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Barriers to antiretroviral treatment access for injecting drug users living with HIV in Chennai, South India

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Abstract

India's National AIDS Control Organization provides free antiretroviral treatment (ART) to people living with HIV (PLHIV), including members of marginalized groups such as injecting drug users (IDUs). To help inform development of interventions to enhance ART access, we explored barriers to free ART access at government ART centers for IDUs living with HIV in Chennai by conducting three focus groups (*n* = 19 IDUs) and four key informant interviews. Data were explored using framework analysis to identify categories and derive themes. We found interrelated barriers at the family and social, health-care system, and individual levels. Family and social level barriers included lack of family support and fear of societal discrimination, as well as unmet basic needs, including food and shelter. Health-care system barriers included actual or perceived unfriendly hospital environment and procedures such as requiring proof of address and identity from PLHIV, including homeless IDUs; provider perception that IDUs will not adhere to ART, resulting in ART not being initiated; actual or perceived inadequate counseling services and lack of confidentiality; and lack of effective linkages between ART centers, needle/syringe programs, and drug dependence treatment centers. Individual-level barriers included active drug use, lack of self-efficacy in ART adherence, low motivation to initiate ART stemming from a fatalistic attitude, and inadequate knowledge about ART. These findings indicate that to facilitate IDUs gaining access to ART, systemic changes are needed, including steps to make the environment and procedures at government ART centers more IDU-friendly and steps to decrease HIV- and drug use-related stigma and discrimination faced by IDUs from the general public and

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health-care providers. Housing support for homeless IDUs and linkage of IDUs with drug dependence treatment are also essential.

Keywords

access to health care; antiretroviral treatment; injecting drug users; India; HIV; AIDS

Introduction

In 2004, the Government of India began providing free first-line antiretroviral treatment (ART) in government ART centers. It is the policy of India's National AIDS Control Organization (NACO) that first-line ART "will be provided to all those who need it" and that ART be provided to people living with HIV (PLHIV) referred from interventions targeting "core high risk groups," including injecting drug users (IDUs) (NACO, 2006).

A 2010 review on IDUs' access to ART found that in China, Vietnam, Russia, Ukraine, and Malaysia, IDUs constituted 67% of HIV cases, but only 25% of those receiving ART (Wolfe, Carrieri, & Shepard, 2010). In India, networks of PLHIV and community organizations reported that marginalized groups living with HIV, including IDUs, had limited access to free first-line ART from government centers (Abraham, D'Costa, Shunmugam, & Chakrapani, 2007; Chakrapani, 2005). In the Indian state of Manipur, where IDUs constitute about half of HIV cases, less than 5% of current IDUs were reported to be on ART (Sharma et al., 2007).

Barriers to ART access in low- and middle-income countries include IDU-related stigma and discrimination in health-care settings, fragmentation of care, lack of access to opioid substitution therapy (OST), and multiple requirements for treatment initiation by IDUs (Wolfe et al., 2010). While qualitative studies among female sex workers (Chakrapani, Newman, Shunmugam, Kurian, & Dubrow, 2009) and sexual minorities (Chakrapani, Newman, Shunmugam, & Dubrow, 2011) in India have identified several barriers to access to free ART in government centers, no information is available on the barriers faced by IDUs. To help inform development of interventions to enhance ART access among IDUs in India, we conducted a qualitative study to identify and understand these barriers in Chennai, where HIV prevalence among IDUs was found to be 29.8% (Solomon et al., 2008).

Methods

Between August and November 2007, we conducted three focus group discussions (FGDs) with IDUs living with HIV and four key informant interviews (two senior physicians who treat PLHIV and heads of two community agencies that provide services to IDUs). FGD participants were recruited by peer outreach workers of two community agencies – one working with IDUs and the other working with PLHIV – using purposive sampling to reflect diversity with respect to current injecting status, duration of contact with service agency, and enrolment in a free government ART program. We chose to conduct three FGDs based on practical considerations, including the availability of HIV-positive IDUs who were willing to participate and resource constraints.

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FGD participants (*n* = 19 males) ranged in age from 26 to 48 years (mean = 35 years). More than one-third (*n* = 7) completed high school and about one-fifth (*n* = 4) completed primary school; about three-fourths (*n* = 14) were married; about half were self-employed (*n* = 10); and about one-third (*n* = 6) were staff of agencies, including peer outreach workers who worked with IDUs. About one-fifth (*n* = 4) were on ART, obtained through government ART centers. Participants in the three FGDs had similar sociodemographic characteristics; one FGD (*n* = 6) consisted of current IDUs and the other two consisted of former IDUs.

We used semi-structured topic guides in Tamil with scripted probes that focused on barriers to ART access and possible strategies to improve access. The duration of FGDs ranged from 60 to 90 minutes; key informant interviews ranged from 45 to 60 minutes. FGD participants received an honorarium of 250 Indian rupees (about 6 USD); key informants were not paid. FGDs and interviews were tape-recorded, transcribed verbatim in Tamil, and translated into English for data analysis. All participants provided written informed consent. This study received approval from the ethics review committee of the Indian Network for People living with HIV/AIDS.

Data were explored using framework analysis (Ritchie & Spencer, 1994). Based on Aday and Andersen’s (1974) framework of access to health services and on previous research about ART access for marginalized groups (Chakrapani et al., 2009, 2011), we hypothesized that barriers to ART access might occur at family and social, health-care system, and individual levels. For coding, we established a-priori categories and also used *in vivo* coding to derive new codes that emerged (e.g., provider-perceived nonadherence); we used a constant comparative method within and across cases (Charmaz, 2006; Strauss & Corbin, 1998). We used peer debriefing and member checking to enhance validity of the findings (Lincoln & Guba, 1985).

Results

Family and social barriers

Lack of family support and fear of societal discrimination—FGD participants reported that many IDUs were evicted by their parents or moved out of their home on their own to avoid bringing shame to their family due to their drug use or HIV-positive status. One IDU reported:

> The main hindrance among the drug addicts to take ART is that most of them are rejected and sent away by their family. He thinks that he earns a bad name for the family, that the society would view the family differently as he is infected by HIV, and due to this fear/stigma … he leaves his family.

Some IDUs living with family members did not want to reveal their HIV status in order to avoid eviction. Furthermore, FGD participants reported that even if family members did allow HIV-positive IDUs to stay with them, they would not support them to initiate ART due to skepticism about IDUs’ efficacy in ART adherence and about the benefits of ART for IDUs.

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IDUs also feared potential discrimination by the general society if they were found to be HIV-positive. This fear prevented IDUs from sharing their HIV-positive status with peer outreach workers, and from enrolling in government ART programs. One IDU said:

> … the society and our relatives would reject us if they come to know that we are [HIV] positive. Due to this we hesitate to get enrolled in ART [program]. If we are on ART, others would come to know [about HIV status] …

Unmet basic needs – food and shelter—

Participants reported that many homeless IDUs who were rejected by their family members did not have access to shelter and adequate food, let alone nutritious food. As a former IDU put it, “He is on the road [homeless IDU]. What will he do if he is given ART? He doesn’t have food to eat … For him food is more important than ART.” Furthermore, as the need for nutritious food was often overemphasized by counselors and peer outreach workers, IDUs hesitated to initiate ART because of their belief that nutritious food is a must after initiating ART. “[Only] the rich can take such food,” said one IDU.

Health-care system barriers

Actual or perceived unfriendly hospital environment and procedures—

FGD participants were discouraged by the dispersal of different aspects of their care in various locations within the government hospital. A former IDU described the experience of an IDU attending a government hospital:

> There he is made to run from pillar to post. When he is asked to go to the 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.

Participants narrated several incidents in which the words, actions, and nonverbal cues of health-care providers suggested that providers were not comfortable with treating or counseling HIV-positive IDUs and feared acquiring HIV from them. As an IDU said, “We are not properly treated …If we appear thin, they move away as if it [HIV] would spread to them through air…”

Perceived or actual discrimination led current IDUs to conceal their drug use status in ART treatment centers; consequently, they would not be referred for drug dependence treatment, might not be screened for hepatitis virus infections, which are common among IDUs, and might not receive relevant information, such as possible increased risk for hepatotoxicity from ART if the liver has already been damaged by infections and/or alcohol use.

In contrast, participants asserted, many former IDUs usually did reveal their past drug use behavior because they did not want to be seen as having contracted HIV from being “sexually promiscuous.”

FGD participants reported that, as per the policy of NACO, ART centers required that PLHIV provide proof of address and identity. Key informants clarified that this requirement was introduced to prevent the previous practice of PLHIV providing a false address, which

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made it difficult for hospital staff to trace them in case of treatment default. However, this requirement posed problems for homeless IDUs, who did not have an address and often did not have identity documents. A physician key informant sympathized with IDUs on this issue: "[IDUs] 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?" Furthermore, IDUs living with their families feared that if they gave a correct home address then hospital staff might come to their home and their HIV-positive status might then be revealed to their family.

Provider-perceived nonadherence—FGD participants and key informants reported that physicians in ART centers were hesitant to start ART for IDUs because they believed IDUs would not adhere to ART. According to a physician key informant, physicians were wary about initiating ART in patients with a history of drug use, even if the clinical criteria for initiation were met. "What if he [IDU] does not take drugs properly and develops resistance?," he asked. "Others would suffer if drug-resistant HIV spreads. We [physicians] do not want to take that risk."

Consequently, some IDUs who wanted to initiate ART concealed their drug use history from health-care providers. According to one IDU, "We don't tell that we use[d] drugs or are on OST because we are afraid that we would not be given ART." Such concealment could have negative consequences, as detailed above.

Actual or perceived inadequate counseling services and lack of confidentiality—FGD participants opined that counselors at government ART centers had relatively little knowledge and skills for counseling IDUs. Hence, many participants suggested training and placing former IDUs as counselors. In addition, high patient load reportedly compelled counselors to conduct group instead of individual sessions on risk-reduction and HIV treatment. IDUs (males) reported discomfort in discussing their sexual or drug use-related risk behaviors in these group sessions, especially when the sessions were conducted by women counselors. According to one IDU:

> We [IDUs] feel shy. We couldn't listen to the counseling they [government ART counselors] give. … they ask [personal] details in a group. We had to look at each others' faces and the ladies had to sit with their heads down.

Lack of effective linkages between ART centers, needle/syringe programs, and drug dependence treatment centers—HIV prevention projects among IDUs in Chennai, supported by NACO, focus primarily on needle/syringe distribution. At the time of this study, only one HIV project had a component of OST for a limited number of people. Drug dependence treatment centers that provide only treatment for withdrawal symptoms are supported by the Ministry of Social Justice and Empowerment (MSJE). Key informants noted that service providers in ART centers often did not refer HIV-positive IDUs to the OST project or drug dependence treatment centers. As an agency head key informant pointed out:

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> On the one hand, they [physicians] hesitate to give ART because he is a drug user, and on the other hand, there is no help for such people. They are not referred anywhere to get rid of their drug habit.

Former IDUs and key informants stressed the need for formal mechanisms to strengthen linkages between ART centers and needle/syringe projects, the OST project, and drug dependence treatment centers, so that more HIV-positive IDUs could be "stabilized" and enrolled in ART. According to an HIV-positive agency head key informant, "If NACO and MSJE sit together and develop some kind of formal referral and coordination mechanisms, then it would be easier."

Individual level barriers

Active drug use—Participants reported that active IDUs are more interested in drugs than in ART. According to a former IDU, "They [messages about HIV and ART] do not reach the person who is under the control of drugs. Drug is the most important thing for him." Agency head key informants pointed out that active IDUs, under the influence of drugs, often could not comprehend messages about HIV and ART conveyed by peer outreach workers.

Lack of self-efficacy and low motivation—Lack of self-efficacy in ART adherence, fatalism, and the need to take lifelong ART prevented some IDUs from starting ART. FGD participants, who were current or former IDUs themselves, believed that it would be a "waste" to give ART to IDUs, as they thought IDUs could not adhere to ART, especially because it has to be taken lifelong. An IDU reported, "As it [ART] has to be taken for the entire lifetime, we are afraid that we might not be able to [do so]." An agency head key informant had heard IDUs expressing, "What is the point in living for a long time? Who respects us?"

Participants reported that counselors in ART centers often emphasized the need for abstinence from drugs and alcohol when taking ART. Consequently, some IDUs did not want to initiate ART. According to a physician key informant, "There are people [former IDUs] who are addicted to smoking and alcohol. When they are instructed not to consume them when they are started on ART, they hesitate … They don't think they could stop them [smoking and alcohol]."

Inadequate knowledge about ART

Some FGD participants believed that "ART does not suit IDUs," "ART will not work for IDUs," or "IDUs have died of ART." Although these beliefs were challenged by other FGD participants, the misconceptions seem to have a strong influence in preventing or delaying initiation of ART. According to a physician key informant:

> When something happens, they [IDUs] blame ART for the effect … they tell others that vision has diminished and they have itching and things like that. They thus spread a wrong opinion about ART, which deters others [IDUs] from taking ART.

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Discussion

We have provided previously unavailable contextual information on multi-level barriers faced by HIV-positive IDUs in accessing free ART provided in government hospitals in India. Stigma and discrimination related to HIV-positive status prevented both current and former IDUs from disclosing their HIV status to their families and even to peer outreach workers of agencies working with IDUs. Also, actual or perceived unfriendly hospital environment and procedures discouraged some IDUs from attending government ART centers. Therefore, when weighing the pros and cons of disclosing their HIV status and enrolling in a free ART program, some IDUs chose the perceived less risky option of not disclosing their HIV-positive status, thereby not gaining access to ART. These findings are similar to those of studies on barriers to ART access among HIV-positive female sex workers (Chakrapani et al., 2009) and men who have sex with men and transgender people (Chakrapani et al., 2011) in Chennai. Other barriers that were similar among these marginalized groups were perceived inadequate counseling services and lack of confidentiality, unmet basic needs, and the individual-level barriers of inadequate knowledge about ART, fatalism, and alcohol use.

However, IDUs faced unique barriers to ART as well: active drug use; multiple stigmas related to drug use, HIV-positive status, and homelessness; challenges in access to drug dependence treatment such as OST; provider-perceived nonadherence to ART; and lack of self-efficacy in ART adherence. These findings indicate that to facilitate IDUs gaining access to ART, systemic changes are needed, including steps to make the environment and procedures at government ART centers more IDU-friendly and steps to decrease HIV- and drug use-related stigma and discrimination faced by IDUs (Latkin et al., 2010) from the general public and health-care providers (including physicians, nurses, and counselors).

The perception that IDUs could not be trusted to adhere to ART was both an individual level and a systemic barrier. This perception was ubiquitous: among health-care providers who denied ART to IDUs by pointing out the alleged problems in adherence and emergence of drug-resistant strains; among family members who thought that IDUs would not adhere to ART and would start using drugs again; among peer outreach workers, that is, former IDUs themselves, who believed that it would be a “waste” to provide ART to IDUs because they would not be adherent; and, importantly, among current IDUs themselves.

Our findings are consistent with other studies that have identified doubt among IDUs about their self-efficacy in ART adherence (Kerr et al., 2005; Wood, Kerr, Tyndall, & Montaner, 2008); that have shown 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); and that have demonstrated the belief among physicians that IDUs may be more likely to develop and transmit anti-retroviral-resistant HIV strains (Wainberg & Friedland, 1998). However, several studies have shown providers to be poor judges of patients’ adherence to ART (Bangsberg et al., 2001; Wood et al., 2008), leading evidence-based reviews and ethical analyses to conclude that physicians should not indefinitely and arbitrarily withhold ART from patients on the presumption that they will not be adherent (Aceijas et al., 2006; Wolfe, 2007; World Health Organization, 2004). Also, the

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concern of providers regarding potential for increased rates of antiretroviral resistance among IDUs and consequent transmission of resistant strains is not supported by evidence (Wood et al., 2008).

The emphasis on the need to be drug-free before starting ART, by health-care providers and even by former drug users, is not based on available evidence-based technical guidelines produced by WHO and UNAIDS (World Health Organization, 2004; World Health Organization Regional Office for Europe, 2007) that specifically state that current or past drug use should not be a criterion for deciding who should receive ART. It is important that health-care providers be properly trained to manage and counsel IDUs living with HIV – especially in relation to ART and its interactions with drugs/alcohol, and management of hepatitis co-infections (Wolfe et al., 2010). Health-care providers should also provide treatment education to IDUs using simple terms, without withholding information due to personal bias.

Individual-level interventions to promote ART access among IDUs may be ineffective in the absence of positive changes in health-care systems that make them IDU-friendly. We found that dispersed service facilities, inadequate infrastructure in government hospitals, and judgmental staff with discriminatory attitudes create an unwelcome environment for IDUs. Thus, steps are needed to improve the infrastructure, to minimize navigation difficulties, to increase health-care providers' (including physicians, nurses, and counselors) understanding about IDUs, and to sensitize providers to their professional obligation and ethical mandate to provide nonjudgmental and proper care.

Our study has also demonstrated that many other issues – active drug use and related drug dependence instability, limited family and social support, and homelessness – create barriers in initiating ART, which have been documented in studies from other countries as well (Gebo, Keruly, & Moore, 2003; Knowlton et al., 2006; Maisels, Steinberg, & Tobias, 2001). These issues indicate the need to link IDUs with drug dependence treatment and to offer housing support for homeless IDUs. Improvements in stability from these measures 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; Sambamoorthi, Warner, Crystal, & Walkup, 2000; Wood et al., 2005); buprenorphine has also shown similar potential (Moatti et al., 2000). As of 2012, India had 62 sublingual buprenorphine substitution treatment centers and 5 methadone maintenance therapy centers serving 5800 IDUs (Rao, Agrawal, Kishore, & Ambekar, 2013), while the demand is much greater. NACO plans to scale up OST in a phased manner to eventually cover 40,000 IDUs (Kumar & Agrawal, 2012; NACO, 2008, 2012), providing an important opportunity for treatment of HIV-positive IDUs, which would greatly help access to ART.

In this qualitative study, we aimed to explore in depth the unique perspectives and lived experiences of IDUs in accessing free ART. The prevalence and relative contribution of the barriers we identified can be further examined in detail through quantitative and mixed-methods studies. The barriers to ART access experienced by our study participants, all of

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whom were recruited through community agencies providing services to IDUs, may have been less severe than barriers experienced by IDUs living with HIV who are not reached by community agencies. Furthermore, our results may not be applicable to IDUs from middle and upper economic classes because they usually do not use services offered by community agencies.

In conclusion, we identified a range of interrelated barriers to accessing free ART at government centers among IDUs in Chennai. To achieve NACO's aim of providing ART to "all those who need it" (NACO, 2006), interventions are needed at the family, social, health-care system, and individual levels that address barriers to ART access for marginalized populations in India.

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