they would say, 'It's ok. You be there'. I would sit little away [from the table] and answer. They are afraid that it would spread to them. They have the fear. But they know how it spreads. They won't sit comfortably and talk to us.'

Perceived low quality of services (esp. counseling)

'Only 10 or 15 minutes would be allotted if fifty of them are there for ART. They[counselors] don't see whether the message reaches him or not. They don't think of the way in which it can be told so that the client understands. They don't use the tool of counseling in the right manner. They are harsh. It makes us feel bad. They would give counseling for five members at a time as if they are taking class. It wouldn't reach him.'

Problems in giving blood for blood tests

'We don't find any vein either in the leg or hand for taking blood. So if we want to search for it even in important places (parts), we would need a hide. When we ask permission to use the private rooms for taking blood, they deny saying...'This is the place where we take food...where we relax...go to some other place to take blood and come back'. So, it is difficult for us even to take blood. We need an advocate even for that. Only a person knows about us better can take blood, the Government staff couldn't.'

Perceived discrimination from paramedical staff

Participants described that many times, lab technicians in the government hospitals find it difficult to take blood because of blockage of most of the superficial veins in IDUs. Hence, lab technicians ask IDUs or the outreach workers (who accompany drug users) to take blood. While some participants perceived it as incompetence on the part of lab technician in taking blood from 'difficult patients', some participants blamed themselves by saying 'What can he do? We [IDUs] block all our vessels by trying to find a good one'. Thus, though some blame themselves for this situation, some others still wanted some kind of assistance in the government hospitals to take blood. They felt being left to take blood by themselves was discriminatory and even they are not given private place if they want to take blood from their 'private parts' (hip or pubic region).

Non-disclosure of drug use status due to fear of discrimination

Participants felt that many former IDUs usually reveal their past drug use behavior to doctors and counselors since they do not want to be seen as having contracted HIV because he was “that type of guy” (meaning ‘sexually promiscuous’). However, a key informant mentioned that some former drug users who are HIV-positive may not reveal their past drug use behaviors because of several reasons: they might think that their past drug use behavior is irrelevant now; they are afraid of facing difficulties in getting enrolled in national ART program if they reveal that they used drugs in the past; and they face the risk of discrimination from health care providers.

Non-disclosure of past drug use behaviors might affect the type of counseling provided by counselors (in relation to risk reduction and ART adherence). Also, as HIV-positive drug users (former or current) may have HBV/HCV co-infections, non-disclosure of past drug use behaviors might have treatment implications (as discussed earlier) since ART might be started even in the absence of the knowledge of a person’s HBV and HCV status. In a focus group, several participants (former and current drug users) shared these views and added that one another reason for not revealing one’s past drug use behavior is the insistence by some physicians on knowing HBV and HCV status before initiating ART, which though may be well-intentioned, is perceived by drug users as a subtle form of discrimination and a tactic to delay initiation of ART.

Perceived lack of competency among counselors (in dealing with drug use related risk reduction and ART counseling)

Several participants stressed the need to have compassionate and competent counselors in the government-run HIV testing and ART centers. Participants and key informants told that though counselors may be competent in dealing with other risk populations, they have relatively little knowledge and skills in relation to counseling IDUs. Thus, they felt that counselors’ risk reduction counseling and ART adherence messages are less likely to meet the needs of former or active drug users.

Lack of compassion in counseling and the need to make counselors ‘understand’

‘In some [government] hospitals they give good counseling. In some hospitals they talk in an unkind manner. Not all [counselors]. Some [counselors] may speak out of fear that they should not get [HIV]. Some talk without understanding. So, we have several problems. We need to motivate them [counselors] on how to talk [to IDUs] in counseling. They need to understand” ‘What they [IDUs] need’ and ‘What they expect from us’. We wish that their counseling messages are simple and easy to understand.’

(An IDU in a FGD)

‘If they [counselors] can speak kindly and with compassion it would be good’

(An IDU in a FGD)

Frightened to death?

‘In the Government Hospital itself they are threatened about ART – “You shouldn’t miss it even a day. If you miss it, you would have vision problems, fits and few other side effects. So if you start ART and stop it then we are not responsible.” So some are afraid to even come to government hospitals.’

(An IDU in a FGD)

7. Lack of former drug users as ART counselors

In both government HIV testing centers and ART centers, only professional counselors are available. The perceived lack of competency of these professional counselors in dealing with specific issues of IDUs, made the participants stress the need for an ‘ex-user’ as peer counselor in both HIV testing and ART centers. They felt that though the professional counselors’ main responsibilities are in relation to risk assessment, risk reduction counseling and ART adherence counseling, and not in relation to drug use *per se*, participants felt that a former user might better

understand the issues of IDUs and if properly trained, can competently conduct risk assessment, risk reduction counseling and ART adherence counseling.

Potential of former drug users to serve as ART counselors

'It would be good and useful if a rehabilitated ex-drug user is appointed as counselor in [government hospitals]. Only a former drug addict can clearly understand a 'drug addict' and others cannot. They can't say which category he belongs to and in what state of mind he is. Only a person who had been a drug addict and has now overcome it could better understand the problems of the drug user. According to me if such a person is appointed it would be better.' (A participant in FGD)

'What I say is that, it would be better if an 'ex-drug addict' who had come out of it is placed in an ART counseling centre. I think so. Correct message would reach [drug users]. He wouldn't accept whatever any other person says. I am a drug addict. When I talk to another drug addict he would understand. As I had undergone the same pain, which he [now] undergoes, it would be easy for me to talk to him. Only a person like this [former user] would be suitable [for counseling].' (A key informant who is a former drug user)

8. Lack of effective linkages of ART centers with de-addiction programs and NGOs working with IDUs in relation to HIV prevention

Participants and key informants suggested that while some counselors and doctors may refer IDUs seen by them to de-addiction and rehabilitation programs (in government hospitals and centers supported by the Ministry of Social Justice and Empowerment - MSJE), most doctors and counselors do not refer IDUs living with HIV to those programs. As a key informant mentioned, "On the one hand they [doctors] hesitate to give ART since he is a drug user, and on the other hand, there is no help to such people [current users]. They are not referred anywhere to get rid of their drug habit."

C. PROGRAMMATIC BARRIERS: UNMET NEEDS AND GAPS IN HIV PROGRAMS AMONG IDUs

1. Insufficient knowledge about ART among outreach workers and peer educators
2. Need for scaling up opioid substitution therapy (OST) to 'stabilize' drug users
3. Lack of effective linkages between needle syringe programs, detox/de-addiction treatment centers, and rehabilitation centers

1. Insufficient knowledge about ART among outreach workers and peer educators

Participants, some of whom are peer outreach workers themselves, complained that many peer outreach workers do not have sufficient knowledge about ART. Hence they questioned how could those outreach workers inform IDUs about ART. Others added that even if the outreach workers have basic knowledge about ART, when they are 'in the field', they usually do not inform IDUs about ART. One FGD participant, defending the action of peer outreach workers, pointed out the practical difficulties in providing information about ART to a group of IDUs in a field. The members of that group then would ask why he is telling all about ART when none of those in that group is HIV-positive and they would even ask him to point out who is HIV-positive in that group for whom

he is telling those information. So, he concluded, 'It is better to keep your mouth shut - just distribute syringes [and] come back.'

Participants suggested that ORWs be well trained on ART so that during their outreach education and face-to-face meetings with IDUs with unknown HIV status as well as IDUs living with HIV, information about ART can be given. Such information might in turn motivate some IDUs to go for HIV testing and among the IDUs who know their HIV-positive status such information may help them to go to ART centers to find out whether they need to be started on ART. Thus, lack of adequate and correct information about ART and its interactions with street drugs/alcohol was seen as a factor that prevent IDUs from taking ART.

Need to talk about ART even to IDUs of unknown HIV status or even if CD4 is >200

'They [outreach staff] won't talk about ART...Only when it is less than 200 they talk about ART.....Reveal everything about it [taking ART] - like the obstacles you would have while you take ART, the way in which you should take it, its merits and demerits. But they should tell this to everyone. I may be [HIV]negative today but maybe I become [HIV]positive tomorrow. I need to know. And I can tell other people.' (An IDU in a FGD)

2. Need for scaling up opioid substitution therapy (OST) to 'stabilize' drug users

Currently there is only one NACO-supported OST project in Chennai that is providing OST to about 100 IDUs out of which about 40 are HIV-positive (Personal communication, Hopers Foundation, Chennai). In spite of the apparent benefits of OST to help IDUs living with HIV to become 'stabilized' in their lifestyle and ultimately free from drug dependence, not many IDUs are on OST. Former users and a key informant pointed out that in addition to the need to scale up OST in Chennai and Tamil Nadu, there is a need to tackle the ideology among some community leaders (former drug users) in advocating for only non-OST based detox/de-addiction and not de-addiction through OST.

3. Lack of effective linkages between needle syringe projects, OST projects, and detox/de-addiction and rehabilitation centers

HIV prevention projects among IDUs in Chennai focus on needle syringe programs and OST (one project). Former users in the FGDs and key informants stressed the need for establishing and strengthening linkages among the needle syringe projects, OST project and detox/de-addiction and rehabilitation centers. Though they complained that these projects are often functioning as stand-alone vertical projects with limited interlinkages, they are seeing recent increase in cross-referrals among these projects. However, they pointed out the need for some kind of formal referral mechanisms connecting these services. As a key informant stressed: "It is a policy issue. If NACO and MSJE sit together and develop some kind of formal referral and coordination mechanisms then it would be easier. Currently we are referring people to other centers by word of mouth or phone calls because we have friends at those centers."

Another key informant, a service provider, also mentioned that the lack of free rehabilitation centers in Chennai is another issue that prevents people from referring and using rehabilitation services. Refuting the claim that there are free MSJE-supported rehabilitation centers, a key informant mentioned, "They are not totally free. Depending upon the center, one has to pay anywhere from Rs.1000 to 2000 per month for food expenses. And though there are private rehabilitation centers, our clients could not afford their charges." Thus, lack of availability of free rehabilitation centers in Chennai might be one of the reasons why many IDUs (including those living with HIV) could not access rehabilitation services.

D. SOCIAL & POLICY BARRIERS

1. Lack of family support and societal discrimination

Participants informed that although some family members reject and evict IDUs, some other family members do not evict IDU out of their house though they do not approve of their drug use behavior. Given this situation, they asserted, IDUs do not want to reveal their HIV status to their family members since that might result in getting evicted from the house and thus leaving one without any support. Hence, taking ARVs within one's house poses the risk of being identified by other family members as HIV-positive with possible negative consequences. Thus, the perceived lack of support and rejection if found to be HIV-positive prevented many IDUs to openly talk about their HIV status as well as to get enrolled in the government ART program.

Participants mentioned that even if the family members know the HIV-positive status of IDUs then there is no support for them to be started on ART since family members, who are fed up with the frequent 'relapse', would be skeptical about whether ART would be of any use and would wonder whether they would continue taking ART

There is misunderstanding about drug users among both their family members as well as the society at large. Often, drug use is seen as an aberration in the moral character and continued drug use is seen as lack of will power to stop using drugs – not understanding the fact that continued drug use produces physical/biological dependency that makes it difficult for drug users to stop taking drugs on their own. Thus, it is not surprising to know that drug users are often disowned by their family members and asked to move out of their home. Sometimes even drug users on their own move out of their home to prevent bringing shame to their family. This is especially more so if the drug user also becomes HIV-positive.

Disowned by family

'The main hindrance among the drug addicts to take ART is that most of them are rejected and sent away by their family.'

Fear of bringing shame to the family

'He thinks that he earns bad name for the family, the society would view the family differently as he is infected by HIV and due to this fear / stigma...he comes out of the family.... This is the basic reason.'

Fear of rejection by the family members and relatives if found HIV-positive

'Generally, the drug users are viewed differently both by the society and their family. It would worsen the situation if they [family] come to know that we are infected [with HIV]. Due to this sense of self-worthlessness alone they find it difficult to come for [HIV] test and to tell others that they are [HIV]positive.'

Interplay of fear of rejection by family, fear of bringing shame to family and fear of lack of confidentiality in the health care system

'Keeping aside poor economic condition of our life, the main hindrance is the thought that the society and our relatives would reject us if they come to know that we are [HIV]positive. Due to this they hesitate to come for [enrolling in] ART [program]. If we undergo ART they would publicize that ...and our family would be affected.'

2. Illicit drug policies and police interference in HIV programs

Carrying illicit drugs for personal consumption (beyond a particular amount) is a criminal offence in India. A key informant mentioned that in reality once a person is identified as a drug user, police keep a suspicious eye on that person and might even file false charges against him/her whenever they have a 'target' to fulfill ('target' – referring to the particular number of cases to be

filed by police in a given time period). Key informants as well as FGD participants agreed that police interference in outreach work among IDUs in Chennai has considerably decreased (in late 2007) possibly due to ongoing advocacy with police officials at various levels by individual activists (including former drug users) as well as by the police advocacy programs initiated by the Tamil Nadu State AIDS Control Society (TNSACS). However, a key informant informed that stray incidents of police interfering in the outreach activities continue to occur since not all police at the ground level have been sensitized. Key informants as well as FGD participants also pointed out the lack of both HIV prevention and treatment services for drug users who are in prisons.

E. FACILITATORS OF ART ACCESS TO IDUs LIVING WITH HIV

In spite of the various barriers identified and expressed, some IDUs are on ART. The following are the perceptions of the participants and key informants regarding what enabled some IDUs to get enrolled in the government ART program.

1. Persistent follow-up and messages delivered by former user (who are ORWs or peer educators)
2. Stabilization by enrolling in OST and De-addiction programs
3. Desire to live for others
4. Seeing healthy PLHIV who are on ART when attending support group meetings of PLHIV
5. Potential facilitators:
 - a. Home visits and hand-delivering ART: A feasible strategy to encourage ART use?
 - b. Would incentive schemes to enroll in ART program be beneficial?

1. Persistent follow-up and messages delivered by peer ORWs

Some IDUs living with HIV are enrolled in ART program. Participants pointed out that it was possible because of the persistence of the peer ORWs and other NGO/CBO staff in persuading IDUs to test themselves for HIV, and asking HIV-positive IDUs to go to government hospitals to know their CD4 count (in order to find out their eligibility for enrollment in ART programs). Also, the rapport built by the NGO staff and their willingness to accompany the IDUs for HIV and CD4 testing and later to ART centers seem to be very important since otherwise IDUs are not willing to spend their money to travel to HIV testing and ART centers, and also give many excuses for not going to such centers.

2. Stabilization by enrolling in OST and De-addiction programs

Participants mentioned that those who are enrolled in OST will get 'stabilized' after some months and any discussion about HIV testing or ART will then be 'heard' (comprehended) by them. Similarly those who participated in drug dependence treatment and now are out of drugs would also 'listen' to peers regarding HIV testing or in finding out whether they need to be enrolled in ART program.

Peer outreach workers and the need to become 'clean'

'He [an IDU] would start understanding only if he become 'clean' [comes out of drugs]. He would understand only if an ex-user goes as a field worker and passes on the message. Presently, two to three NGOs do so in Chennai. Ex-users serve as field workers.'
(A key informant who is a service provider)

3. Desire to live for others

Especially those IDUs who have been stabilized on OST or who are now out of drugs would like to test themselves for HIV or would like to get enrolled in ART program since now they want to remain healthy to take care of their children and/or spouse.

4. Seeing healthy PLHIV who are on ART when attending support group meetings of PLHIV

Those IDUs who attend the support group meetings of PLHIV come to hear about the stories shared by PLHIV who are on ART – on how they have now become healthy after having started ART – also motivates IDUs in finding out whether and when they need to be started on ART.

While some IDUs do attend narcotic anonymous (NA) meetings, participants mentioned that only drug related issues are discussed in NA meetings and not HIV related issues. However, a few participants mention that they do share their HIV-positive status in NA meetings and also motivate others to live healthy life including the benefits of ART.

5. Potential facilitators:

a. Home visits and hand-delivering ART: A feasible strategy to encourage ART use?

Participants in various focus groups as well a key informant felt that if the peer outreach workers could make home visits and hand-deliver ARVs then IDUs living with HIV might be willing to take them and adhere to treatment. Otherwise, IDUs might not like to be started on ART as well as might have difficulties in adhering to it. They also expressed that if it could be introduced then maybe IDUs might be motivated to attend ART centers by themselves and continue to take ART. Some other participants however felt that home delivery of ARVs and close follow-up may not be always possible since many IDUs living with HIV are concerned about their confidentiality and hence would not like anyone to come to their home and give ARVs since there is a possibility that they might not have already disclosed their HIV status to their family members or spouse. One key informant argues against any such proposal. He felt that the responsibility of giving ARVs to IDUs living with HIV and following up them should not be left to NGOs or drug user groups because the government is just transferring its responsibility to the NGOs/CBOs. He also pointed out the difficulties in implementing that recommendation since he felt that government would not be willing to give ARVs to NGOs or drug user groups.

b. Would incentive schemes to enroll in ART program be beneficial?

Participants also suggested that some kind of incentive schemes to get enrolled in the govt. ART program and for adhering to the ART might help, since incentives seem to have helped in increasing the number of IDUs who get tested for HIV. However, other participants differed in that opinion and said that unless one simultaneously focuses on enrolling them in OST and/or drug de-addiction programs, enrolling and retaining IDUs in government ART program would be difficult.

IV. DISCUSSION

This report identified and summarized the various barriers faced by IDUs living with HIV in accessing ART. Although for convenience sake, we divided the barriers as individual, health system, program and social level barriers, they are all intricately intertwined.

Why 'personal' is also 'contextual'?

Even a factor that is apparently seen only as an 'individual level factor' is more likely to be beyond the individual. For example, the assumption that lack of knowledge about ARVs among the IDUs is an individual level factor suggests that it is the IDU then who is primarily responsible for his/her situation of not knowing about ARVs and hence not accessing ART services. However, an IDU may have no or inadequate knowledge about ARVs not because he/she does not want to but: because there is no support for him to come out of drug dependency and consequently he could not be concerned about his health when he is always trying to get drugs to prevent withdrawal symptoms; because he is not given proper information about ARVs by the outreach workers since the outreach workers themselves may not have correct and adequate knowledge about ART or they thought that IDUs would not listen to them if they are going to talk about ART while he is high; because there are no mass media messages about ART which IDUs would have otherwise seen or listened to; because the doctors and counselors who counseled IDUs after their HIV-positive diagnosis thought that IDUs could not adhere to ART regimen and may spread drug-resistant HIV strains, and thus preferred not to provide necessary information about ART or down-played the efficacy of ART. Thus it is not a simple issue of 'lack of knowledge' about ART among IDUs living with HIV but also a matter of doubts in the minds of the service providers regarding the comprehensibility of IDUs about information on ARVs; lack of motivation among service providers to provide correct knowledge about ART; and the mistrust among health care providers that lead them to deliberately withhold information about ART; and ignorance or oversight among the government on the need to provide simple messages about ART in the mass media messages.

Similar to our study findings, studies from international settings have also demonstrated that a primary individual level issue is the common perception among IDUs that the side effects of ART will be intolerable (Bassetti et al., 1999; Kerr et al., 2004; Shannon et al., 2005). Thus, there is a need to provide accurate and adequate information about ART and its side-effects – to IDUs as well as peer outreach workers and counsellors.

The images of 'untrustworthy IDU' and the need to change that image

The (mis)belief that IDUs could not be trusted was ubiquitous among various persons. That belief is present not only among the health care providers who denied ART to IDUs by pointing out the alleged problems to adherence and emergence of drug-resistant strains, but also among family members who thought that IDU would not adhere to ART since they have seen the user frequently getting into relapse; and among peer outreach workers, that is, former drug users themselves, who believed that it would be a 'waste' to provide ART to IDUs since they would run into drugs again and they might even sell ARVs to get money for buying drugs. Our study finding that even former drug users themselves doubted their ability in adhering to ART is consistent with findings from other studies that identified doubt about one's ability in ART adherence as a barrier to initiate ART (Bassetti et al., 1999; Kerr et al., 2005; Wood et al., 2008). Such uncertainty and lack of belief in their self-efficacy are more likely to be due to the frequent relapse experienced by drug users. But it just points out that IDUs - whether current or former users - require support for initiation of and adherence to ART. And it is important to provide that support to them – in the form of enrolling them in drug-dependence program or opioid substitution program before ART initiation or while they are on ART; and enrolling them in relapse prevention programs and post-de-addiction rehabilitation programs.

Our findings are also consistent with other studies that have demonstrated that physicians may be reluctant to prescribe ART to IDUs because of the perception that IDUs may not properly

adhere to ART (Bassetti et al., 1999; Ding et al., 2005; Escaffre et al., 2000; Gross et al., 2002) and the belief among physicians that IDUs may be more likely to develop and transmit ARV-resistant HIV strains (Wainberg et al., 1998). While IDUs are known to have lower levels of ART adherence because of various reasons (Wood et al., 2008), studies have demonstrated that many IDUs can manage high ART adherence (Wood et al., 2003; Wood et al., 2008). The conclusion reached by many ethical analyses that physicians should not indefinitely and arbitrarily withhold ART from patients on the basis of the presumption that they will not be adherent is strengthened by many studies (Bangsberg et al., 1997; Bangsberg et al., 1999; Bangsberg et al., 2001) that have shown that providers are poor judges of patients' adherence to ART (Wood et al., 2008). Also, the concern of providers regarding potential for increased rates of ARV resistance among IDUs and potential for community transmission of ARV-resistant HIV strains is not supported by evidence (Wood et al., 2008).

Which deters IDUs from accessing ARV services: Lack of treatment-seeking behavior among IDUs or lack of client-friendly services?

It is a complex issue. Traditionally the treatment-seeking behavior of marginalized groups is studied with the good intentions to find out the extent of such 'behavior' and offer solutions to improve that behavior. While individual level interventions to promote marginalized groups may be necessary, they may be insufficient by themselves and ineffective in absence of positive changes in the health care systems that make them client-friendly or client-attractive. Judgemental staff with discriminatory attitude, dispersed service facilities, and inadequate infrastructure of the government hospitals create an unwelcome environment for patients to seek treatment. Not generalizing to all hospitals, the very image of a government hospital has been negative among potential clients and this deters them from seeking treatment. Thus, in addition to taking steps to improve the infrastructure and minimizing/eliminating navigation difficulties, it is also crucial to increase health care providers' understanding about marginalized groups including IDUs and realize their professional obligations and ethical mandate to provide proper care to IDUs and treat them with dignity.

The emphasis on the need to be drug-free before starting ART, by health care providers and even by former drug users, though well-intentioned, is not based on available evidence-based technical guidelines. In spite of the many technical guidelines produced by WHO and UNAIDS that specifically state that current or past drug use should not be a criterion for deciding who should receive ART, health care providers continue to exclude IDUs on the assumption that they would not adhere to ART regimen. WHO guidelines specifically state to health care providers: "counsel every patient on all possible interactions of ARVs with other drugs administered, including substitution therapy drugs, illicit/recreational drugs, and medications for tuberculosis, hepatitis B, hepatitis C, and opportunistic infections. Awareness of interactions and reporting and management of symptoms is critical for the patient's well-being, treatment adherence and effectiveness, and management of drug interactions" (WHO Regional Office for Europe, 2007). It is important that health care providers be properly trained on managing and counseling IDUs living with HIV – especially in relation to ART and interactions with drugs/alcohol. Health care providers should also provide treatment education to IDUs (and other people) using simple terms, without withholding any information and without providing inaccurate information due to personal bias. High patient load or the argument that counselors in ART or VCTC centers focus on HIV risk and not drug use is no excuse for counselors or doctors to not to be competent in providing appropriate counseling in relation to risk reduction and ART adherence among drug users.

Need for better programmatic strategies to address sociostructural barriers

In India, outreach programs for IDUs traditionally focus predominantly, if not exclusively, on HIV prevention and harm reduction. Consequently, there inadequate attention might be given to improving access to ART for HIV-positive IDUs and to assist them in adhering to ART. These outreach programmes can help in identifying HIV-positive IDUs and refer them to HIV treatment and care programs as some programs in other countries have

demonstrated the usefulness of such an approach (Martinez et al., 2003; Molitor et al., 2005; Molitor et al., 2006.). Obviously, increased referrals of IDUs to voluntary HIV testing and counselling will help in identifying IDUs who are unaware of their HIV status and thus linking them with treatment programs.

Like other studies (Angelino et al., 2001; Bangsberg et al., 1997; Chander et al., 2006; Gebo et al., 2003; Knowlton et al., 2006; Lucas et al., 2001; Maisels et al., 2001; Treisman et al., 2001; Weiser et al., 2004), our study has also demonstrated that many other issues - drug dependence-related instability, limited family and social support, and homelessness - create barriers in even initiating ART. Hence there is a need to link drug users with drug dependence treatment and offer housing support for homeless IDUs. Studies have shown that improvements in stability from drug dependence treatment and housing support for homeless IDUs may also help to address physician reluctance to prescribe ART (Maisels et al., 2001). Methadone maintenance therapy has been associated with both improved uptake and adherence to ART (Clarke et al., 2003; Palepu et al., 2006; Sambamoorthi et al., 2000; Wood et al., 2005). In India, methadone maintenance therapy is illegal and unavailable, though NACO is going to scale up sublingual buprenorphine substitution therapy. More recently, buprenorphine has also shown similar potential as that of methadone maintenance therapy (Moatti et al., 2000). Since ongoing drug use significantly contribute to reduced access and lower ART adherence, drug dependence treatment will be very useful since there is evidence that people infected with HIV through injection drug use and who have stopped using drugs may have similar adherence to other risk groups (Lucas et al., 2001). Thus, there is an urgent need to strengthen linkages between the NACO's (National AIDS Control Organisation) needle syringe exchange programs and opioid substitution programs, as well as between these NACO programs and de-toxification/drug abstinence-based de-addiction programs of Ministry of Social Justice and Empowerment (MSJE).

Several studies have demonstrated that police interference can prevent IDUs in accessing HIV prevention and treatment programs (Bluthenthal et al., 1997; Case et al., 1998; Chakrapani et al., 2007 & 2008c; Grund et al., 1992; Koester, 1994; Maher & Dixon, 1999; Rhodes et al., 2006; Rich, Dickinson, & Case, 1998). While advocacy activities might have contributed to minimal interference of police in outreach activities among IDUs in Chennai, there is a need for continued and intensified advocacy with all cadres of police to sustain current support and also to ensure that in the future police do not interfere with HIV outreach prevention and treatment education activities among IDUs.

Action is needed both at the national and state level

Evidence-informed policy formulation requires evidence. In absence of data on how many of the PLHIV who are receiving ART from the government ART centers are from the various marginalized groups (IDUs, MSM, and sex workers), one could not tell whether the free ART is accessed by "all who need it" – as stated by NACO. Both the national and state governments need to develop mechanisms to collect this information and use that information for developing action plans to improve access to ART from all subgroups of people living with HIV – including IDUs living with HIV. Having a national and state policy on equity in ART access, and developing an action plan to ensure equity in ART access is much needed.

Study limitations

As a qualitative study, the primary aim was not to generalize the study findings, but rather to explore in depth the unique perspectives and lived experiences of IDUs (current and former) in terms of ART access. Since the recruitment of study participants was done through persons who previously worked as peer outreach workers, the study participants are more likely to have better information and assistance in access to health services since they are connected to NGOs providing services to IDUs. This suggests even greater problems among IDUs living with HIV who are not reached out by NGOs in terms of ART access. Barriers might be the same or different for those IDUs who are not connected to NGOs that provide services to IDUs; and those who are

from the middle or upper class who usually do not use services offered by NGOs. However, since ART provision is a highly centralized system (implemented through the NACO), the study findings are more likely to be similar for IDUs living with HIV in other cities in India. Thus, when interpreting these findings one should understand that the study has mainly captured the experiences of specific subgroups of IDUs. Study participants from these subgroups had numerous insightful and experience-based suggestions that may inform programs and policies to increase acceptability and accessibility of ARV services for IDUs. The persuasiveness of the various barriers identified in this qualitative study can be further examined in detail through quantitative and mixed-methods studies.

V. RECOMMENDATIONS

1. Treatment education for IDUs and IDUs living with HIV

- Repeat and reinforce prevention and treatment messages to IDUs - in different forms and through different people (peers, doctors and counselors). Treatment messages should not be restricted only to those IDUs who are known to be HIV-positive. Giving ART-related treatment messages to all IDUs (irrespective of their HIV status) helps diffusion of this information among the drug user networks; avoids labeling an IDU as HIV-positive if only he receives treatment messages from outreach workers; and may also motivate IDUs to come forward for HIV testing and enrolment in ART program.

2. Maximize access to quality services in government centers

- Ensure that standard clinical guidelines are followed in screening people living with HIV (especially former or active IDUs living with HIV) for Hepatitis B and C before starting ART or even at the time of HIV-seropositive diagnosis.
- Develop mechanisms to support IDUs (including those living with HIV) for treatment for Hepatitis B and C infections.
- Consider appointing trained peer counselors in government ART centers & HIV testing centres.

3. Training for service providers

- Train professional counselors in government ART centers and HIV testing centres on issues related to IDUs: Drug dependence; Issues surrounding ART adherence in IDUs; and management of co-infections (HIV and HBV/HCV).
- Train outreach workers and peer educators working with IDUs in HIV prevention and treatment programs on: ART-related issues – initiation, side-effects, and monitoring/follow-up, and facilitating ART adherence among IDUs living with HIV; Hepatitis B and C co-infections; TB; and OST and drug dependence treatment.
- Train doctors on proper clinical management of IDUs living with HIV (especially ART management; screening and treating co-infections such as HBV and HCV; and OST) as well as sensitization about drug users and drug dependence.

4. Establish better linkages and coordination at policy and service delivery level

- Establish and strengthen communications among relevant ministries – especially between the National AIDS Control Organization (NACO) coming under the Ministry of Health and Family Welfare and the Ministry of Social Justice and Empowerment (MSJE). At the state level, linkages need to be built among State AIDS Control Society (SACS) and State Department of Social Welfare.
- Screen IDUs (including those living with HIV) for current polydrug abuse and alcohol abuse/dependence and link them to needle syringe programs, OST programs, or de-addiction programs.
- Develop a national policy and action plan on equity to ART access for IDUs (and other marginalized groups) living with HIV and ensure implementation of that plan.

VI. GLOSSARY

(References: <http://hrw.org/reports/2006/ukraine0306/1.htm> http://www.unodc.org/pdf/report_2000-11-3_1.pdf)

Buprenorphine: A medication used in opioid substitution therapy programs. It is included in the World Health Organization (WHO) Model List of Essential Medicines.

Harm reduction: Refers to a set of interventions designed to diminish the individual and societal harms associated with drug use, including the risk of HIV infection, without requiring the cessation of drug use. In practice, harm reduction programs include syringe exchange, drug substitution or replacement therapy using substances such as methadone, health and drug education, HIV and sexually transmitted disease screening, psychological counseling, and medical care.

Injecting Drug User (IDU):

In this report, a broad definition of 'IDUs' has been used to cover people who have injected experimentally or continue to inject occasionally up to and including heavily dependent drug users who may inject several times each day. IDUs may inject legal or illegal drugs, stimulants (such as amphetamines and cocaine), depressants (such as heroin and benzodiazepines) or other drugs such as steroids. They may inject intramuscularly (into the muscle) or intravenously (into the vein).

(Adapted from the definitions of the WHO and UNODC:

<http://www.cdc.gov/outreach/who/Glossary.pdf>; http://www.unodc.org/pdf/report_2000-11-30_1.pdf)

Injection equipment: Items such as syringes, cottons, cookers, and water used in the process of preparing and injecting drugs. Each of these can be contaminated and transmit HIV or hepatitis. The broader term "drug paraphernalia" comprises injection equipment as well as items associated with noninjection drug use, such as crack pipes.

Needle or syringe exchange points: Programs that provide sterile syringes in exchange for used ones. In addition to exchanging syringes, needle exchange points often provide HIV prevention information and screening, primary health care, and referrals to drug treatment and other health and social services.

Substitution or replacement therapy: Substitution therapy is the administration of a psychoactive substance pharmacologically related to the one creating substance dependence to substitute for that substance. Substitution therapy seeks to assist drug users in switching from illicit drugs of unknown potency, quality, and purity to legal drugs obtained from health service providers or other legal channels, thus reducing the risk of overdose and HIV risk behaviors, as well as the need to commit crimes to obtain drugs.

Syringes or needles: The main components of a syringe are a needle, a tubular syringe barrel, and a plastic plunger. Graduated markings on the barrel of a syringe are used to measure the water or saline solution used to dissolve a solid substance into liquid form. Syringes and needles vary in size and do not always come as one piece; a syringe with the needle attached is often referred to as an "insulin syringe." While disinfection of syringes is possible, public health authorities recommend a new sterile syringe for every injection.

VII. REFERENCES

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