



INDIAN NETWORK
FOR PEOPLE LIVING
WITH HIV/AIDS

Barriers to Free Antiretroviral Treatment Access for Men Who have Sex with Men & Transgender Women in Chennai, India

November 2008

Barriers to Free Antiretroviral Treatment Access for Men who have Sex with Men (MSM) and Transgender Women in Chennai, India

November 2008



*Venkatesan Chakrapani, M.D.¹, Peter A Newman, Ph.D.²,
Murali Shanmugam, M.S.W.¹, Sandy Michael, M.S.W.¹*

¹ Indian Network for People living with HIV and AIDS (INP+), India

² University of Toronto Faculty of Social Work / Centre for Applied Social Research

Copyright © Indian Network for People living with HIV (INP+), 2008.

Suggested citation: Chakrapani, V., Newman, P.A., Shanmugam, M., Michael, S. (2008). Barriers to free antiretroviral treatment access for men who have sex with men (MSM) and transgender women in Chennai, India. Indian Network for People living with HIV and AIDS (INP+), India.

Contact

Indian Network for People Living with HIV and AIDS (INP+),
New No 41 (Old No 42/3), Second Main Road,
Kalaimagal Nagar, Ekkaduthangal, Chennai - 600 097
Ph: + 91-44-22254670-74/ 42641580
Web: www.inppplus.net
E-mail: inppplus@eth.net, inp@inppplus.net

First author contact e-mail: cvenkatesan@hotmail.com

Contents

- *Acknowledgements (p-4)*
- *Acronyms and Abbreviations (p-4)*
- *Abstract (p-5)*

I. Introduction (p-6)

II. Methods (p-7)

III. Findings (p-9)

- A. Individual level barriers (p-9)
- B. Social barriers (p-13)
- D. Healthcare System and Programmatic Barriers (p-14)

IV. Discussion (p-19)

V. Recommendations (p-21)

VI. Glossary (p-23)

VII. References (p-24)

Acknowledgements

Indian Network for People living with HIV (INP+) thanks all the study participants for openly sharing their personal life experiences, views, and opinions on the various factors that influence access to antiretroviral treatment for men who have sex with men (MSM) and Aravanis/Hijras (Transgender women) in Chennai, India.

We thank the following Chennai-based community-based organizations for their help in data collection: Social Welfare Association for Men (SWAM), Sahodaran, South India Positive Transgender Foundation (SIPTF), and Transgender Rights Association. We thank other INP+ team members - Mr. James Anthony, Mr. Christuraj Puthotta and Mr. Alagarswamy – for their support in study implementation. We also thank Dr. Jaikumar Velayudham, M.D., and Mr. D. Dinesh Kumar for assisting in data analysis.

We also appreciate the hard work and commitment of our community-based field research team. And our sincere thanks to INP+ board members – especially Mr. K.K. Abraham and Mr. Bobby Jayanta – for their guidance and support. This study was supported by the International Treatment Preparedness Coalition (ITPC), and ‘Sarvojana’ project funded by EU/HIVOS.

Acronyms and Abbreviations

- AIDS** – Acquired immunodeficiency syndrome
- ARV** – Antiretrovirals
- ART** – Antiretroviral treatment or therapy
- CBO** – Community-based organization
- FGD** – Focus Group Discussion
- HIV** – Human Immunodeficiency Virus
- ICTC** – Integrated Counseling and Testing Centres
- INP** – Indian Network for People living with HIV
- KII** – Key informant in-depth Interview
- MSM** – Men who have Sex with Men
- 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

Since 2004, Indian government policy has mandated free first-line antiretroviral treatment (ART) for people living with HIV. To assist in developing policies and programs to ensure equity in ART access, we explored barriers to ART access among men who have sex with men (MSM) and Aravanis/Hijras (transgender women) living with HIV in Chennai. Six focus group discussions among MSM and Aravanis (n=34 participants) and 6 key-informant interviews were conducted, audio-taped, transcribed and translated. Data were explored using framework analysis to identify categories and derive themes. Findings reveal barriers at several levels – individual, social, and healthcare system and programmatic. Barriers to ART access for MSM and Aravanis need to be addressed by: implementing interventions to reduce stigma at societal and health care system levels; adopting MSM- and transgender-friendly procedures in healthcare settings; providing treatment education on ART and eligibility criteria; training peer outreach workers and staff of non-governmental organizations on treatment education; strengthening linkages between HIV prevention and treatment programs; addressing unmet basic needs; and creating and implementing a national action plan to ensure equitable access to ART for all marginalized groups.

I. INTRODUCTION

The availability of antiretroviral treatment (ART) has significantly changed the prognosis of people living with HIV (PLHIV). Although not a cure, life-long ART controls viral replication, restores immune system function, and improves the quality of life of PLHIV. It also reduces infectiousness, thus exerting a major synergistic impact on HIV prevention.

In India, an estimated 2.47 million people were living with HIV at the end of 2006 (NACO, 2008a), the third highest number in the world. Since April 2004, the government of India has been providing free first-line ART through government ART centers.

India's National AIDS Control Organisation (NACO) estimates that among the 2,376,140 adults living with HIV in India, about 25% (603,125) require ART. Of these, only 20% (118,052) were receiving free ART from government ART centers as of December 2007 (NACO, 2008a). A major challenge for government ART centers is to expand access to free ART. Another key challenge is ensuring equitable access to free ART for marginalized populations such as men who have sex with men (MSM) and transgender women (Hijras/Aravanis).

Based on the work of Braveman and Gruskin (2003), equity (vertical equity) refers to policies and programs that aim to address the prevention of health inequalities – differences in the health outcomes that are unnecessary, avoidable and unfair. Vertical equity therefore applies to the process of reaching equal outcomes, and involves allocating greater resources to ensure reductions in health outcomes differentials. By necessity, vertical equity also entails addressing power imbalances that underlie inequalities in outcomes and processes (Braveman & Gruskin, 2003). With regard to ART, vertical equity implies equal opportunity to access ART across populations of persons living with HIV.

MSM and transgender women have been recognized by NACO among “core high risk groups” that are worst affected by the HIV epidemic in India (NACO, 2007a). The estimated size of MSM and male sex worker populations in India is 2,352,133 and 235,213 respectively (NACO, 2006); no numbers are available for transgender women. HIV prevalence among MSM in India has been estimated at 7.4%, over 20 times the general population rate and in Tamil Nadu, it is 6.6% (NACO, 2008b). No official data is available on the HIV prevalence among Aravanis in Chennai.

NACO maintains that public health facilities need to ensure that ART is provided to PLHIV referred from interventions targeted toward marginalized communities, including MSM and transgender women, as well as female sex workers and injecting drug users: “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, 2006 – p.114). However, in practice, free ART from government centers is available on a first-come-first-served basis, for those who satisfy medical eligibility criteria.

At the end of August 2007, only 128 Hijras (transgender women) were receiving ART through the 127 ART centers supported by NACO. No information is available from NACO on the number of MSM on ART through its national program (NACO official, e-mail communication).

Positive people networks and community organizations working with marginalized groups report that marginalized groups living with HIV including MSM and transgender women have limited access to free first-line ART provided in the government ART centers and this has been documented in a series of reports from the International Treatment Preparedness Coalition (ITPC) (Chakrapani, 2005; Chakrapani et al, 2006a & 2006b; Abraham et al., 2007a & 2007b). An ITPC report quotes a community leader, “MSM who are very feminine

face discrimination in the government centers and thus many do not want to go to visit them. In addition, many MSM are reluctant to seek ART access because they are afraid that other MSM will find it out" (Chakrapani, 2005).

To address inequities in ART access for marginalized groups, it is crucial to identify their different needs and constraints when accessing ART and to design interventions accordingly (Kalanda et al., 2007; Braveman, 2003). Hence, this study was conducted with the goal of developing suitable strategies to enhance ART access to MSM and Aravanis living with HIV.

The **purpose** of this study was to explore and understand the barriers faced by MSM and Aravanis living with HIV in Chennai to access free ART provided in the government ART centers.

ART Availability in Chennai

ART is only one component of comprehensive HIV clinical management, which includes among other components – treatment and prophylaxis for opportunistic infections, and treatment adherence counseling. In this article, when we refer to ART access, we mean the free first-line ART regimens available in the government ART centers supported by National AIDS Control organization (NACO), India. The first-line ART regimens available are: a combination of zidovudine, lamivudine, and nevirapine; and another combination of stavudine, lamivudine, and nevirapine. For patients on treatment for Tuberculosis, nevirapine is substituted with efavirenz. The three NACO-supported government ART centers that provide ART to adults are located within the major government hospitals in Chennai. MSM and Aravanis living with HIV usually take ART from one of these ART centers.

II. METHODS

Six focus groups, three among MSM (n=17) and three among Aravanis (n=17), and 6 key informant interviews were conducted in the last quarter of 2007. Key informants were community leaders of agencies that work with MSM (n=2) and Aravanis (n=2) in Chennai. Focus group participants were recruited using purposive sampling through four community-based organizations to reflect diversity in terms of area of residence, living situation (with family members or alone) and duration of contact with the service agency. Recruitment was conducted by volunteers from these community-based organizations by word-of-mouth only to avoid potential risks to participants through being identified as MSM or PLHIV. Participants also were selected based on ability to articulate their own and their peers' experiences and perspectives in relation to accessing free ART from government ART centers.

Key informant interviews focused on exploring perspectives and experiences in relation to free ART access for MSM and Aravanis as well as eliciting insights on how to address barriers in ART access.

All focus groups were conducted in a private room at organizations that work with MSM and Aravanis. All participants provided written informed consent, 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 and key informant interviews were approximately 60 minutes. An honorarium of 250 Indian rupees (about 7 US dollars) was given to focus group participants. 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, 2008a) and sexual health services (Chakrapani et al, 2008b), we hypothesized that barriers to ART access might occur at several levels: individual, social and healthcare system. 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 MSM and Aravanis' access to free ART from government health care centers.

Using the framework approach, we devised an a priori coding scheme to identify themes at different levels (i.e., individual, healthcare system, etc.). Three data analysts coded two focus groups and two interviews 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, by consensus. 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 hypotheses. Theoretical coding was undertaken to identify higher-level codes and relationships among categories (Charmaz, 2006; Glaser, 1978). In presenting the themes and sub-themes, we incorporate 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 MSM and Aravanis. 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). Member checking was not conducted among focus group participants due to concerns about confidentiality; no information was collected to track participants. Researcher triangulation between investigators in India and Canada, 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

MSM participants (n=17) ranged in age from 23 to 43 years (mean = 32 years). Twenty-four percent (n=4) had completed higher-secondary education; 53% (n= 9) were self-employed; 41% (n=7) were married; and 29% (n=5) were on ART. Eight (n=47%) participants engaged in sex work (part-time).

Aravani participants (n=17) ranged in age from 23 to 46 years (mean = 34 years). Twenty-four percent (n=4) had completed high school; and 24% (n=4) were on ART. Eleven (n=63%) participants engaged in sex work.

III. FINDINGS

A. INDIVIDUAL LEVEL BARRIERS

Fear of adverse consequences of disclosure of HIV status

Some participants were worried about initiating ART because of the increased chances of their HIV-positive status being known to others with its potential adverse consequences. Fear of rejection by one's own community was a commonly cited reason:

“There is a belief among Aravanis that [when HIV-positive status] is exposed, they might be rejected [in the Aravani community]. So they decide not to disclose their [HIV status] and take medicines as far as they live.” (An Aravani participant)

An Aravani key informant offered similar reason:

“[Some Aravanis say] ‘I live in a group. If I take ART regularly in morning and evening, my community will come to know. Whatever measures I will take to cover up my HIV-positive status, my community people will eventually come to know that I have this disease [HIV]...’ There are some reasons like this [that hinders ART initiation].”

Another Aravani key informant said: “Jealousy and envy are more common among Aravanis. They always think in what way to attack other [Aravanis]. In this situation, if I take medicine regularly, they will tell that, ‘she has got *Pootchi* [a code language – referring to HIV].”

Similar concerns were shared by Kothi-identified MSM. As a kothi participant said: “Some [MSM] hesitate to take these [ART] tablets. We can take these tablets in the hand and go. Surely among the friends circle, they will ask why he is continually taking tablets.” Thus, anticipation of practical difficulties in taking tablets and having heard about involuntary disclosure of HIV status of kothis once they start taking tablets and subsequent isolation prevent many people from initiating ART.

Aravanis in sex work were afraid of losing their clients and thus loss of income if their HIV status is outed by their sex work colleagues. This fear seems to be a strong deterrent in initiating ART. As an Aravani participant said: “While in sex work, if their [HIV-positive] status is revealed, that will reduce the number of clients and their business [income] will be affected. So knowingly they do not take tablets. This is the main reason.”

However, some Aravanis do voluntarily come forward to get ART from government ART centres in spite of the potential stigma and discrimination. As expressed by an Aravani key informant: “A few Aravanis voluntarily coming to get ART say, ‘What has the society done me? What we are going to do by being afraid of society? Our body and health is important for us’.” Thus, some Aravanis who gives priority to take care of their health come forward to get ART though other enabling factors might also be responsible.

Unlike Aravanis, many Kothi-identified MSM live with their biological family members but without disclosing their sexuality and HIV-positive status. Hence, they are afraid that since they need to give their personal profile and contact details while registering in ART center, their acquaintances might come to know about their HIV status and thus their entire family will be looked down upon by the society. This fear of bringing shame to the family often deters them from initiating ART. As a kothi key informant said: “Some kothis think that, ‘if we go to hospital, we have to write the names of our parents. [Then] everyone will eventually come to know about this’. Then, [society] will look at the entire family in a different way.”

Unmet basic needs

Key informants and participants stated that once the family members come to know about what they perceive as gender-inappropriate behavior of their son, Aravanis are evicted from their home or they run away from their home because of the pressure to behave in a masculine manner or to get married to a woman. These Aravanis then come to cities like Chennai and take shelter in low income areas such as slums where even basic amenities are hard to access. As an Aravani key informant said:

“Most of us don’t have our basic needs met. We don’t have proper place to stay. Only slum [people] supports us. In slums, there will not be adequate cleanliness, water facilities will not be fine, food will not be hygienic, mosquitoes problem... typhoid and malaria will come... they [Aravanis] have told in our field [visit] that due to these issues they are not taking [ART].”

Similar to Aravanis, most Kothis are from lower socio-economic status and their struggle to meet their day-to-day needs prevent them from initiating ART. As expressed by a kothi-identified MSM participant: “[Some Kothis would say] ‘we are struggling even for our survival, above this, what I am going to get by taking ART?’.”

Participants reported that some kothi-identified MSM engage in sex work – part- or full-time – to meet their day-to-day needs. Thus, if their HIV-positive status is known to others – other kothi friends or their male clients – they may lose earning money – thus affecting their very survival. Thus, kothis in sex work prioritize engaging in sex work over ART to sustain themselves. As a kothi key informant said, “They are living with hundred rupees per day [that comes] from sex work. When things are like that, only that [money] could be their priority. Only for that [money], they [Kothis] will give first preference.” Key informants mentioned that absence of adequate education and lack of other job opportunities also prevent some Kothis from engaging in any other work.

Practical difficulties in taking ART during sex work hours was another reason cited by the participants:

“...[Some] could not allocate time for taking medicine [ART] while going for *pick up* [English term as used. In this context, the term ‘pick up’ refers to sex work - going to cruising site to find male clients].” (A kothi key informant)

Similar reason was offered by an Aravani participant: “Mostly Aravanis are in to sex work and clapping [refers to going from shop-to-shop to get money from shopkeepers]. So they would not able to take tablets [ARVs] on time... Hence they avoid [initiating ARV] tablets.”

Lack of knowledge about HIV status and late diagnosis

Knowing one’s HIV status is important for getting enrolled in ART program. However, MSM and Aravanis face several barriers in knowing their HIV status. Some get tested for HIV only when they experience severe or prolonged symptoms suggestive of HIV illness. As an Aravani key informant said: “[Aravanis might say] ‘only when I get symptoms, I will check my body. Until that, whatever [number of] counseling sessions I attend, I never go [HIV testing]’.” Thus, lack of early diagnosis means often an infected person presents only at a relatively later stage.

For some Aravanis, low HIV risk perception prevents them from knowing their HIV status. As expressed by an Aravani Key informant: “There also people who says, ‘let us see when it [HIV] comes. Now I am healthy and ... strong enough’.” For some others, fear of rejection and isolation within the Aravani community prevent them from knowing their HIV status. As an Aravani participant said: “The reason for [lack of HIV testing] is... They [Aravanis] think

that, 'if our community comes to know [about HIV-positive status], they will isolate us'. For every small issue, they [community] will say, 'you have *pootchi* [code word for HIV]."

Similarly, some Kothis are reluctant to get tested for HIV. Even if they come to know about their HIV-positive status, they lack interest in further follow-up or treatment. As expressed by a kothi key informant: "Some [MSM] will never come for HIV testing, even if they come, they say, 'it is all right, let us spend our life like this [as usual]'."

Not seeing any benefits in taking ART

Even after knowing one's HIV-positive status and medical eligibility for ART, some do not see any benefits in taking ART. As told by an MSM key informant, "[Some Kothis will say] 'it is okay, let us live like this [without taking medicine]. Death can happen at 6 years or 100 years [referring to a Tamil proverb which means that a person can die at any age and hence one should not be afraid of death]'." Thus, fatalism and pessimism might also play a role in not initiating ART.

There could be several reasons behind inadequate understanding about the possible benefits in taking ART. A married person who is HIV-positive may want to take ART for the sake of his/her family. But in the absence of supportive family members, and lack of a steady male partner and legal recognition of marriage with a man, some kothis and Aravanis lack motivation to initiate ART. As a kothi key informant said:

"Generally, kothis don't have [interest] that 'we have to live'. ... There also people like – 'We don't have married life. Why we have to live? Okay, we live till my beauty and youth remains. See, already I got this [HIV]. Thus living for ten to fifteen more years is enough. My life is that's all. Then, why should I take treatment?"

An Aravani key informant suggested the need for appropriate communication materials that appeal to Aravanis: "If posters without many words but with a picture stating, 'I am living healthy by taking this medicine [ART]'... This will reach out to our people [Aravanis]."

Having seen or heard about people on ART who are living healthily for several years helps some people to initiate ART. As an Aravani key informant said, "[some Aravanis think] 'If someone is living for 20 years by taking ART, we can also live'. That motivates them from taking the medicine." Similar explanation was offered by a Kothi-identified MSM who is also a peer educator:

"We will tell them [other Kothis]. 'See, there are people who live for twenty years with HIV. We will not die immediately after becoming positive. If we take proper food and ART we shall live for many years'. Like this, we advice them and ask them to take ART."

Thus, peer educators motivate others to take ART by citing those healthy MSM and Aravanis living with HIV who are on ART.

Alcohol use

Participants mentioned that patients who get registered for ART are strictly advised by counselors and doctors not to consume alcohol while on ART to ensure adherence to ART. Some Kothis who regularly take alcohol do not want to initiate ART since that might require stop taking alcohol. As expressed by kothi key informant: "They [kothis] don't wish to stop drinking or smoking. Since that is not suitable for ART, they are not taking it."

Also, some kothis are afraid of side-effects if they resume alcohol use while on ART. This fear potentially prevents them from initiating ART. As a kothi-identified MSM participant said:

“What they [kothis] think is those who drink alcohol cannot take this tablet [ARVs] and one who takes this tablet should not be consuming alcohol. In case they take ART along with alcohol there will be side effects... some may feel so... may be due to this [reason] they do not want to take [ART].”

Similarly, some Aravanis who use alcohol face practical difficulties in foregoing alcohol use even if they are eligible for ART. As an Aravani key informant said, “If CD4 [count] is reduced and they [Aravanis] get referred to ART, they cannot stop that habit [alcohol use]. If stopped suddenly, their hands and legs will start shaking [referring to the alcohol withdrawal symptoms]...”. An Aravani informant pointed out the reason behind alcohol use:

“You asked us why we consume alcohol... several reasons – we were evicted from our home by our own family members. Now there is no one to support and we don’t have a decent job for our livelihood. On the top of everything, we face problems from our [sex work] *customers* and *beelis* [referring to ruffians]. To forget all these sufferings, we drink. If we need to stop drinking alcohol – you need to stop all these problems we face.”

Thus, we need to address alcohol dependence among Aravanis not only to improve access and adherence to ART but also to address the various issues that primarily compel them to consume alcohol.

Lack of self-efficacy in ART adherence

Some Aravanis and MSM are hesitant to take ART since once initiated it has to be taken lifelong. As an Aravani key informant said: “[Some say] ‘If I initiate ART, I have to take it for life long’. ...they tell reasons like this ... and keep postponing taking it...[or] don’t go for check-up for CD4 [count].”

Currently, ART regimens offered in the government hospitals have to be taken twice daily. For some, adhering to twice-daily regimen seems difficult. A kothi participant said, “Some kothis think that they could not regularly take it [ARVs] twice daily. For them, that [taking twice-daily] is a problem”. Another Kothi participant said:

“What they [counselors] said was - we need to take [ART] continuously similar to sugar tablets [anti-diabetes medications]. Even if it [ART] missed for a day, [it] will become big problem. So we are afraid that we might get some other problem if we do not take regularly. Hence [they] hesitate to take ART.”

Thus, not sure about being adherent and worried about the consequences of non-adherence make some people to delay or not to initiate ART.

Insufficient and incorrect knowledge about ART, and Belief on alternative medicines

Some kothis do not possess adequate knowledge about medical eligibility for ART and places of ART availability. As a kothi key informant said: “What many people think is, ‘Only when the [CD4] count becomes very low, we have to take ART’. They don’t have in-depth knowledge about when to take ART. Don’t know where it is available.”

As an Aravani key informant said: “Some people think that, ‘Ah! Why should we take ART? We are taking good diet. Isn’t it? Then whether ART is necessary for us? No’.” While this could be because of fear of side-effects and belief that adequate food alone may control HIV disease, such a belief also prevents them from even knowing whether they are medically eligible for ART initiation.

Some Kothis and Aravanis believe that there is cure for HIV in alternative and traditional medicines. While peers and health care providers keep stressing that there is no cure for

HIV, some practitioners of alternative and traditional medicine promise cure for HIV. Hence, some want to try these medications. As a kothi participant said: “In Siddha and Unnani [medicines] they [practitioners] say that they cure it [HIV] 100%. They do what the *English* [allopathic] medicine can not. So [people] believe this and they go.” An Aravani community leader also shared that view: “Apart from ART, I have heard about Homeopathic medicine... they [Aravanis] told that this homeopathic medicine is better.”

B. SOCIAL BARRIERS

Lack of family support

Participants reported that many Aravanis are evicted from home by their family members and are forced to live in low income areas alone or together with other Aravanis. An Aravani key informant expressed the connection between family support and ART initiation:

“[Aravanis] need love from someone. Aravanis needs support. Someone should encourage me when I think – ‘Why should I take ART?’ Only once, counselor can tell like this, - ‘Take food on time, only then you will be fine’. Even for me, if my family supports, I will be healthier.”

Participants mentioned that though some kothi-identified MSM live with their parents or wife, some kothis lack family support and live alone. Loneliness and lack of family support discourage them from initiating ART:

“Those who live with their family will take ART regularly. If father and mother knows about this matter [HIV status], they will tell, ‘Time is 9’O clock, take medicine [ART]’. There is no one for me. I am living alone for two years. No one will tell me to take ART.” (A Kothi who is considering initiating ART)

Even those kothis who live with their family members usually do not disclose their sexuality and HIV status. According to a kothi key informant: “Only 10 out of 100 tell that they have HIV to their family while the remaining kothis’ families will not be aware of it...”. Thus, in spite of living with their family members for fear of negative consequences kothis usually do not disclose their HIV-positive status resulting in not getting any potential support from their family members.

Usually if kothis reveal their HIV-positive status without disclosing their sexuality, there might be tolerance and family members especially wife may take care of that person. However, kothis who had disclosed their sexuality to family members reported not getting adequate support. A kothi-identified MSM narrated:

“My parents were looking for an alliance for me. Hence I wanted to know whether I have HIV – since I had sex with several men...It was a shock that I was found to be [HIV-]positive. My parents eventually came to know that I have HIV as well as how I got it. They told me they would take care of me even if I am HIV-positive – but they had one condition – that I should not tell others how I got it...Even now my relations with my parents and brothers are strained...No dignity. But life goes on.”

Thus, in spite of living with his family members, this kothi did not seem to have the much needed psychosocial support.

Some Kothis who are married or living with their family members are motivated to take ART. As a kothi key informant shared: “Kothis think that we have to live for the sake of our family. We have to save some money for them before we die. Thus they want ART.”

Discrimination and Lack of support from Aravani community

Aravanis living with HIV face discrimination from their own community. As shared by an Aravani key informant: “No one is encouraging them [HIV-positive Aravanis] to take medicines properly or console them to take care of their life. There is no adequate awareness and sensitization within our community. If there are ten Aravanis living together in a place and if one found to have HIV then the other nine Aravanis will discriminate her. No one takes care.”

A similar view was shared by an Aravani participant:

“Taking tablets would reveal one has HIV. You can take tablets for 5 days – 10 days. But for lifelong? Others will [eventually] come to know. Even if I take ordinary tablets for cold – my [Aravani] friends are asking ‘Do you have *Pootchi* [HIV]? – It has become a joke. But once an Aravani is found to have HIV then she will be isolated. Some avoid taking any tablets for this matter.”

In spite of the apparent lack of support for HIV-positive Aravanis from Aravani community, participants and key informants desired a proactive role of Aravani community members in taking care of PLHIV from their own communities.

An Aravani key informant suggested that peers can take up the role of caregivers who can help with preparing food, accompany them to hospitals to find out whether they need ART and then to monitor adherence if ART is initiated:

“If we arrange food in time for them, there are more chances [for them to get enrolled in ART program] ... if a *TG* [English word as used – referring to the term ‘transgender’] is on ART, some other *TG* should always monitor her... For others, we need to ask - whether taking ART or not, what is the reason [for not finding out their eligibility for ART]. If we do like this, they will come to take ART.”

Similarly, another key informant suggested increased home visits to Aravanis living with HIV to help them in enrolling in government ART program and to follow-up with those who are on ART:

“More chances to start ART will occur, when peers [peer educators] go to [field and] home visits. The reason is, I cannot tell my problems to a men or women but I will express it to another Aravani. Even if they don’t solve my problems, at least they will listen to me and talk a few words in a friendly manner.”

However, an Aravani key informant who manages a community-based organization said that: “Many Aravanis [living with HIV] go and take ART with the help of our outreach staff and volunteers.” But she agreed that outreach to Aravanis living with HIV need to be scaled up. Some Aravani participants also acknowledged that referrals by program staff of non-governmental organizations helped them in ART initiation.

C. HEALTHCARE SYSTEM AND PROGRAMMATIC BARRIERS

Negative experiences with health care providers

Though in some government hospitals, the attitude of health care providers are in general considered positive by many study participants and key informants, several incidents of discrimination against Aravanis and MSM communities in some centers were narrated. Having had prior negative experiences and having heard from people who had faced discrimination in the government health care system act as a strong deterrent for some people to go ART center.

A Kothi participant narrated an experience when he went for check-up for sexually transmitted infections in the government hospital:

“They [doctors] know that I have [HIV]. They will tell ‘open and show’, ‘turn this’, ‘turn that side’. They will not touch us at all [in the genital examination]. For namesake they will wear gloves but they will not touch. They will ask us to show. ‘Ok, Ok, now close and wash your hands’. If the doctor is sitting here we will be sitting 5 to 10 meters away, this is what happens in a Government Hospital.”

Some kothis were concerned about the possible discrimination from doctors that prevented them from revealing their sexual orientation. As a kothi shared:

“[Doctor] asked me ...‘Where did you go and get this disease?’ I did not want to tell that I am a kothi [same-sex attracted person]. I told him, ‘I went to [a place near Chennai] once. I [had sex] with a woman there’. Then he asked, ‘Is your wife [living] with you [now]? I told, ‘yes’. Immediately he said, ‘you should have done all this with [only] your wife’ Otherwise it [HIV] would not have come’...Imagine what would have happened had I told him that I have sex with men?.”

Thus, while some kothis might still access government hospitals for HIV related services, the stress associated with potential discrimination from providers may prevent some from even accessing basic health care services.

Aravanis complained about the negative attitude of other health care staff when they go for health care check-up. Non-verbal cues and facial expression of supportive staff were seen as unfriendly and humiliating to Aravanis:

“Even while entering inside [the government clinic]... Lower rung staff such as *Aayah* [woman helper] and ward boys will laugh [negatively] at us. We don’t know how we appear to them. According to us, we look good.”

Some Aravanis reported verbal abuse by supportive hospital staff for no specific reason: “Even when we go in queue like everyone else, they would simply shout at us to stand in line without humanity” (an Aravani participant).

Some Aravanis strongly believed that there is a deliberate delay in providing them the necessary services when they visit ART centers:

“When [patients] come to get ART, *normal* [in this context refers to ‘biological’] women will be given ART and sent early. But, when they [pharmacists] see people like us [Aravanis], there is laziness and they will say, ‘Wait for sometime, I will give ART’.”

Thus, both actual negative experiences, and perceived and anticipated discrimination discourage some people from accessing the existing services including ART.

Lack of transgender-friendly registration and admission guidelines

Near lack of understanding of the gender identity of Aravanis pose barriers during registration for ART initiation as an outpatient or in-patient.

An Aravani participant summarized the complex and direct link between gender identity of Aravanis and access to ART:

“Whenever I think of going to hospital I feel as though my life has gone and then come back. [We can not] stand in the queue for males or females. We are bad-mouthed by people standing there as well as by hospital staff. [I] will get very anxious. [We] ran away from [our parent's] home being convinced that we are woman. Now our life has become worse than that of a dog. Why we should lose our respect to get this medicine [ART]. Instead I would rather die. Saying like that, I walked away [from ART centre].”

An Aravani key informant shared that view: “There are lots of things that need to be changed. There is separate queue for men and women. Those men and women see Aravani as an object to mock at.”

Aravanis also face ‘ward problems’, as an aravani participant noted, “That is, hospital [authorities] are confused about whether to admit them in male or female wards.” In some ART centers, PLHIV who are eligible for ART need to be admitted in the hospital for two weeks to initiate ART under medical supervision. Aravanis are concerned about the lack of sensitive guidelines on this. As an Aravani key informant said:

“Some hospitals put us in male wards and some in female wards. Until recently, in [name of the hospital] we were asked to put on a male dress and admitted in male ward even if we are *Nirvan* [emasculated] and in *Chatla* [in woman's attire]. Now there is relatively better understanding.”

In Tamil Nadu, recent initiatives from the government has resulted in some, but not all, Aravanis getting ‘ration card’ (card to get essential food items at a subsidized price) and voter's identity card. To facilitate follow-up of patients, a valid identity / address proof is required for getting enrolled in government ART program. This poses problems for some Aravanis who may not have any valid identity card in their female name. Some Aravanis who are living their biological family members have their name entered in their family ration card as a male and thus they are asked by the ART centre staff to get registered only in their male name. While some Aravanis half-heartedly agree with this requirement out of need for free ART, for some other Aravanis it is very humiliating since they want to be recognized as a woman or transgender woman. As expressed by an Aravani key informant:

“When [patients] go for ART, they [service providers] ask for address proof. They will ask either to bring *ration card* or *voter* identity card. Until now, Aravanis have not been recognized as Aravanis [means no legal recognition of being an Aravani] ... they [Aravanis] are asked to bring *ration card*, if they bring in male name, the name called out in their [biological] family... they [service provider] tell that, ‘If you are in that name [name mentioned in proof], I will not give ART or else I will give [ART] only in [your] male name’... They [Aravanis] get confused and do not know what to do. They will think, ‘How we could get [ART] in male name when we rejected it [being a male].’”

However, key informants reported that those Aravanis who are accompanied by community organizations usually do not face this problem, since the organizations convince service providers that they will follow-up with those patients if they are enrolled in the ART program.

Counseling services: Perceived inadequacy and the need for community counselor

In general, many participants mentioned that counseling services in the government hospitals have improved a lot over the years. Some Kothi participants reported getting adequate information about ART in the government ART centers. As a kothi participant said, “They [counselors] gave full information about ART. Some people understood and wanted to take ART.”

However, some Aravanis were not satisfied with the quality of counseling services offered in government ART centers. Aravanis expected more details to be given to them when they go for counseling. As expressed by an Aravani key informant:

“In Govt. hospitals [ART centres] counselors are only telling about how to take ART – but no details on how to increase CD4 count such as – ‘If you take milk, your bones will become stronger; If you take date fruits, you will get iron’ – are given. They only tell that your CD4 count is low - you have to take ART.... If they [counselors] make them [PLHIV] to sit and give counseling only as a mere routine [without involvement], I would say that what they do is not fair.”

Participants pointed out that lack of privacy during counseling inhibit Kothis and Aravanis from discussing about connections between sexual behavior and ART, or even to get more details about ART. Key informants added that since many government hospitals lack adequate private rooms, following the recommended national guidelines such as providing counseling in a private room do not happen: “They don’t even have a door [in the counseling room], there is only one screen. People keep coming and going. People peep-in to check whether the talk [counseling session] is over or not. I can’t ask any details. She [counselor] also does not have time. Many are waiting...There is no privacy.” Thus, lack of adequate time due to high patient load and lack of private room means not adequate time is spent in counseling people on ART which might be the reason for the resentment among Kothis and Aravanis living with HIV.

Key informants said that ART centers do not employ counselors from the Aravani community in spite of selected number of Aravanis having been trained on HIV counseling. Not having an Aravani counselor in the government hospitals was a lacunae expressed by many participants, possibly because of the debate during the time of data collection on whether to employ people who are HIV-positive or from the marginalized communities in the government centers. An Aravani key informant expressed that, ‘general’ counselors are less likely to have adequate knowledge and sensitivity to deal with Aravanis – especially they may be ill-equipped to deal with the key issues of Aravanis – which is their gender identity:

“They are counselors from general population. How come they can have that much sensitivity or understanding [about Aravanis]? They don’t know about Aravanis. They might think – ‘Oh! They [Aravanis] have HIV too’. Beyond that, maybe not much will be done by them. How will they call [Aravanis] and ask them to sit [referring to which pronouns they will use]? These are important to us.”

An Aravani key informant offered another reason for why Aravani counselor might do a better job: “It would be nice, if Aravanis are there to give counseling for us... Because, they will have in mind that these people belong to my own community. We have to take care of them’ Thus, the job [services] will be good. Everyone will be benefited.” Thus, she felt that because of the sense of belongingness and sensitivity, trained Aravani counselors can provide quality counseling services.

Inadequate mechanisms to address the need of Aravanis who migrate often

Aravanis who have started taking ART from Chennai often face problems in getting ART when they migrate to other places even within Tamil Nadu. As expressed by an Aravani participant:

“[Some] Aravanis are never attached to a place. They keep shifting places often. There are also some Aravanis who will stay in Chennai away from their native places. They will be on ART here [in Chennai] and when they go to [their] native place to stay there [for some months], then getting ART [from the nearest ART centre] is a big problem. They cannot change the record details to get it in a different

place. We have to get a letter from the doctor [in Chennai]. In this way there are so many procedures to be followed.”

Having heard these stories, some Aravanis hesitate to take ART even if they are willing to take. As participants noted, some Aravanis in Chennai have another issue – they want to take ART from an ART centre which is not located in Chennai since they are concerned about their HIV-positive status being known to other Aravanis. However, they too find it difficult to get enrolled in ART centers in other places because of the need for valid address proof at that locality. Those Aravanis who frequently change their city of residence found it very inconvenient to cope with all the bureaucratic procedures to be followed for getting transferred from one ART center to another each time they change their residence.

Because of these various difficulties faced in the government health care system, some prefer to receive ART through agencies that work for Aravanis and MSM:

“Many people [Aravanis] think, ‘it is difficult to get ART through hospitals [ART center] and it would be fine if it is given through organizations that work for us [community-based organizations].’ (An Aravani community leader)

Lack of adequate information on ART in government-supported HIV programs

Participants and key informants said that in targeted interventions among MSM and Aravanis, much focus is given on providing HIV prevention education, and condom promotion and distribution but relatively little attention is given to providing ART-related information. Key informants opined that lack of adequate training among outreach workers and peer educators could be another reason why adequate information on ART is not provided:

“Both in NGOs and CBO, focus is only on how to protect oneself from getting HIV. Outreach worker is not telling what [to do] after one gets HIV ...[They] distribute condoms, give *jelly* [water-based lubricants], [and talk about] how to do safe sex ... [But] No clear information on ART is given [by outreach workers]. [NGO] have to train them. Will they [outreach workers] always have to tell only about STD and HIV [in the field]? They can also tell about ART.”

Aravani participants complained that even counselors with NGOs give little information about ART though they give adequate information about nutrition and hygiene for PLHIV. Often, they seem to provide ART-related information only when the medical eligibility is satisfied:

“[In NGOs] if they become HIV positive, counseling will be given like this – ‘Take this food. Take healthy food. We have to increase CD4 count’ and so on. Even in NGOs, it is rare for them to talk about ‘there are first-line and second-line in it [ART]’. Only 20% tells that...They talk about ART only after seeing CD4 count. Before that, no one talks about ART”

By not providing adequate information to all PLHIV coming to NGOs or the government hospitals, ART initiation might be delayed for some PLHIV.

Lack of mass media campaigns on ART and free government ART program was another reason for limited knowledge of ART among MSM and Aravanis. As a kothi participant said, “Government has to start [ART] campaigns. They often give advertisement about HIV testing. Similarly, they need to give ‘advertisements’ on ART in the public media. And everyone wants to see that.” Similar view was shared by a Kothi key informant, “MSM who are not reached out by NGOs do not have chance to know about ART. Through mass media one can tell about ART that, ‘If [HIV-positive] people take ART, they can live longer’.”

IV. DISCUSSION

MSM and Aravanis in Chennai face a variety of barriers to accessing ART, even as it is ostensibly provided free of charge by the government. Obstacles to ART access emerged at individual, social and healthcare system levels. A primary individual-level barrier is strongly linked to the social level: many MSM and Aravanis fear adverse consequences if their HIV-positive status is revealed to others. Strong motivations to keep one's HIV-positive status and same-sex attraction (MSM) secret was intimately connected with HIV/AIDS stigma prevalent in their families and the larger society. Adverse consequences of disclosure include rejection by family, marital discord, eviction from home, and social isolation (Chakrapani et al., 2004, 2007 & 2008), which present powerful disincentives to accessing ART. Those MSM and Aravanis who engage in sex work were reluctant to disclose their HIV status to their sex work colleagues for fear of having their HIV status disclosed to clients, which would result in loss of subsistence income. As a result of fears of disclosure, many MSM and Aravanis postpone initiating ART as long as possible, until they become symptomatic.

While many MSM and Aravanis in Chennai have adequate general knowledge about HIV (APAC, 2006; NACO, 2007b), the present study indicates limited knowledge about ART and treatment-related issues. Similarly, lack of knowledge about ART was found in a multi-state study conducted among MSM and Hijras/Aravanis living with HIV (Chakrapani et al., 2007). Systemic steps that could be taken to improve knowledge about ART include incorporating information about ART into targeted interventions among MSM and Aravanis (WHO, 2003), 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 same-sex attracted and transgender people; and government mass media campaigns on ART availability.

Lack of adequate knowledge may also explain excessive fear of ART side effects, which along with skepticism about allopathic medicine motivates some to seek alternative and traditional medicines in place of ART. There is a common belief among wide segments of the population that alternative and traditional medicines with virtually no side effects can cure chronic diseases that are not cured by allopathic medicine (Chandrashekhara et al., 2002; Gogtay et al., 2002; Mehrotra et al., 2004). Thus, education about ART should include accurate and unbiased information about what alternative and traditional medicines can and cannot do. Recently, the Indian government announced a ban on advertisements that offer potential cures for HIV infection (The Hindu, 2008).

Staff and health care providers at government ART centers share with the broader society negative attitudes toward MSM and Aravanis and conceptions about sexual morality and gender-appropriate behavior, which may lead to inadequate care for MSM and Aravanis. 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 MSM and Aravanis or people from other marginalized groups during these training programs. Misconceptions about same-sex attracted and transgender people as well as the criminalization of adult consensual same-sex sexual behaviors (Section 377 of the Indian Penal Code), often lead people including health care providers to have prejudices and negative attitude towards these communities and justify discrimination. Lack of understanding of transgender people and their marginalization may also account for the lack of trans-friendly procedures in healthcare settings. Public education campaigns to counter HIV/AIDS stigma and discrimination and to promote acceptance of PLHIV, including those

from marginalized groups such as MSM and Aravanis, need to be implemented, as recommended by UNAIDS (2007).

Proper training for healthcare 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 proportionate to the client load in the public health systems in general and the government ART centers in particular.

Few other studies have focused on barriers to ART access in India among MSM and Aravanis. Policy reports recommend adoption of an action plan to ensure equitable access to ART for MSM and Hijras (Chakrapani, 2005; Chakrapani et al, 2006a & 2006b; Abraham et al., 2007a & 2007b). In Mumbai, since 2006, Medicines Sans Frontiers (MSF) has provided ART to patients who have been excluded from the government ART program, most of whom “come from marginalized groups such as transgender women (Hijras), men who have sex with men, commercial sex workers, migrant workers and those living in poverty.” (MSF, undated)

WHO recommends collecting disaggregated data from treatment sites on the number of people from various segments of the population, including marginalized groups such as sex workers, MSM and injecting drug users (IDUs) (WHO, 2004). However, at the time of publication of this report, NACO was not collecting this data, which is needed to determine whether MSM/Aravanis and members of other marginalized groups have equitable access to ART from government ART centers. WHO also states that specialized interventions are necessary to meet the specific needs of members of marginalized groups living with HIV. For MSM, Aravanis, female sex workers and IDUs, these interventions should address legal status, social isolation, police abuse, and discrimination in health services (WHO, 2004).

Limitations to this study include the small sample size of MSM and Aravanis purposively sampled from community organizations. Caution should be exercised in generalizing the results to others. As a qualitative study, however, our intention was not to generalize findings across the various subpopulations of MSM or Aravanis in Chennai; rather, the purpose was to explore in depth potential barriers to ART access from the perspectives of individuals from these communities. Since recruitment of study participants was done through community-based organizations working with MSM and Aravanis, the level of knowledge and community support may be higher than among MSM and Aravanis who are not associated with NGOs; it is possible that the latter may experience even greater barriers to ART access. Additionally, other subpopulations of MSM such as ‘double-deckers’ and gay- or bisexual-identified MSM (NACO, 2008a; Chakrapani et al., 2002 & 2007) – may experience different barriers to accessing ART. Our MSM study population was almost exclusively kothi-identified, some proportion of whom engage in sex work; thus results may be most applicable to kothis. Future studies should include other subgroups of MSM and Aravanis in other localities with systematic comparisons by age, marital and living status, substance abuse, and other variables, to help determine targeted interventions to address what may be context-specific barriers.

In conclusion, we identified an array of barriers to accessing free ART at government centers among MSM and Aravanis in Chennai. In order to be effective, policies and programs should be designed and implemented to address barriers to ART access at individual, social and healthcare system levels. This will help NACO meet its commitment to ensure availability of ART to “all those who need it.”

V. RECOMMENDATIONS

1. Address stigma and discrimination faced by MSM and Aravanis living with HIV

- Implement educational and sensitization programs for the general public to reduce stigma associated with HIV/AIDS, same-sex sexuality, and transgenderism, and also educate them to accept and not to discriminate against PLHIV, and MSM and Aravanis/transwomen.
- Anti-discriminatory policies should be introduced and implemented in health care settings to ensure non-discriminatory and quality care for marginalized communities such as MSM and Aravanis.
- Create supportive environment for PLHIV among MSM and Aravani communities by promoting acceptance of PLHIV and creating supportive peer norms through targeted interventions and with the help of community leaders.

2. Address psychological and other individual level barriers to ART initiation

- Psychological barriers such as lack of self-efficacy in ART adherence, fatalism, and fear of adverse consequences due to disclosure of HIV status prevent some from initiating ART. Hence outreach workers, counselors, and doctors should be trained to be competent in eliciting and providing tailored counseling to address the various psychological barriers to initiate ART.
- People who are dependent on alcohol need to be linked with de-addiction services.

3. Provide treatment education to MSM and Transwomen, including those living with HIV

- Provide and reinforce treatment messages to MSM and Aravanis – in different forms and through different people (peers, outreach workers, doctors, and counselors).
- Treatment messages should not be restricted only to those who are known to be HIV positive. Giving ART related treatment messages to all (irrespective of their HIV status) help diffusion of this information among the community and avoid labeling people as PLHIV if only he or she receives treatment messages from outreach workers. Additionally, these ART messages shall be tailored in such a way to replace people's incorrect knowledge about ART such as cure for HIV in alternative medicines and to remove misconceptions related to side-effects of ART.
- Publicize accurate information about ART and its availability in selected government hospitals through mass media and innovative communication campaigns that appeal to and reached out to MSM and Aravanis, especially those living with HIV.

4. Ensure availability of quality counseling and treatment services

- Lack of appropriate identity/address proof should not limit needy PLHIV from getting ART: consider alternative arrangements (e.g., recommendation letter from NGOs or PLHIV networks).
- Ensure that ART centers are friendly and health care providers (especially counselors and doctors) offer competent, non-judgmental, non-discriminatory and quality counseling and treatment services to people from marginalized communities living with HIV including those who are MSM and Aravanis. Health care providers require training on issues specific to the marginalized groups, including ART access and adherence issues.
- Quality counseling for MSM and Aravanis need to be offered in government ART centers and HIV testing centers. Besides the information to be delivered as per NACO guidelines, following issues need to be addressed when counseling MSM and Aravanis: mental health issues; alcohol abuse; pros and cons of disclosure of HIV status and sexuality to family members, peers, and others; identifying referral needs to provide psycho-social support.

- In addition to professional counselors, in selected ART centers, appoint trained peer/ community counselors to promote ART uptake among MSM and Aravanis living with HIV.
- Develop 'standards of care' for ART initiation, management, and monitoring for marginalized groups living with HIV including MSM and Aravanis.
- Consult with Aravani/transgender communities and develop guidelines for sensitively dealing with the gender identity-related issues faced by Aravanis/transgender women: name and gender of enrolment; ward admission (women's or separate ward).

6. Develop and implement action plan to ensure equity in ART access for marginalized groups including MSM and Hijras/transwomen

Develop a national policy and action plan on equity to ART access for marginalized groups living with HIV and ensure implementation of that plan. Action plan should address: quantifying inequity information; monitoring health inequity; and implementing steps towards eliminating inequities.

VI. GLOSSARY

Hijras / Aravanis

Hijras are biological/anatomical males who reject their 'masculine' identity in due course of time to identify either as women, or "not-men", or "in-between man and woman", or "neither man nor woman". Thus they can be considered to come under the international umbrella term 'transgender (male-to-female) people'. Hijras in the state of Tamil Nadu are called 'Aravanis.'

Kothis

Kothis are a heterogeneous group. 'Kothis' can be described as males who show varying degrees of 'femininity' (which may be situational) and who are involved mainly, if not only, in receptive anal/oral sex with men. Some proportion of Kothis have bisexual behaviour and many may also get married to a woman. A significant proportion of Hijra-identified persons also identify themselves as 'Kothis'. In this report, the term 'Kothi-identified MSM' is used to denote feminine males who self-identify themselves as 'Kothis' but not as Hijras.

Men who have Sex with Men (MSM)

This term is used to denote all men who have sex with other men, regardless of their sexual identity or sexual orientation. This is because a man may have sex with other men but still considers himself to be a heterosexual or may not have any particular sexual identity at all. This, basically an epidemiological term, coined by public health experts, focuses exclusively on sexual behavior for the purpose of HIV/STD prevention.

Sex Worker

The term 'sex worker' is intended to be non-judgmental, focusing on the conditions under which sexual services are sold. Alternate formulations are: 'women/men/people who sell sex.' Clients of sex workers may then also be called 'men/women/people who buy sex.' The term 'commercial sex worker' is no longer used, primarily because it is considered to be saying something twice over in different words (i.e. a tautology).

Transgender person

A term used to describe those who transgress social gender norms; often used as an umbrella term to mean those who defy rigid, binary gender constructions, and who express or present a breaking and/or blurring of culturally prevalent/stereotypical gender roles. Transgender people usually live full or part time in the gender role opposite to the one in which they were born. In contemporary usage, "transgender" has become an umbrella term that is used to describe a wide range of identities and experiences, including but not limited to: pre-operative, post-operative and non-operative transsexual people; male and female cross-dressers (sometimes referred to as "transvestites," "drag queens," or "drag kings"); intersexed individuals; and men and women, regardless of sexual orientation, whose appearance or characteristics are perceived to be gender atypical. (A male-to-female transgender person is referred to as '*transgender woman*' and a female-to-male transgender person is referred to as '*transgender man*.')

Transsexual person

Individual whose gender identity is that of the opposite gender (sex). There are male-to-female and female-to-male transsexuals. A transsexual may or may not have had sex reassignment surgery and thus could be 'pre-operative' transsexual, 'post-operative' transsexual or 'non-operative' transsexual. (A male-to-female transsexual person is referred to as '*transsexual woman*' and a female-to-male transsexual person is referred to as '*transsexual man*.')

Definitions are adapted from:

Chakrapani, V., Kavi, A. R., et al. (2002). HIV Prevention among Men who have Sex with Men (MSM) in India: Review of Current Scenario and Recommendations. Retrieved February 10, 2007, from http://indiaglbthealth.info/Authors/Downloads/MSM_HIV_IndiaFin.pdf

Chakrapani, V., Newman, P. A., Mhaprolkar, H., Kavi, A.R. (2007). Sexual and Social Networks of men who have sex with men (MSM) and Hijras in India: A qualitative study. The Humsafar Trust, Mumbai, India. April 2007.

VII. REFERENCES

- Aday, L.A., & Andersen, R. (1974). A framework for the study of access to medical care. *Health Services Research*, 9, 208–220.
- AIDS Prevention and Control Project (APAC). (2007). Behavioral Surveillance Survey Report (BSS) Report. Tamil Nadu – Wave X. Retrieved November 5, 2008, from http://www.apacvhs.org/PDF/BSS%20WAVE%20X_opt.pdf
- Abraham, K.K., Chakrapani, V., Ram, E., et al. (2006a). India Chapter in the report - Off target for 2010: How to avoid breaking the promise of Universal Access. <http://www.aids-treatment-access.org/itpcupdatefinal.pdf>
- Abraham, K.K., Chakrapani, V., Ram, E., et al. (2006b). India Chapter in the report - Stagnation in AIDS treatment scale up puts millions of life at risk – Second six-month update to ITPC's AIDS treatment report from frontlines. http://www.aids-treatment-access.org/mtt3_final.pdf
- Abraham, K.K., D'Costa, C., Ram, E., et al. (2007a). India Chapter in the report – Time is Running out to End AIDS – Treatment and prevention for All! <http://www.aids-treatment-access.org/itpc4thfinal.pdf>
- Abraham, K.K., D'Costa, C., Shunmugam, M., Chakrapani, V. (2007b). India Chapter in the report - Improving AIDS drug Access and Advancing Health care for all. <http://www.aids-treatment-access.org/itpc5th.pdf>
- Braveman, P., Gruskin, S. (2003). Theory and Methods. Defining equity in health. *J Epidemiol Community Health*, 57, 254-258.
- Chakrapani, V., Babu, P., Ebenezer, T. (2004). Hijras in sex work face discrimination in the Indian health-care system. *Research for Sex Work*, 7: 12-14.
- Chakrapani, V. (2005). A Report on HIV/AIDS treatment Access from the frontlines. India Chapter. Retrieved November 15, 2008 from <http://www.itpcglobal.org/images/stories/doc/India-1.pdf>
- Chakrapani, V., Newman, P., Shunmugam, M., McLuckie, A. & Melwin, F. (2007). Structural violence against Kothi-identified men who have sex with men in Chennai, India: A qualitative investigation. *AIDS Education and Prevention*, 19(4), 346–364.
- Chakrapani, V., Newman, P.A., Shunmugam, M. (2008). Secondary HIV Prevention among Kothi-identified MSM [Men who have Sex with Men] in Chennai, India. *Culture, Health & Sexuality*, 10(4), 313-327.
- Chakrapani, V., Shunmugam, M., Michael, S., Velayudham, J., & Newman, P.A. (2008). HIV testing Barriers and facilitators among populations at-risk in Chennai, India. Indian Network for People living with HIV (INP+) and Asia Pacific Council of AIDS Service Organizations, Malaysia
- Chakrapani, V., Mehta, S., Buggineni, P., & Barr, F. (2008). Males-at-risk in India: Sexual and Reproductive Health (SRH). Needs and Barriers to SRH services. India HIV/AIDS Alliance.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Chandrashekhara, S., Anilkumar, T., Jamuna, S. (2002, February). Complementary and alternative drug therapy in arthritis. *Journal of Association of Physicians of India*, 50, 225-227.
- Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Gogtay, N.J., Bhatt, H.A., Dalvi, S.S., & Kshirsagar, N.A. (2002). The use and safety of non-allopathic Indian medicines. *Drug Safety*, 25(14), 1005-1019.
- Kalanda, B., Makwiza, I., Kemp, J. (2007, March). Framework for monitoring equity in access and health systems issues in antiretroviral therapy programmes in southern Africa. *Malawi Medical Journal*, 19(1), 20-24.
- Lincoln, Y.S., & Guba, E. (1985). *Naturalistic enquiry*. Newbury Park, CA: Sage.

- Mehrotra, R., Bajaj, S., Kumar, D. (2004, September/October). Use of complementary and alternative medicine by patients with diabetes mellitus. *Natl Med J India*, 17(5), 243-245.
- Medecins Sans Frontieres (MSF) (undated). Retrieved October 7, 2008, from <http://www.msfindia.in/msf-in-india.html#mumbai>
- National AIDS Control Organisation (NACO). (2006). Strategy and Implementation Plan - National AIDS Control Programme Phase III [2007-2012]. Ministry of Health and Family Welfare. Government of India.
- National AIDS Control Organisation (NACO). (2007a). Targeted Interventions under NACP-III: Operational Guidelines. Volume 1. Core high risk groups. Ministry of Health and Family Welfare. Government of India.
- National AIDS Control Organisation (NACO). (2007b). National Behavioural Surveillance Survey (BSS) - Men who have Sex with Men (MSM) and Injecting Drug Users (IDUs) -2006. Ministry of Health and Family Welfare. Government of India.
- National AIDS Control Organisation (NACO). (2008a). UNAIDS Country Progress Report 2008 – India. Reporting period – Jan 2006 to December 2007. Retrieved November 5, 2008, from http://data.unaids.org/pub/Report/2008/india_2008_country_progress_report_en.pdf
- National AIDS Control Organisation (NACO). (2008b). HIV Sentinel Surveillance and HIV Estimation in India 2007 A Technical Brief. Retrieved November 5, 2008, from http://www.nacoonline.org/upload/Publication/M&E%20Surveillance,%20Research/HIV%20Sentinel%20Surveillance%20and%20HIV%20Estimation%202007_A%20Technical%20Brief.pdf
- Pinagapany, M., Shanmugam, M. (2008). Review of the existing STD/HIV/AIDS training curriculum for doctors in Tamil Nadu, India. Indian Network for People living with HIV (INP+), India.
- Ritchie, J., & Spencer, E. (1994). Qualitative data analysis for applied policy research. In Bryman, A. and Burgess, R.G. (eds.) *Analyzing Qualitative Data*. London: Routledge.
- Schutt, R.K. (2004). *Investigating the social world—The process and practice of research* (4th Ed.). Newbury Park, CA: Sage.
- Strauss, A. and Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. (2nd edition). Thousand Oaks, CA: Sage.
- Satpathy, S. K., Venkatesh, S. (2006). Human Resources for Health in India's National Rural Health Mission: Dimension and Challenges. *Regional Health Forum*, 10 (1). Retrieved November 5, 2008, from http://www.searo.who.int/LinkFiles/Regional_Health_Forum_Volume_10_No_1_03-Human_Resources_for_Health_in_Indias_National.pdf
- Tamil Nadu State AIDS Control Society (TANSACS). (2007). State project implementation plan [based on NACP-3].
- The Hindu. (2008, October 2). Court: follow fiat, don't deny treatment to AIDS patients. Retrieved from <http://www.thehindu.com/2008/10/02/stories/2008100261591300.htm>
- World Health Organisation (WHO). (2004). *Guidance on ethics and equitable access to HIV treatment and care*. Geneva.
- World Health Organisation (WHO). (2003). *Entry points to antiretroviral treatment*. Geneva: World Health Organization (WHO/HIV/2003.16).