



INDIAN NETWORK
FOR PEOPLE LIVING
WITH HIV / AIDS



Access and Adherence to tuberculosis treatment: **BARRIERS & FACILITATORS**

A Mixed Methods Study

Conducted among People with TB

- including People Living with HIV (PLHIV) and Injecting Drug Users (IDUs)

- in Imphal and Erode, India

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ABBREVIATIONS & ACRONYMS

ACTION	Advocacy To Control TB Internationally
ART	Antiretroviral Treatment
AIDS	Acquired Immuno-Deficiency Syndrome
CBO	Community Based Organization
DMC	Designated Microscopic Centers
DOTS	Directly Observed Treatment Strategy
FGD	Focus Group Discussion
FSW	Female Sex Workers
HCP	Health Care Provider
HCV	Hepatitis C Virus
HBV	Hepatitis B Virus
HIV	Human Immuno-deficiency Virus
IDUs	Injecting Drug Users
INP+	Indian Network for People Living with HIV/AIDS
KII	Key Informant Interview
MDR	Multi-drug Resistance
MSM	Men who have Sex with Men
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NGO	Non-government Organization
OST	Opioid Substitution Treatment
PLHIV	People Living with HIV
RNTCP	Revised National Tuberculosis Control Program
SACS	State AIDS Control Society
TB	Tuberculosis
XDR	Extreme Drug Resistance

EXECUTIVE SUMMARY

1. Background

People living with HIV (PLHIV) and injecting drug users (IDUs) are at increased risk of getting TB compared with HIV-negative people and people who do not use drugs. While the lifetime risk of developing active tuberculosis in immune-competent persons is 5% to 10%, people living with HIV have an annual risk of 5% to 15%. In IDUs, decreased immunity associated with active drug use, malnutrition, and alcohol use, all increase the risk of developing active TB disease.

Delay in diagnosis and initiation of TB treatment poses risk of transmission of TB to greater numbers of people, in addition to unnecessarily prolonging the suffering of, and sometimes even leading to death of people with TB. Understanding the various factors that lead to the delay between initiation of symptoms and accurate diagnosis and initiation of TB treatment is thus crucial. Furthermore, efforts to improve TB treatment outcomes require comprehensive and holistic understanding of barriers to and facilitators of access and adherence to TB treatment, and patients' experiences of taking treatment.

2. Objectives

To better understand the various factors that influence access and adherence to TB treatment among people with TB – including people living with HIV and injecting drug users. We also aimed to find out the level of nonadherence to TB treatment and factors associated with nonadherence.

3. Methodology

From July 2009 to February 2010, in Imphal, Manipur and Erode in Tamil Nadu, we conducted a mixed methods study by recruiting study participants through government DOTS centres, NGOs that serve as DOTS providers (free TB medications supplied by the government), PLHIV networks and organisations working with DUs/IDUs (in Imphal).

Quantitative component (n=550): Survey was administered among 300 participants (198 men and 102 women). Among men, 97 were IDUs in Imphal and 250 participants (167 men and 83 women) in Erode. The survey was restricted to people who have been taking anti-TB treatment for at least 2 months prior to enrolment in the study. The sample was primarily a convenience sample of people recruited from government and non-governmental DOTS centres and through PLHIV networks and NGOs working with IDUs. The questionnaire contained sections on sociodemographic characteristics, measures to assess delay in TB treatment initiation, items to measure TB knowledge (and to score the knowledge), TB treatment adherence determinants scale, ART adherence mini-scale (for PLHIV on ART and TB treatment), and social support.

Qualitative component (n=178): We used purposive sampling to recruit the participants for focus group discussions (FGDs). Participants were selected for inclusion with the goal of capturing diversity of experience, particularly regarding the unique circumstances that facilitate or impede access and adherence to TB medications. Key informants were chosen based on their expertise and experience in relation TB and HIV programs, policies and services. Seventeen focus groups with a total of 95 participants (5 focus groups with 25 participants in Erode and 12 focus groups with 70 participants in Imphal) from various

subgroups were conducted. Thirteen key informants (5 key informants in Erode and 8 key informants in Imphal) were interviewed. Key informants were officials of State AIDS Control Society (SACS) and State and district TB units of RNTCP, community leaders, directors of NGOs/ CBOs and DOTS providers.

Analysis: Survey data were analyzed using the SPSS-17. Focus group and key informant interview data were explored using framework analysis to identify categories and derive themes.

4. Key Findings

Survey Findings

Imphal

1. Paying for TB medications: 29.7% (89/300) are currently paying for TB medications (and presumably all are on daily TB regimens). Among them, more than half (51%) pay more than Rs. 500 per month for TB medications.

2. Travel distance from residence to TB treatment centre: Among the 210 participants who traveled to get TB medicines, about 42% (n=89/210) traveled at least 2 to 3 km to reach the TB treatment centre while 19% (n=39/210) traveled more than 4 km to reach the TB treatment centres.

3. Access delay (Delay in TB treatment initiation)

- Total delay: more than 4 weeks - 70.3% (211/300)
- Patient delay: more than 2 weeks - 80.3% (241/300)
- Health system delay: more than 1 week - 9.3% (28/300)

4. TB treatment adherence:

- Never skipped TB medications – 72% (n=217/300). Hence, at least 28% (n=83/300) skipped their TB dose at least once.
- Ever missed doses for 2 consecutive months – 1.3% (n=4/300)
- Ever missed doses for more than 1 month – 1.3% (n=4/300)
- Ever missed doses for more than one week – 6.7% (n=20/300)

Note: Among IDUs, 28% (n=27/97) skipped their TB dose at least once. About one-tenth (11.3%; n=11/97) missed doses (consecutively) from one week to more than two months.

5. Drug and Alcohol use: Injecting drug use in the past one month – 5.3% (n=16/300). Consumed alcohol in the past one month – 7.7% (n=23/300)

Erode

1. Paying for TB medications: None. All the participants were being treated at government DOTS centres.

2. Travel distance from residence to TB treatment centre: About one-third (30%; n=75/250) traveled at least 2 to 3 km to reach the TB treatment centre while 23% (n=57/250) traveled more than 6 km to reach the TB treatment centre.

3. Access delay (Delay in TB treatment initiation)

- Total delay: more than 4 weeks – 50.4% (126/250)
- Patient delay: more than 2 weeks -37.6% (94/250)
- Health system delay: more than 1 week – 19.6% (49/250)

4. TB treatment Adherence:

- Never skipped TB medications – 77.6% (n=194/250). Hence, at least 22.4% (n=56/250) skipped their TB dose at least once.
- Ever missed doses for 2 consecutive months – 6 % (n=15/250)
- Ever missed doses for more than 1 month – 4% (n=10/250)
- Ever missed doses for more than one week – 6.8% (n=17/250)

5. Drug and Alcohol use: Ever injected drugs – 1.6% (n=4/250). Consumed alcohol in the past one month – 7.6% (n=19/250)

ART and TB Treatment

In Imphal, among 300 participants with TB, 149 were HIV-positive. Among PLHIV with TB (n=149), only 94 were on ART. In Erode, among 250 participants with TB, 110 were HIV-positive. Among PLHIV with TB (n=110), only 85 were on ART. These data indicate that, although the national and international guidelines state that HIV-positive people with TB should be started on ART, about one-tenth to one-third of PLHIV with TB in this study were not on ART. This could indicate the lack of effective linkages between government DOTS centres and ART centres. Data from focus groups offered another explanation as well. Some HIV-positive people do not reveal their HIV-positive status to the health care providers and consequently HIV-positive people with TB are not referred to ART centres – at least until the health care providers come to know.

Qualitative Findings

Barriers to Access: Delay in TB Diagnosis and Treatment Initiation

Patient-related factors in delay in treatment initiation

- Non-specific nature of symptoms
- Misattribution of symptoms: Classic symptoms of TB such as cough and loss of weight were attributed to HIV infection; being on OST (drug users); and active drug and alcohol use.
- Atypical and non-pulmonary symptoms
- Initial visits to providers of alternative medicine

Provider and healthcare system-related factors for delay in treatment initiation

- Sometimes, there was considerable delay in diagnosing TB in private medical settings. (e.g. the delay due to other associated illness such as hepatitis-C; and false-negative TB result given by a private lab)
- Stigma associated with TB and HIV: Many patients were initially reluctant to visit the government DOTS centres, because it could be interpreted by acquaintances that they have TB.
- In Imphal, the negative image of government health centres being unfriendly; not having sufficient infrastructure; lack of privacy and confidentiality; and incidents of discrimination people have heard from others – all prevent or at least slow down the patients' access to government DOTS centres.
- TB drug resistance testing in Erode and Manipur are not free and not available in the government centres. The need to pay a huge amount (about Rs.6000) in private labs means delay in the initiation of appropriate treatment in some patients.

Facilitators – Factors promoting early health care seeking

- Severe symptoms (blood in the sputum or fainting)
- Knowledge about TB through mass media or counsellors/doctors (especially PLHIV)
- Previously treated for TB
- Family members have had TB

- Associated with PLHIV network, or receiving services from NGOs working with IDUs (OST program and/or outreach).

Barriers to TB Treatment Adherence

Individual-level barriers

- *Limited knowledge and misconceptions about TB drugs*
 - Fear of side-effects
 - Mistrust about the quality of government TB medications
 - PLHIV were concerned about taking TB medications along with anti-retroviral treatment (ART) as “eating a lot of tablets” were thought to harm the body
- *Active drug use and alcohol use*
- *Fatalism*: Appears to be connected with financial difficulties, and drug and alcohol use
- *Financial constraints*: Most participants were of low socioeconomic status with problems meeting their daily basic needs. Thus, some of them had interruptions in the TB treatment before they find a way to get free TB medications from the government DOTS centres or NGO DOTS providers.
- *Lack of family support*: Some IDUs, FSWs, and MSM reported not having adequate support from their family members.

Health system and other structural barriers

Perceived lack of adequate treatment education and counselling

- IDUs expressed the need for information on some specific areas: Whether taking ART and anti-TB treatment together will further affect their liver condition which is already compromised because of hepatitis (HCV/HBV) and/or alcohol? Whether it is okay to be on opioid substitution treatment (OST) and on TB treatment?
- Need for ‘treatment preparedness’ – the need to prepare the patients for a long-term treatment such as TB treatment – is important, similar to that of preparing patients for lifelong ART.
- Participants suggested providing information in each subsequent visit on side-effects as well as to reinforce the importance of adherence.

Insurgency situation in Imphal and connection to TB treatment adherence

- During bandhs, mobility of the general population is affected though sometimes the government health care facilities may remain open for some hours.
- Some people, not wanting to miss doses, buy TB drugs from nearby pharmacies – an added financial burden for them.

5. Recommendations

1. Address psychological and other individual level barriers to TB treatment access and adherence

- **Provide training to healthcare providers to address individual level barriers**: Psychological barriers such as fear of side-effects and fatalism prevent some from initiating TB treatment. Hence outreach workers, counsellors, and doctors should be trained to be competent in eliciting and providing tailored counselling to address the various psychological barriers.
- **Create linkages with other services**: IDUs with TB who are dependent on alcohol and/or drug use need to be linked with drug dependence treatment and harm reduction services (needle/syringe programs, OST, residential rehabilitation, etc.).

- **Link IDUs with OST programs:** IDUs have difficulty accessing TB diagnostic facilities and TB treatment initiation because their priority is on drug use (due to severity of withdrawal symptoms). Hence, IDUs need be linked with OST programs to help them attain a stable lifestyle and to assist them in adhering to TB treatment (and ART).
- **DOTS providers** need to be provided with the skills for managing repeated defaulters by training them on identifying factors for defaulting and addressing them appropriately.
- **Health Care providers** need to be sensitized about the sexual orientation of the patients and sensitize them on non-discriminatory behavior towards them.

2. Address structural barriers to TB treatment access and adherence

- Develop programmes to **increase support from family and society** through education (mass media) and counselling (one-to-one) to provide accurate information about TB and reduce stigma and discrimination.
- Develop mechanisms to **address the financial barriers** faced by a proportion of patients with TB. These could be provision of travel allowance for appointment-related trips to clinics and not charging for lab tests in the government centres. Another mechanism could be strengthening referrals with income-generation initiatives (government and non-government) for needy and willing PLHIV, IDUs and FSWs.
- Ensure that **TB drug resistance testing** is available (in strategic locations in Manipur) for patients - especially PLHIV, who require treatment for relapse to identify early diagnosis and treatment of Multi-drug resistant (MDR) and Extreme drug-resistant (XDR) TB.

3. Provide TB treatment and prevention education to marginalized groups, including those living with HIV

- **Provide TB education to PLHIV and marginalized groups through multiple avenues:** Provide and enforce prevention and treatment messages to PLHIV, FSWs, IDUs, and MSM - in different forms and through different providers (peers, outreach workers, doctors, and counsellors).
- **Provide ongoing adherence counselling** – throughout the TB treatment course - tailored to the needs and circumstances of the patients with TB.
- **Educate all members of marginalized groups about TB (irrespective of HIV status):** Treatment messages should not be restricted only to those who are diagnosed with TB. Giving TB - related treatment messages to all (irrespective of their HIV status) helps diffusion of this information among the community. These messages should address commonly held misconceptions related to severity of side-effects (to reduce the risk of not taking TB medications when experiencing side effects) and quality of drugs provided in the government centres (to overcome the mistrust in government's free TB medications); and emphasize the importance of completing the full course of TB treatment even if they feel well before completing the entire course.
- **Intensify awareness campaigns on TB treatment availability and information about symptoms of non-pulmonary forms of TB:** Publicize accurate information about TB treatment and its availability in selected government hospitals through mass media and innovative communication campaigns that appeal to and reach out to marginalized groups, including those living with HIV. Education on the symptoms of extra-pulmonary symptoms (e.g., swelling of lymph glands) needs to be provided especially for PLHIV and IDUs.
- **Strengthen the capacity of PLHIV networks and marginalized groups:** Capacity of the PLHIV networks and CBOs working with marginalized groups needs to be strengthened to provide TB treatment education/counselling (through in-centre counselling, support groups, and outreach) and to follow-up TB-infected clients to ensure adherence.

4. Ensure availability of quality TB counselling and treatment services

- **Ensure people-friendly environment and quality services:** Ensure that government DOTS centres are friendly and healthcare providers (doctors and counsellors) offer competent, non-judgmental, non-discriminatory and quality counselling and treatment services to TB patients irrespective of their HIV status and being from marginalized communities (IDUs, FSWs, and MSM).
- **Ensure screening of all PLHIV for HBV/HCV:** Ensure that standard clinical guidelines are followed in screening people living with HIV and IDUs (irrespective of HIV status) for HBV/HCV before starting TB treatment.
- **Support treatment of HCV/HBV co-infections among TB patients including those who are HIV - positive:** Develop mechanisms to support treatment for HCV and HBV infections in IDUs (including those living with HIV) with TB.
- **Consider 'smart cards' for easy access to TB treatment irrespective of the native place of TB patients:** Similar to the initiative in the national ART program, consider providing 'smart cards' (electronic) for TB patients to ensure uninterrupted and easy access to TB treatment from any government (and non-government) DOTS centre. Availability such cards can help TB patients who frequently travel from one place to another.

5. Develop and implement an action plan to ensure equity in TB treatment access for PLHIV and marginalized groups such as IDUs and FSWs

- **Ensure that the specific TB prevention and treatment-related needs of PLHIV and marginalized groups are not overlooked on the assumption that they are not of substantial size that warrants specific attention.** Ensure that the current TB/HIV coordination mechanisms (policy and program levels) address their needs.
- Develop mechanisms to **monitor inequalities in TB treatment adherence:** Collect disaggregated data according to marginalized group status (PLHIV, IDUs, FSWs, MSM) in DOTS centres, and quantify inequity information on TB treatment access and adherence.
- **PLHIV networks and marginalized groups should be actively involved** at all levels to make effective use of their experience-based expertise in monitoring and review of TB programs to ensure equitable access to TB treatment and improve adherence. State and district TB/HIV coordination committees should involve representatives of PLHIV networks and marginalized groups.



INTRODUCTION

Tuberculosis (TB) is a major contributor to the global burden of disease, especially in developing countries like India¹, where TB epidemic is being fuelled by the HIV epidemic². An estimated 8.9 million new cases of TB occurred worldwide in 2004 and two million people die of TB each year³.

The incidence of tuberculosis (TB) in India is estimated as 1.8 million cases per year⁴. People living with HIV and injecting drug users (IDUs) are at increased risk of getting TB compared with HIV-negative people and people who do not use drugs. While the lifetime risk of developing active tuberculosis in immune competent persons is 5% to 10%, people living with HIV have an annual risk of 5% to 15%. Similarly, in IDUs, decreased immunity associated with active drug use, malnutrition, and alcohol use – all increase the risk of developing active TB disease.

Global data indicate that up to half of all of patients with TB do not complete treatment⁵ – leading to prolonged infectiousness, drug resistance (multi-drug resistance – MDR, and extreme drug resistance – XDR), relapse, and death⁶. Several studies in both developed and developing countries have documented various reasons for delay in TB treatment initiation as well as a variety of barriers to TB treatment adherence. Although several studies among TB patients have been published from India, most of these studies have focused on TB treatment outcomes and some also focused on delay⁷ in treatment initiation (barriers to access). There are very few Indian studies that explored barriers to access and adherence beyond the individual-level^{8,9} and almost none of the published studies (except one¹⁰), to our knowledge, have focused on barriers to access and adherence among people living with HIV and injecting drug users. Also, gender-disaggregated data on TB treatment access and adherence are very limited.

A recent international review of qualitative studies on adherence to anti-TB treatment

(Munro et al., 2007) found only three studies^{11,12,13} that focused on the experiences of TB-infected people with or without HIV. No specific recommendations for TB-infected PLHIV or IDUs with TB emerged from that review. The authors of that review explicitly called for more studies among PLHIV with TB and PLHIV taking both antiretroviral treatment and anti-TB treatment.

Delay in diagnosis and initiation of TB treatment poses risk of transmission of TB to greater numbers of people, in addition to unnecessarily prolonging the suffering of, and sometimes even leading to death of people with TB. Understanding the various factors that lead to the delay between initiation of symptoms and accurate diagnosis and initiation of TB treatment is thus crucial¹⁴. Furthermore, efforts to improve TB treatment outcomes require comprehensive and holistic understanding of barriers to and facilitators of access and adherence to TB treatment, and patients' experiences of taking treatment.^{15,16}

Our study's focus was to better understand the various factors that influence access and adherence to TB treatment among people with TB – including people living with HIV and injecting drug users. We also aimed to find out the level of nonadherence to TB treatment and factors associated with nonadherence.

Research questions:

1. What is the level of non-adherence among people with TB (including people living with HIV and IDUs) on TB treatment?
2. What are the various individual, health care system, and social/policy barriers that hinder or facilitate access and adherence to TB treatment?
3. What are the similarities and differences (if any) in relation to access and adherence to TB treatment between:
 - HIV-negative (or unknown HIV status) people and PLHIV with TB
 - IDUs and non-IDUs with TB
 - Men and women with TB

Box 1: Definitions – Access, Adherence and Nonadherence

Access to TB medications:

Refers to access to free first-line or second-line TB regimens that are available in the government hospitals through the Revised National TB Control Program (RNTCP-II) or affordability of TB medications prescribed by the private medical practitioners.

Treatment adherence:

Refers to how closely patients follow a prescribed treatment regimen. It includes patient's willingness to start treatment and patient's ability to take medications exactly as directed.

Nonadherence:

In general, the term 'nonadherence' is used to refer to:

- Not taking medication as prescribed (e.g., taking too many or too few pills, taking medications at incorrect times, not following specific dietary restrictions)
- Terminating the treatment prematurely
- Not initiating a recommended treatment

In the survey, we measured the degree of non-adherence in terms of ever skipped TB medications, and whether patients missed TB medication doses consecutively for more than a week, one month and two months.

Box 2: DOTS and RNTCP

DOTS (directly observed treatment, short course) is the internationally recommended control strategy for TB¹⁷, which is the main strategy of the India's Revised National Tuberculosis Control Programme (RNTCP) of the Central TB division, Government of India. Under RNTCP, directly observed treatment (DOT), is a 6- to 8-month regimen with a combination of anti-TB drugs. The first 2 months is known as the 'intensive phase' in which a combination of three or four drugs are provided. The next 4- to 6-month follow-up period is the 'continuation phase' and usually two drugs are provided. The drugs used in treatment and the duration of the treatment may vary depending upon factors such as severity of TB, type of TB (pulmonary or extra-pulmonary), HIV status, and previous TB treatment experience.



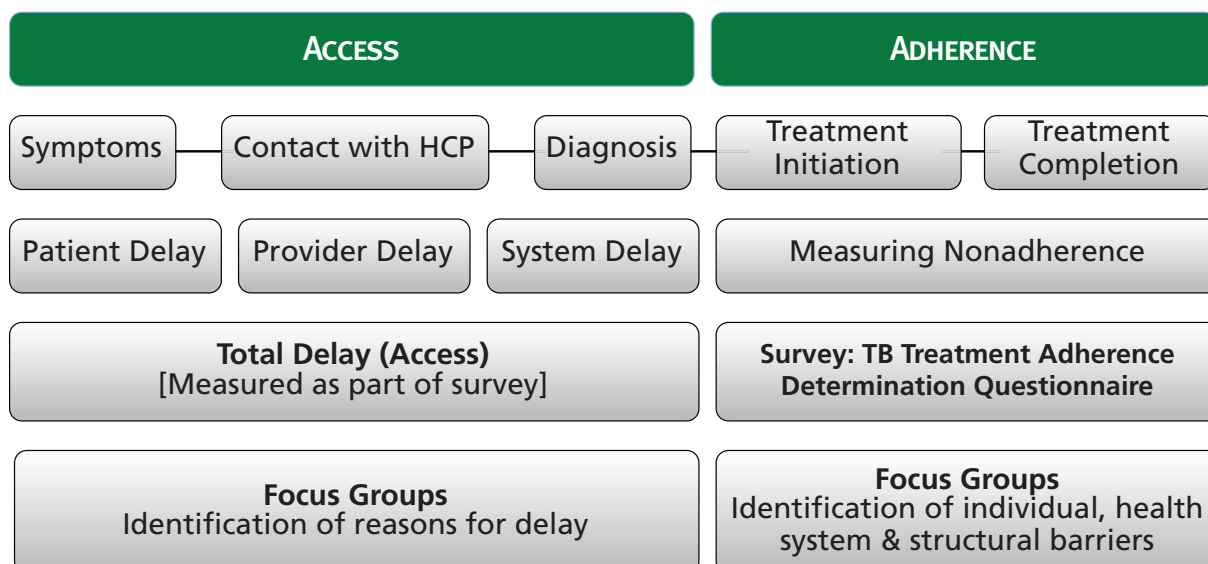
METHODOLOGY

We conducted a mixed methods study by recruiting participants from two sites: Imphal District in Manipur and Erode District in Tamil Nadu. In Imphal, participants were recruited between July and October 2009, through government DOTS centres, NGOs that serve as DOTS providers (free TB medications supplied by the government), PLHIV networks and organisations working with injecting drug users. In Erode, data collection was conducted between September 2009 and February 2010, primarily through two TB DOTS centres functioning in two hospitals in Erode (Erode Government Headquarters Hospital and Perundurai Medical College Hospital), Government ART centre, and Erode PLHIV network.

Conceptual framework of the mixed methods study

The overall framework of the mixed methods study is depicted in diagram 1. The conceptual framework for the adherence part of the survey component was adapted from that of McDonnell et al., 2001. That framework was a merger of Orem’s self-care deficit theory of nursing (Orem, 1991¹⁸) and the model of adherence proposed by DiMatteo & DiNicola (1982)¹⁹, and Gritz, DiMatteo, & Hays (1989)²⁰. Delay in the treatment initiation (‘Access delay’) was measured in 4 ways (see box 3). Survey questionnaire measured the duration of delay and qualitative component (focus groups) explored the reasons behind the delay. Survey measured the level of adherence, and assessed the various factors that influence TB treatment adherence - using a standard TB Treatment Adherence Determination Scale. Also, various levels of barriers (individual, health care system and structural) and facilitators to TB treatment were explored in the focus groups and key informant interviews.

Diagram 1: Conceptual framework of the study



1. Quantitative component

Survey was administered among 550 participants in two sites: Imphal - 300 participants that included 198 men [among men, 97 were IDUs] and 102 women; Erode – 250 participants that included 167 men and 83 women.

The survey was restricted to people who have been taking anti-TB treatment for at least 2 months prior to enrolment in the study. We aimed at recruiting people from various subgroups (HIV-negative, HIV status unknown, and known HIV-positive) in both sites. Additionally, participants from the marginalised communities - IDUs and female sex workers were recruited in Imphal. The sample was primarily a convenience sample of people recruited from government and non-governmental DOTS centres and through PLHIV networks and NGOs working with IDUs.

Box 3: Delay in TB treatment initiation (“Access delay”): Operational definitions used in the quantitative survey

Access delay was analyzed in four ways.

1. **Total delay:** Delay in the period between onset of TB symptoms and initiation of TB treatment. If the time period is more than 4 weeks, it was considered delay.
2. **Patient delay:** Delay in the period between onset of TB symptoms and first visit to any formal (allopathic/English medicine) health provider. If the time period was more than 2 weeks, it was considered a delay.
3. **Provider delay:** Delay in the period between first visit to any formal (allopathic/English medicine) health provider and proper diagnosis of TB. If the time period was more than 1 week, it was considered a delay.
4. **Health care systems delay:** Delay in the period between diagnosis of TB by any formal (allopathic/English medicine) health provider and initiation of TB treatment. If the time period was more than 1 week, it was considered a delay.

Survey Instrument

An interviewer-administered structured questionnaire was administered in Meitei in Manipur, and Tamil in Erode. The questionnaire contained sections on socio-demographic characteristics, measures to assess delay in TB treatment initiation, items to measure TB knowledge (and to score the knowledge), TB treatment adherence determinants scale (explained below), ART adherence mini-scale (for PLHIV on ART and TB treatment), and social support. The Tuberculosis Treatment Adherence Determinants Questionnaire was adapted, with permission, from an instrument designed to study factors related to adherence to TB in Georgia, USA²¹. Responses were reported on a three-point Likert scale (a modification from the five-point Likert scale used in the original questionnaire).

Procedure

Potential participants were screened by research staff for eligibility (medical diagnosis of TB, over 18 years of age) and ability to participate and provide informed consent (no altered mental status). After informed consent was obtained, participants were interviewed in a private room in the clinic, office of non-governmental organisations or patient’s home. If a home visit was made, prior permission to visit was first obtained through the agency staff and then by calling the patient.

Analysis

Data were analyzed using the SPSS-17 for Windows. Prior to analysis, we conducted statistical diagnostic studies to ensure that data conformed with the assumptions (of linearity, homoscedasticity, independence, and normality) underlying regression analysis. These assumptions were met.

2. Qualitative component

We used purposive sampling to recruit the participants for focus group discussions (FGDs). All FGDs and most key informant interviews were conducted in Meitei in Imphal and Tamil in Erode. Subgroups were decided based on the need to obtain maximum variation to document heterogeneous and multiple perspectives²² into the study. Participants were selected for inclusion with the goal of capturing diversity of experience, particularly regarding the unique circumstances that facilitate or impede access and adherence to TB medications. Key informants were chosen based on their expertise and experience in relation TB and HIV programs, policies and services.

Seventeen focus groups with a total of 95 participants (5 focus groups with 25 participants in Erode and 12 focus groups with 70 participants in Imphal) from various subgroups were conducted. Thirteen key informants (5 key informants in Erode and 8 key informants in Imphal) were interviewed. Key informants were officials of State AIDS Control Society (SACS) and State and district TB units of RNTCP, community leaders, directors of NGOs/ CBOs and DOTS providers. (See Box 4)

Semi-structured qualitative guides were used for conducting FGDs and key informant interviews. FGDs and key informant interviews were audiotaped, transcribed verbatim in Meitei (for Manipur) and Tamil (for Erode site), and translated into English. During transcription, all personal identifiers were removed.

FGDs and key informant interviews conducted in the Imphal and Erode were audiotaped, transcribed verbatim in native languages, and translated into English. During transcription, all personal identifiers were removed. FGD and key informant interview data were explored using framework analysis (Ritchie & Spencer, 1994²³) to identify categories and derive themes. In accordance with framework analysis, we developed a hierarchical thematic framework and used the framework to classify and organise data according to key themes, concepts and emergent categories. Framework analysis is particularly appropriate for applied qualitative research when a study is oriented towards policy outcomes (Green, 2005²⁴). An adapted version of Aday and Andersen's²⁵ (1974) framework of access to health services was used for analysis.

Ethics and consent

The study protocol was reviewed and approved by the Institutional Review Board of the Indian Network for People living with HIV/AIDS (INP+). All participants provided informed written consent. All participants in the quantitative survey, and FGDs were paid 300 Indian rupees to compensate for their time and travel-related expenses. Key informants were not paid.

Sociodemographic characteristics

Survey participants

Table 1 summarises the sociodemographic characteristics of the survey participants recruited from Imphal and Erode.

Focus group participants

Imphal site: Eight focus groups were conducted among 70 participants (38 men and 32 women) including 50 PLHIV. Fifty-six percent (n=39/70) had completed high school and five participants were illiterate. About half of the participants (n=34/70) were unemployed and 19% (n=13/70) were staff of voluntary organizations. More than one-third (41.4%; n=29/70) of the participants were currently married and were living with their spouse. About half (51.4 %; n=36/70) of the participants were injecting drug users (32 HIV-positive male IDUs and 4 female IDUs). Among the four female IDUs, three also engaged in sex work. Sixty-three percent (n=20/32) of the HIV-positive male IDUs were HCV-positive and 13% (n=4/32) were HBV-positive.

Erode Site: Five focus groups were conducted among 25 participants (17 men and 8 women) including 10 PLHIV. Fifty-two percent (n=13/25) of the participants had completed high school and about one-third (28%; n=7/25) were illiterate. Most of the participants belonged to lower socio-economic status. Sixty percent (n=15/25) had an average monthly income of less than 2000 Indian rupees per month. Forty-four percent (n=11/25) were unemployed. Sixty percent (n=15/25) of the participants were currently married and were living with their spouse. About 20% (n=5/25) of the participants had at least one family member with TB.

Inference Quality ('Validity') and Inference Transferability ('Generalizability')

Quantitative component

For the survey, inference quality is ensured by several ways. For example, having adequate effect size; having chosen appropriate statistical tests; and having met the

assumptions of the statistical tests. These are further explained in the methods and findings section – where appropriate.

Qualitative component

'Member checking' was conducted with key informants to increase credibility of the findings (Lincoln & Guba²⁶, 1985). 'Peer debriefing' (Lincoln & Guba, 1985) was undertaken with IDU community leaders and health care researchers to increase trustworthiness of the findings. The findings correspond to the emergent categories/themes; all quotations are drawn from the interviews and focus groups.

Limitations in the generalizability of the survey findings

The survey among people with TB yielded significant and valid results – as explained in the findings section. However, generalizability of the survey findings needs to be made with caution. People with TB – including PLHIV and IDUs – in other parts of India may not be similar to those in Imphal and Erode, especially in relation to sociodemographic characteristics, family support, and association with NGOs/CBOs and PLHIV networks. For example, in general, IDUs in Imphal are most likely to be educated, living with their family, and relatively well connected to NGOs/CBOs working with IDUs. Most of the IDUs being on OST could be a key reason for the high level of TB treatment adherence seen in this study sample, which also underscores the importance of connecting IDUs on ART or TB treatment with OST services. In the future, multi-centre studies among both people living with HIV and male/female IDUs are needed to find out variations in access and adherence to TB treatment – due to geographical and contextual factors.

Table 1. Sociodemographic Characteristics of Survey Participants

Characteristics	IMPHAL								ERODE					
	Overall Sample (n=300)		Men (n=198)				Women (n=102)		Overall Sample (n=250)		Men (n=167)		Women (n=83)	
			IDU (n=97)		Non-IDU (n=101)									
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Age														
18 – 22	17	5.7	1	1.0	6	5.9	10	9.8	19	7.6	9	5.4	10	12.0
23 – 27	13	4.3	1	1.0	6	5.9	6	5.9	14	5.6	6	3.6	8	9.6
28 – 32	42	14.0	10	10.3	12	11.9	20	19.6	35	14	18	10.8	17	20.5
33 & above	228	76.0	85	87.6	77	76.2	66	64.7	182	72.8	134	80.2	48	57.8
	Mean: 41.6 Median: 39.0		Mean: 37.5 Median: 37.0		Mean: 46.2 Median: 45.0		Mean: 41.1 Median: 40.0		Mean: 41.19 Median: 39.5		Mean: 43.34 Median: 42.0		Mean: 36.87 Median: 35.0	
Gender														
Male	198	66.0	97	100	101	100			167	66.8	167	100		
Female	102	34.0					102	100	83	33.2			83	100
Education														
Illiterate	2	0.6	1	1.0			1	1.0	81	32.4	42	25.1	39	47.0
Haven't completed primary	45	15.0	4	4.1	19	18.8	22	21.6	13	5.2	12	7.2	1	1.2
Completed primary school	49	16.3	9	9.3	22	21.8	18	17.6	51	20.4	38	22.8	13	15.7
Completed elementary school	57	19.0	19	19.6	20	19.8	18	17.6	48	19.2	33	19.8	15	18.1
Completed high school	58	19.3	27	27.8	14	13.9	17	16.7	31	12.4	26	15.6	5	6.0
Completed 12th grade	57	19.0	22	22.7	15	14.9	20	19.6	21	8.4	11	6.6	10	12.0
Completed college degree	30	10.0	14	14.4	10	9.9	6	5.9	4	1.6	4	2.3		
Completed diploma	2	0.7	1	1.0	1	1.0			1	0.4	1	0.6		
Monthly household income (Rupees)														
< 2000	91	30.3	27	27.8	30	29.7	34	33.3	146	58.4	89	53.3	57	68.7
2001 - 5000	136	45.3	42	43.2	49	48.5	45	44.1	74	29.6	60	35.9	14	16.9
5001 – 10000	53	17.6	20	20.6	17	16.8	16	15.7	14	5.6	10	6.0	4	4.8
10001 & above	20	6.6	8	8.2	5	5.0	7	6.9	5	2.0	3	1.8	2	2.4
Don't Know									11	4.4	5	3.0	6	7.2
Employment														
Unemployed	96	32.0	26	26.8	22	21.8	48	47.1	90	36	47	28.1	43	51.8
Student	8	2.7			2	2.0	6	5.9	2	0.8	2	1.2		
Daily-wage labourer	9	3.0	2	2.1	6	5.9	1	1.0	105	42	74	44.3	31	37.3
Government staff	14	4.7	3	3.1	9	8.9	2	2.0	7	2.8	5	3.0	2	2.4
Private company staff	136	45.3	51	52.6	55	54.5	30	29.4	17	6.8	12	7.2	5	6.0
Voluntary organization staff	15	5.0	7	7.2	1	1.0	7	6.9	1	0.4			1	1.2
Self-employed	18	6.0	8	8.2	4	4.0	6	5.9	28	11.2	27	16.2	1	1.2
Sex worker	1	0.3			1	1.0								
Others	3	1.0			1	1.0	2	2.0						
Alcohol use														
None	277	92.3	86	88.6	90	89.1	101	99.0	231	92.4	149	89.2	82	98.8
Current use	23	7.7	11	11.3	11	10.9	1	1.0	19	7.6	18	10.8	1	1.2
Drug use														
None	203	67.7			101	100	102	100	246	98.4	163	97.6	83	100
Last one year	97	32.3	97	100					4	1.6	4	2.4		
Last 3 months	16/97	16.5	16	16.5										
HIV status														
Not tested/ do not know	84	28.0	1	1.0	46	45.5	37	36.3	10	4	6	3.6	3	3.6
Negative	67	22.3	3	3.1	28	27.7	36	35.3	130	52	90	53.9	41	49.4
Positive	149	49.7	93	95.9	27	26.7	29	28.4	110	44	71	42.5	39	47.0

Box 4: Qualitative methods and Sample size

Focus Group Discussions (FGDs) (Total: 12 FGDs. 70 participants)

Imphal site (Total: 12 FGDs. 70 participants)	Erode site (Total: 5 FGDs. 25 participants)
1 FGD among care-givers (n=6 participants)	2 FGDs among men and women living with HIV (n=10)
4 FGDs among IDUs (n=24 participants) <ul style="list-style-type: none"> • IDUs on ART • IDUs not on ART • IDUs on Opioid Substitution Treatment (OST) • IDUs with HBV/HCV co-infection 	1 FGD among men who completed TB treatment without interruption (n=5)
2 FGDs among Women Living with HIV/AIDS (n=12)	1 FGD among defaulters (i.e., discontinued TB treatment for more than 2 months) (n=5)
1 FGD among PLHIV who completed TB treatment successfully (n=6)	1 FGD among HIV-negative women with TB (n=5)
1 FGD among HIV-negative women with TB (n=6)	
1 FGD among Female IDUs (including those who are sex workers) (n=4)	
1 FGD among men who have sex with men (MSM) (n=6)	
1 FGD among defaulters (i.e., discontinued TB treatment for more than 2 months) (n=6)	

Key Informant Interviews (KIIs) (Total: 13)

Imphal site (n=8 participants)	Erode site (n=5 participants)
<ul style="list-style-type: none"> • Physician treating PLHIV • Staff in-charge of an NGO DOTS program – 2 persons • State TB Official • A doctor in the DOTS centre • Doctor managing an ART centre • Consultant of State TB unit • MSACS Official of Manipur State AIDS Control Society 	<ul style="list-style-type: none"> • PLHIV network leader -1 • Staff of government DOTS centres – 4 (includes treatment supervisor and treatment educator)



KEY FINDINGS

Quantitative Findings

A. Access delay (Onset of symptoms to treatment initiation)

The summary of various types of access delay experienced by the study participants is given below.

Imphal site

Total delay: more than 4 weeks - 70.3% (211/300)

Patient delay: more than 2 weeks - 80.3% (241/300)

Health system delay: more than 1 week - 9.3% (28/300)

Erode site

Total delay: more than 4 weeks – 50.4% (126/250)

Patient delay: more than 2 weeks -37.6% (94/250)

Health system delay: more than 1 week – 19.6% (49/250)

These data suggest that patient delay is more likely to contribute to the overall delay in the initiation of TB treatment. And once patients are seen by a qualified medical practitioner, most are started on TB treatment within a reasonable time.

In Imphal, among 300 participants with TB, 149 were HIV-positive. Among PLHIV with TB (n=149), only 94 were on ART. In Erode, among 250 participants with TB, 110 were HIV-positive. Among PLHIV with TB (n=110), only 85 were on ART. These data indicate although the national and international guidelines state that HIV-positive people with TB should be started on ART and studies have shown that death among PLHIV was strongly associated with the absence of ART during TB treatment²⁷, about one-tenth to one-third of PLHIV with TB in this study were not on ART. This could indicate the lack of effective linkages between government DOTS centres and ART centres. Data from focus groups offered another explanation as well. Some HIV-positive people do not reveal their HIV-positive status to the health care providers and consequently HIV-positive people with TB are not referred to ART centres – at least until the health care providers come to know.

B. TB treatment adherence

Participants were asked about whether they missed doses consecutively for more than 2 months, 1 month and 1 week. In Imphal, the percentage of participants who answered in affirmative were 1.3% (n=4/300), 1.3% (n=4/300) and 6.7% (n=20/300) respectively. In Erode, the percentage of participants who answered in affirmative were 6 % (n=15/250), 4% (n=10/250) and 6.8% (n=17/250) respectively.

In Imphal, 72% % (n=217/300) never skipped TB medications. In other words, at least 28% (n=83/300) skipped their TB dose at least once. Similarly, in Erode, 77.6% (n=194/250) never skipped TB medications. That is, at least 22.4% (n=56/250) skipped their TB dose at least once.

Box 5: Key survey findings

Imphal

- 1. Paying for TB medications:** 29.7% (89/300) are currently paying for TB medications (and presumably all are on daily TB regimens). Among them, more than half (51%) pay more than Rs. 500 per month for TB medications.
- 2. Travel distance from residence to TB treatment centre:** Among the 210 participants who traveled to get TB medicines, about 42% (n=89/210) traveled at least 2 to 3 km to reach the TB treatment centre while 19% (n=39/210) travel more than 4 km to reach the TB treatment centre.
- 3. Access delay (Delay in TB treatment initiation)**
 - Total delay: more than 4 weeks - 70.3% (211/300)
 - Patient delay: more than 2 weeks - 80.3% (241/300)
 - Health system delay: more than 1 week - 9.3% (28/300)
- 4. TB treatment adherence:**
 - Never skipped TB medications – 72% (n=217/300). Hence, at least 28% (n=83/300) skipped their TB dose at least once.
 - Ever missed doses for 2 consecutive months – 1.3% (n=4/300)
 - Ever missed doses for more than 1 month – 1.3% (n=4/300)
 - Ever missed doses for more than one week – 6.7% (n=20/300)

Among IDUs, 28% (n=27/97) skipped their TB dose at least once. About one-tenth (11.3%; n=11/97) missed doses (consecutively) from one week to more than two months.
- 5. Drug and Alcohol use:** Injecting drug use in the past one month – 5.3% (n=16/300). Consumed alcohol in the past one month – 7.7% (n=23/300)
- 6. ART and TB Treatment:** Among 300 participants with TB, 149 were HIV-positive. Among PLHIV with TB (n=149), only 94 were on ART. In response to the statement “I feel that having to take both ART and TB medications makes it more difficult to take all doses”, among those currently on ART and TB treatment, nearly 90% agreed or strongly agreed and remaining 10% disagreed or strongly disagreed.

Erode

- 1. Paying for TB medications:** None. All the participants were being treated at government DOTS centres.
- 2. Travel distance from residence to TB treatment centre:** About 30% (n=75/250) traveled at least 2 to 3 km to reach the TB treatment centre while 23% (n=57/250) traveled more than 6 km to reach the TB treatment centre.
- 3. Access delay (Delay in TB treatment initiation)**
 - Total delay: more than 4 weeks – 50.4% (126/250)
 - Patient delay: more than 2 weeks -37.6% (94/250)
 - Health system delay: more than 1 week – 19.6% (49/250)
- 4. TB treatment Adherence:**
 - Never skipped TB medications – 77.6% (n=194/250). Hence, at least 22.4% (n=56/250) skipped their TB dose at least once.
 - Ever missed doses for 2 consecutive months – 6 % (n=15/250)
 - Ever missed doses for more than 1 month – 4% (n=10/250)
 - Ever missed doses for more than one week – 6.8% (n=17/250)
- 5. Drug and Alcohol use:** Ever injected drugs – 1.6% (n=4/250). Consumed alcohol in the past one month – 7.6% (n=19/250)
- 6. ART and TB Treatment:** Among 250 participants with TB, 110 were HIV-positive. Among PLHIV with TB (n=110), only 85 were on ART. In response to the statement “I feel that having to take both ART and TB medications makes it more difficult to take all doses”, among those currently on ART and TB treatment (n=85), nearly 48.2% agreed or strongly agreed and remaining 51.8% strongly disagreed.

Qualitative Findings

Table 2: List of Key Barriers to Access and Adherence to Tuberculosis Treatment

Individual Level Barriers	Healthcare System Barriers
<ul style="list-style-type: none"> • Non-recognition of or misattribution of TB symptoms • Limited knowledge and misconceptions about TB • Belief in alternative (non-allopathic) medicinal system • Active drug and alcohol use • Fatalism • Financial constraints • Lack of family support and Social stigma 	<ul style="list-style-type: none"> • Challenges to early diagnosis of TB among PLHIV and IDUs • Delay in getting results from some government diagnostic centers • Perceived discrimination and suboptimal care in government centres • Perceived lack of adequate TB treatment education and counseling in treatment centres

A. Barriers to TB Treatment Access: Delay in TB Diagnosis and Treatment Initiation

The main reasons for delay in TB treatment initiation were both patient-related and health care system-related.

1. Patient-related factors for delay in TB treatment initiation

On the part of the patients, the delay was due to several reasons.

Non-specific nature of symptoms

Among both HIV reactive and non-reactive people fever or chronic cough was attributed to other illness or just 'ordinary' throat infection or fever. Although some PLHIV were concerned that the symptoms could be due to TB and thus contacted an appropriate health care provider early, some other PLHIV attributed the symptoms to their diminished general immunity.

Misattribution of symptoms

Sometimes, loss of weight was attributed to HIV infection; being on OST (drug users); and active drug and alcohol use. Some IDUs thought that smoking was responsible for their chronic cough and delayed seeking medical care. Active drug use also prevented IDUs from seeking health care early since they were high. Even those people who recently completed TB treatment could not identify that the relatively mild symptoms of cough they experienced could be due to failure of TB treatment or second episode of TB disease. This was because they were forewarned by the medical practitioners that some are likely to experience cough and difficulty in breathing even after successful completion of treatment. Thus, some patients have delayed up to 4 months in seeking medical care.

Atypical and non-pulmonary symptoms

Having several episodes of cough with periods of no cough and mild fever led some patients to ‘wait-and-see’ or to take self-medications – wishing that the symptoms will subside or go away on their own.

Initial visits to providers of alternative medicine

Some patients reported visiting medical practitioners of alternative medicine such as homeopathy. They took medications from those providers from a few days to a week before switching to an allopathic medical provider.

On the other hand, patients made an early visit to a health care provider if the symptoms were severe (blood in the sputum or having had dramatic events like fainting), have had knowledge about TB through mass media or counsellors/doctors (especially PLHIV), previously treated for TB, family members have had TB, and associated with PLHIV networks, or receiving services from NGOs working with IDUs (OST program and/or outreach).

2. Provider and healthcare system-related factors for delay in TB treatment initiation

Qualified private (allopathic) medical practitioners do not seem to have much problem in suspecting TB. Usually, an initial course of antibiotics is given to rule out minor throat infections that may be associated with cough and fever. Sometimes, patients switch providers if the symptoms persist. However, once the clinician has a strong suspicion of TB or if the X-ray and skin test indicate TB, initiation of TB treatment is decided swiftly - based on whether the patients are willing to buy medications on their own or want to be referred to a government DOTS centre. Some patients preferred visiting government DOTS centres. Even those patients who initially preferred to buy TB medications on their own, due to financial difficulties, after some time they asked their physicians to refer them to government centres.

Challenges to early diagnosis of TB among people living with HIV or injecting drug users

Only some patients reported that there was considerable delay in diagnosing TB in private medical settings. For example, in one bed-ridden HIV-positive person the delay appeared to be due to other associated illness such as hepatitis-C; and in another patient the delay was because of the false-negative TB result given by a private lab (later the lab in the government centre correctly diagnosed TB in that patient).

Delay in getting results from government diagnostic centers and connection with initiation of TB treatment in private settings

In Imphal, people living with HIV who are already seeing physicians in the government health centres seemed to have relatively good knowledge about TB. They quickly approached government health care centres (ART centres) and once diagnosis of TB was confirmed through lab tests, they seemed to have two options. First option: the government HCPs offers the patients to refer them to the nearby DOTS centres from which they can get free TB medications. Second option: some government physicians are concerned about the possible delay in initiation of treatment in the government DOTS centres and thus suggest them to take daily TB regimen from private practitioners. This is because the lab test results from the government hospitals are reportedly not accepted in the government DOTS centres (presumably because of some bureaucratic reasons or not believing in the quality of lab) and lab tests are repeated in the DOTS centre. Thus, to avoid that kind of unnecessary delay in treatment initiation, some government physicians advise the patients to purchase TB medications and mostly prescribe daily regimen of anti-TB drugs. A doctor key informant in Imphal informed that some physicians (including those in the government hospitals) are of the opinion that daily regimen based on brand drugs are better than the free thrice-weekly regimen of anti-TB drugs given in the government DOTS centres.

Lack of access to free TB drug resistance testing in Manipur (at the time of finalizing this report) and the need to pay a large amount (about Rs.6000) in private labs mean delay in the initiation of appropriate treatment in some patients.

Perceived discrimination at the government centres

An important barrier in delay in accessing TB treatment is stigma associated with TB and HIV. Many patients are reluctant to visit the government DOTS centre, because it can be easily interpreted by others (neighbors and people in their locality) that they have TB. Also, Manipur being a high HIV epidemic state, a person with TB could also be suspected to have HIV. Given that

background, patients are afraid of the possible negative consequences such as discrimination and social isolation. Also, the negative image of government health centres being unfriendly; not having sufficient infrastructure; lack of privacy and confidentiality; and incidents of discrimination people have heard from others – all prevent or at least slow down the patients' access to government DOTS centres.

In Imphal, upon the request of some patients (mostly PLHIV, IDUs and female sex workers), private and government medical practitioners (including those in government DOTS centers) refer the patients to the nearby NGO DOTS providers, from which patients continue taking free TB medications.

Table 3: Illustrative quotes for patient- and healthcare systems-related reasons for delay in TB diagnosis and treatment initiation

Patient-related reasons for delay in TB diagnosis and treatment initiation	
Misattribution of TB-related symptoms	
<i>To ordinary sore-throat and smoking</i>	<p>“Initially I didn’t know. I kept on coughing but not like the usual cough. It [coughing] became frequent at night. I thought it [coughing] may be due to drinking water. Before I consulted a doctor, I contacted an NGO and did sputum test and was found to be positive [for TB].” (A TB patient, FGD, Imphal)</p> <p>“I did not visit any doctor because I thought that the cough was due to smoking. But my friends insisted me to go for testing [TB].” (A TB patient, FGD, Imphal)</p> <p>“I thought the cough worsened due to smoking. So I went to see [doctor] only after two weeks.” (A male, FGD, Erode)</p>
<i>To drugs injected</i>	<p>“I used to cough a lot at the beginning and became very weak. I did not give much importance as I thought it was just due to the drugs that I took. Only when my health worsened, I went for check-up after I informed people at [NGO]...Well, that was before I was on OST [Opioid Substitution Therapy].” (An IDU TB patient on OST, FGD, Imphal)</p> <p>“As I am a drug user, I took it [initial TB symptoms] lightly because of this reason [drug use]. I did not do any test before, but later as it [TB symptoms] became worse, I underwent the [sputum] test and came to know I got it [TB].” (An IDU TB patient, FGD, Imphal)</p>
<i>To side-effects of Opioid Substitution Therapy (OST)</i>	<p>“My body weight decreased from 60 Kg to 50 Kg. I assumed that it could be the side-effect of OST.” (An IDU TB patient on OST, FGD, Imphal)</p>
<i>To hard work</i>	<p>“I was very careless about it [initial TB symptoms]. I never thought that at first the illness would be of this kind [TB]. So, I did not go for check-up. I thought for a long time that the [chest] pain was due to hard [manual] work.” (A TB patient, FGD, Imphal)</p>
Atypical and non-pulmonary symptoms	
<i>No cough</i>	<p>“Cough is the common symptom of TB. Since he was not coughing no tests were done for [TB] but other tests were done.” (Caregiver of a pulmonary TB patient, FGD, Imphal)</p>
<i>Inconsistent or on-and-off symptoms</i>	<p>“Sometimes, I would feel well and did not have any breathing problems. Sometimes my cough would go away while talking with people. So, I thought I recovered from my cough curse. It was much later when I went for check-up [TB diagnosis].” (An IDU TB patient, FGD, Imphal)</p> <p>“After two months only [I was diagnosed with TB in a government hospital]. Before that, whenever I have fever, I used to visit different hospitals. [The body health] will be fine only for a day or two. None of [those doctors] had told me about [TB infection].” (A female TB patient, FGD, Erode)</p>
<i>Delay in diagnosing non-pulmonary TB</i>	<p>“My son and husband did not cough; they had no [TB] symptoms like others. It could not be detected when their sputum was tested. Only after other tests, my son was found to have gland [lymph node] TB.” (Caregiver of a TB patient living with HIV, FGD, Imphal)</p> <p>“I had swelling in my neck for two months. I went to many local hospitals but it did not subside. Finally, I came to [government hospital] just for a consultation. Now, I got diagnosed with TB.” (A woman living with HIV, FGD, Erode)</p>

Provider and healthcare system-related factors for delay in treatment initiation	
<i>Delay in getting diagnostic test (X rays) results from government centres</i>	“I went for X-ray at the [government hospital] but they said I would have to wait for the result since the X ray film could not be developed till the film-roll was [completely used]. They said it would take 15 days or so. Meantime, my physical condition was deteriorating and I did not want to delay any more. [He then went to a private clinic/lab].” (A TB patient, FGD, Imphal)
<i>Lack of testing facility for extra-pulmonary TB in a government centre</i>	“When I mentioned about the neck swelling I had, they told that the test [Fine Needle Aspiration Cytology (FNAC) for diagnosing glandular TB] is not available, so referred me [for diagnosis] to private hospital.” (PLHIV with TB, FGD, Erode)
<i>Inability to diagnose TB early because of associated illnesses</i>	“At the initial stage my complexion changed and periodic fever continued. Loss of hunger, cough, and chest pain were there. I had been hospitalized for a long time without knowing that I have TB.” (An IDU TB patient on ART, FGD, Imphal)
<i>Perceived discrimination and improper assessment</i>	“When a patient first visits the hospital, detailed case history and profile should be taken. This should include [lab] test history, instances of earlier illnesses, whether there is TB or not or whether he got the infection from exposure to someone having TB, whether the person is an IDU, etc. Instead, they [doctors] act as if they don’t want to come near us and were very uncomfortable. I even missed out on doing a blood test since proper case history taking process was missing.” (An IDU TB patient on ART, FGD, Imphal)
<i>Lack of educational materials for PLHIV on TB</i>	“[People living with HIV have more chances for contracting TB. Hence, it would be more useful if we distribute the IEC materials [about TB infection]. This will motivate many [PLHIV] to get tested for TB.” (A PLHIV network leader, Erode)

B. Barriers and Facilitators of TB Treatment Adherence

Several barriers prevent people with TB from adhering to TB treatment.

1. Individual-level barriers

Limited knowledge and misconceptions about TB drugs

Both fear of side-effects as well as sense of well being were associated with non-adherence. Participants were concerned about having serious side effects from taking TB medications: vague symptoms like ‘weakness of the body’ and ‘feeling tired’ to taking TB medications were interpreted as side effects. As a result, at least some participants reported stopping the TB medications for some period. On the other hand, feeling better after taking TB medications for a few months also led some participants to temporarily stop taking TB medications.

In Erode site, people were satisfied with the quality of TB medicines provided in the government DOTS centers. However, in Imphal, mistrust about the quality of government TB medications and the negative image associated with government hospitals prevented some people from going to government hospitals or DOTS centres and initiate TB treatment there. Consequently, some people chose to buy medications though eventually a proportion of them discontinued not able to afford the costs. One health care provider, however, felt that these days the price of TB medications have come down and he personally negotiates with the pharmaceutical company agents to get TB drugs in bulk for his patients at an affordable price - as low as Rs. 1500 to 2000 for the entire course. Even then, this price could not be affordable to some people – not taking into account the costs associated with travel and lab tests.

PLHIV were concerned about taking TB medications along with anti-retroviral treatment (ART) as “eating a lot of tablets” were thought

to harm the body; some had stopped taking medications at least for some time in the past. However, some other PLHIV on antiretroviral treatment have become accustomed to taking a lot of medications as they have devised strategies to take ART – daily – on time. Thus, they used similar techniques to take TB medications regularly.

Some people expressed that they wanted to adhere to TB treatment and not stop in-between since otherwise they need to restart the regimen right from the beginning. While that could be because of the treatment education from the providers, it could as well be because of strong warnings by doctors about negative effects of stopping TB medications. A medical practitioner admitted that sometimes doctors need to “threaten the patient” about what would happen if they stop the medications on their own.

Active drug use and alcohol use

In Imphal, key informants – IDU activists and health care providers – reported that the main priority of IDUs is obtaining drugs because of their psychological and physical dependence (to avoid painful withdrawal symptoms). They opined that even if IDUs are started on TB treatment, they tend to be forgetful or not particular about adhering to TB treatment. While health care providers counsel and advise against taking drugs or alcohol while on TB treatment, some IDUs justify taking drugs and alcohol by saying that TB medications make them restless and tired, and to counter that they need to take drugs and alcohol.

For female sex workers who also inject drugs, the ever-present stress to earn money to buy both drugs as well as to look after themselves and their children is further increased by the need to pay for the travel-related costs in attending DOTS centres. FSWs reported having missed collecting their TB medications, once in a while, from the DOTS centres. Often, FSWs may not reveal that they engage in sex work unless that could be inferred by the government DOTS centre staff depending on which agency

has referred that patient to them or which NGO she wants to be “transferred-out” - to continue taking TB medications from.

In Erode, DOTS centre staff key informants opined that alcohol use among TB patients prevented them from adhering to TB treatment and many ‘defaulters’ were alcohol users.

Fatalism

Some participants expressed fatalistic attitude – not interested in wanting to live further or disinterested in living. Thus, they are not very particular about taking TB medications regularly or without interruption. Fatalism seems to be more common among PLHIV compared to those who are HIV-negative; and among IDUs and sex workers. Fatalism was a reason mentioned by some defaulters for stop taking TB medications. Fatalism appears to be connected with financial difficulties, and drug and alcohol use. Not being treated with dignity, lack of self-worthiness and feeling guilty all seem to be related to fatalistic attitude, which in turn makes them not concerned about taking medications regularly.

Financial constraints

Most participants were of low socioeconomic status with problems meeting their daily basic needs. Though some participants were initially paying for their TB medications, eventually they or their family members could not afford to pay for TB medications. Thus, some of them had interruptions in the TB treatment before they found a way to get free TB medications from the government DOTS centres or NGO DOTS providers.

Even for those receiving free TB medications from the government DOTS centres, travel costs and loss of daily wages sometimes led to missing appointments to collect TB medications. Relatives of some participants help in collecting their TB medications.

For sex workers, leaving a day’s work and not able to earn money (especially when they also have dependent children) was a hard decision to make. However, at least one SW reported being determined to take care of herself (by not missing TB medications) in order to take care of her child. But for a male IDU, the need to earn for his children led him to miss collecting TB medications from DOTS centre.

Lack of family support and Social stigma

Many participants reported having at least some level of support from their family members. However, some IDUs, including IDUs living with HIV, and MSM reported not having adequate support from their family members. Some IDUs reported not receiving any financial or emotional support from their family members for their HIV-related treatment including TB treatment. They also felt guilty about being a burden for their family members. MSM with TB reported that since their family had disowned them on account of their perceived sexuality and gender-variant behaviour, they too lacked family support.

Some of the IDUs and MSM living with their family members had to hide taking TB medications for fear of disclosure of their HIV status – for TB can be considered a proxy for HIV infection in Imphal. MSM and FSWs who are living alone had no support from their family members.

Table 4: Illustrative quotes for individual level barriers to TB treatment adherence

Misinformation about TB drugs and Pill burden	
<i>Fear of deterioration in the health if both HIV and TB drugs are taken together</i>	<p>“Some patients who take medications for both HIV and TB fear that their health condition will worsen further since they take many tablets and they don’t turn up.” (An NGO staff, Imphal)</p> <p>“Taking both [ART and DOTS] is very hard. We feel very tired due to overdose [word as used] and could not able to stand or walk.” (A person living with HIV, FGD, Erode)</p> <p>“Patients on only TB medications are taking [the medicines] correctly. But patients with HIV and TB, for some reasons, not taking medications [DOTS] correctly. Maybe they have more side-effects which prevent them from taking medicines continuously.” (Staff of a government DOTS centre, Erode)</p>
<i>Misattributing body weakness to TB medications</i>	<p>“My sister was not willing to continue, but we forced her. She complained of weakness due to the medicine she was taking.” (A caregiver, FGD, Imphal)</p>
<i>Government’s free medicines are perceived to be of low quality</i>	<p>“Since [TB] medicines are provided free-of-cost under DOTS [program], some people think that medicines must be of lower quality.” (A male TB patient, FGD, Imphal)</p>
<i>Perception that private company drugs are better than government’s free TB medicines</i>	<p>“I then heard [from other people] that it is better to purchase the [TB] medicines [than getting from the government centres]. That’s what I did.” (A male IDU, FGD, Imphal)</p> <p>“I am on ART. So [government] doctor told me to buy TB medicines from outside [from private pharmacy]. Moreover, I heard that DOTS medicine [TB medications given at the government hospital] causes spinal problem.” (A male IDU, FGD, Imphal)</p> <p>“Some people say, ‘How many tablets I have to take! This is too much. If I go to private hospital, they will give us only 3 tablets per day. But in [Govt. DOTS center] we need to take 7 tablets’...” (Staff of a government DOTS centre, Erode)</p>
<i>Improvement in health makes some people to stop continuing the drugs</i>	<p>“I had to go out of Manipur for my singing performances [routine work]. Also, I started feeling well [after initiating TB treatment]. Hence, I took it very lightly and stopped taking medication.” (A defaulter, FGD, Imphal)</p> <p>“After taking medication for 2 months and getting some immune-power [words as used], [TB patients] decide that they do not want to take medicines anymore.” (Staff of a government DOTS centre, Erode)</p>
<i>Side-effects and pill burden</i>	<p>“I did not feel too well on the days I took medicine. I had stomach cramps and my urine colour changed totally. Then I stopped them for some time.” (A male IDU on both ART and TB medications, FGD, Imphal)</p> <p>After starting TB medication, some would get itching sensation, vomiting, and fever. These [side effects] would be there till they complete [some] doses. After taking some [doses], they would become alright. But, some people out of fear of these side effects stop taking [DOTS].” (A government healthcare provider, Erode)</p> <p>“Patients accept some minor [side-effects] like change in color of urine. But when we inform them about other possible side-effects like vomiting or stomachache, they get scared to take medicines.” (Staff of a government DOTS centre, Erode)</p>

Active drug use and alcohol use	
<i>IDUs reported that their main priority was getting drugs to avoid withdrawal symptoms</i>	<p>“I did not find time even to check my health, although I wanted to. I was so busy in searching money for my drugs [intoxicants] and not wanting to suffer [from withdrawal symptoms].” (Former drug user, FGD, Imphal)</p> <p>“I was doing [injecting] drugs at that point of time [when I had severe cough due to TB]...My energy was spent on getting my next dose and I really didn't have the time or inclination to do anything else.” (A female IDU, FGD, Imphal)</p> <p>“We [NGO staff/DOT provider] tell them the importance of adherence - which they do follow unless they are current users”. (An NGO DOTS provider, Imphal)</p>
<i>Taking drugs to get relief from perceived side-effects of TB medicines</i>	<p>“Most of my friends [drug users] say that they used to feel tired and restless because of the [TB] medicine. Sometimes, they can't think properly [without drugs]...so they take drugs to get relief.” (A male IDU, FGD, Imphal)</p>
<i>Justifying alcohol use: To relieve body-pain caused by work</i>	<p>Whatever information we give, some people especially coolie [unskilled labors] do not listen to our words. They take alcohol for body pain [while on TB treatment].” (Staff of a government DOTS centre, Erode)</p>
<i>Alcohol use deters adherence</i>	<p>“I tend to use alcohol at sometimes. Sometimes I forget [to take TB medicines].” (A male IDU on TB medications, FGD, Imphal)</p> <p>“I don't do drugs but take alcohol. I was told to be on medication and I did that for a month then I stopped it. I make country alcohol at home to sell it. I am hooked to it and I cannot stop taking alcohol use and because of that I was unable to continue taking TB medications.” (A female former drug user, FGD, Imphal)</p> <p>“For some patients even after finishing two courses of TB treatment, treatment failed. It was absolutely because of alcohol use. Some of them consumed alcohol daily.” (Staff of a government DOTS centre, Erode)</p>
Fatalism	
<i>Not interested in living</i>	<p>“My family do not talk to me. They have disowned me...Sometimes; I feel that it does not matter even if I die.” (An IDU on OST, FGD, Imphal)</p> <p>“[Sometimes I would think] What life is this? Why should we live [by taking all these medicines].” (A person living with HIV, FGD, Erode)</p>
Financial constraints	
<i>Not afford to pay for TB medications</i>	<p>“I find it difficult [to spend Rs. 500 per month]. As the medicines have to be taken non-stop, I approached an NGO to support when a situation came that I could no longer afford to buy. But I missed taking some doses [before getting free medications].” (A Caregiver, FGD, Imphal)</p> <p>“My son used to buy my medicines and I was on TB medication for about 2 months but then he could not afford them. So, I stopped taking the medicines as there was no one to support.” (A male living with HIV, FGD, Imphal)</p>
<i>Not able to work while during DOTS treatment</i>	<p>“While taking [DOTS], [patients] tend to take rest and cannot work. Hence, [patients] face many issues for money.” (A participant who successfully completed treatment, FGD, Erode)</p>
<i>Lack of money for paying TB diagnostic tests</i>	<p>“Most of them [IDUs with TB] are poor and they don't have money even paying for X-ray test.” (An NGO director, KII, Imphal)</p>
<i>Priority on fulfilling the family needs over self-care</i>	<p>“I am the only member in my family to earn. In the struggle to earn money for the sake of my children, I did not show much interest [to continue TB medications]...If there was somebody else in my family who could earn for our daily needs, I would not have stopped taking medications.” (A defaulter, FGD, Imphal)</p>

2. Health system and other structural barriers

Perceived lack of adequate treatment education and counselling

PLHIV with TB seem to have relatively better knowledge about TB since apparently they receive information about TB from government ART counsellors, peer counsellors/outreach workers and from support group meetings run by PLHIV networks. However, IDUs were not satisfied with the treatment information provided to them; they wanted information on specific areas of importance to them. For example, whether taking ART and anti-TB treatment together will further affect their liver condition which is already compromised because of hepatitis (HCV/HBV) and/or alcohol? Whether it is okay to be on opioid substitution treatment (OST) and on TB treatment? Even NGO service providers were not sure about how to counsel their clients in relation to the above-mentioned issues.

While some DOTS providers educate the patients about the possible side-effects and stress the importance of adherence (in spite of minor side effects), some fail to give adequate education to patients initiating treatment. The need for 'treatment preparedness' – the need to prepare the patients for a long-term treatment such as TB treatment – is important, similar to that of preparing patients for lifelong ART. People with TB who are not HIV-positive and who are not receiving services from NGOs, however, reported not receiving adequate information from their doctors and other health care providers. One person even wondered whether there is a treatment educator/counsellor in the DOTS centre as he did not meet one so far. Participants suggested providing information in each subsequent visit on side-effects as well as to reinforce the importance of adherence. According to some FGD participants, treatment education in govt. DOTS centres seems to be relatively low when comparing to private non-profit organisations – probably because of the more time they have and relatively less formal environment in an NGO setting.

Negative attitude of health care providers

People with TB narrated varying degrees of negative attitude among the health care providers depending upon the associated HIV and drug use status. In general, people with TB perceived that health care staff at the lower rung seem to look down upon them when compared with doctors. Some medical providers looked after women co-infected with HIV and TB so well that those women in the FGDs reported that their health care providers treated them even better than HIV-negative TB patients. IDUs – whether or not living with HIV – appeared to be treated with contempt by the medical providers and sometimes in a subtle way that made it difficult to determine whether they discriminated.

Some participants reported that health care providers wanted to keep some distance from them literally – maybe because of the fear of being infected with TB – which was, however, perceived by the participants as discriminatory (based on their HIV status). Sometimes it is not clear whether the incidents narrated as discrimination were due to the TB, HIV or drug use status of the participant. These negative experiences may further diminish the confidence in the quality of care provided in the government hospitals (or in some cases NGOs), thus preventing participants from adhering to TB treatment or even resulting in termination of treatment. Also, if these incidents are shared with other people, others would not want to attend government hospitals even though the medications and services are free.

Insurgency situation in Manipur and connection to TB treatment adherence

'Bandhs' (voluntary or compelled closure of private or public facilities as a mark of protest) and 'strikes' are common in Imphal district, as elsewhere in Manipur, due to insurgency, local community conflicts and demonstrations against police and army actions. Sometimes, even curfews are imposed. Even during the study data collection period, there were several bandhs and curfews that posed challenges for data collection. During bandhs, mobility of the general population is affected though sometimes the government health care facilities may remain open for some hours.

The government DOTS centres as well as NGO service providers have developed several strategies to prevent treatment interruption in bandhs and curfews. These include: giving TB medications for an entire month to the TB patients or their relatives; not making it mandatory for the TB patients to come and collect the medications in person; and keeping at least some government centres open for a few hours even during bandhs. In spite of these strategies supposedly in place, some participants reported having missed taking at least some doses of TB medications during bandh periods. Some people, not wanting to miss doses, buy TB drugs from nearby pharmacies – an added financial burden for them.

All the subgroups – MSM, IDUs and female sex workers have faced harassment by police. MSM and FSWs reported physical and verbal abuse, and forced sex by police.

TB treatment interruption due to police detention/imprisonment (Imphal site) and lack of continuity in care

In Imphal, IDUs reported having faced harassment by police. Detention by police and imprisonment result in treatment interruption – at least for some days. In Imphal, prison inmates in a particular jail who are suspected to have TB are referred to a government referral hospital. If TB diagnosis is confirmed, usually TB medications are given for one month and they are asked to come for refill. After release from the prison, often there is no formal referral of the patient to DOTS centre. However, information regarding the DOTS centre that is nearest to the residence of the patient is provided and the patient is asked to continue medication from that centre. This lack of continuity in TB care, sometimes, results in treatment interruption from days to weeks.

Table 5: Illustrative quotes for healthcare system and structural level barriers to TB treatment adherence

Limited education about TB treatment	
<i>Limited Information provided at government facilities</i>	“The [Govt.] doctor didn’t say much. But detailed information are given to us when we go to [a non-governmental agency].” (A male IDU, FGD, Imphal)
<i>Information about side-effects is not provided in advance</i>	“The doctor didn’t mention about side-effects. We also have not thought much about them.” (A caregiver, FGD, Imphal) “They [healthcare providers] don’t really tell about side-effects to everyone.” (A male TB patient, FGD, Erode)
<i>Not satisfied with counselling provided at DOTS centre</i>	“There was no TB counselling at all. At [a government hospital], they do say certain things but don’t do it properly.” (An IDU on ART, FGD, Imphal) “I don’t know if they are counsellors or not but there are some staff who give us advice.” (A male living with HIV, FGD, Imphal)
<i>Need for periodical counselling</i>	“Doctors, NGOs used to give counseling only once in the very beginning of the medication, so instead of only once, if the person during his 5 to 6 months medication goes for counseling every month then I think it will be much better.” (An IDU on OST, FGD, Imphal)
<i>Need for educational materials about TB and DOTS</i>	“Educational materials about TB treatment and chances of getting re-infection are needed to cure TB completely. There are many educational materials available for HIV, but we do not have any materials for TB among people living with HIV” (A PLHIV network leader, Erode) “There are no educational materials about symptoms of extra-pulmonary TB.” (A IDU community leader, Imphal)
Testing facilities, Infrastructure, and TB drugs availability	
<i>Winding-up the treatment course without sputum testing</i>	“For me they informed that I would be alright that I had completed the full course (without sputum test). They only told me to come whenever I am not feeling well.” (A male living with HIV, FGD, Imphal)
<i>Lack of facility to do resistance testing</i>	“Only certain laboratory centres are accredited to do that. Imphal falls under the National Laboratory in Delhi. Our IRL [Intermediate Referral Linkage] here, once it is functional, it will be able to do cultural sensitivity in the near future.” (A medical provider, KII, Imphal) “In my opinion, I think that there should be free liver tests and [TB drug] resistance test. Currently we pay for them.” (A PLHIV network leader, Imphal)
<i>Delay in getting drug sensitivity reports</i>	“So presently, we send to lab at Delhi [for sputum testing]. But getting the report takes a long time - about 2-3 months. This is free of cost but if one goes to [name of a private clinic] or private clinics or Kolkota, it takes about Rs. 5000-6000.” (A medical provider, KII, Imphal)
<i>Delay in disbursement of drugs from headquarters and stock-outs to NGO service outlets</i>	“Sometimes, the medicines would not have reached the [State TB] head office at all. It’s been 2-3 months now streptomycin injection [part of Category-II regimen], distilled water are not available. So we have to ask the clients to buy on their own.” (An NGO DOTS provider, KII, Imphal)
<i>Space at DOTS centre</i>	“There is no room for confidentiality. All of us will be in an open room and they will easily talk about our status. It is uncomfortable. We would like a separate space but there’s no separate room at all.” (A male living with HIV, FGD, Imphal)

<i>Need for safe drinking water</i>	“Those [people on DOTS] who are coming here, need to be provided with distilled water, and each one need to have a separate [disposable] tumbler. But currently the only one stainless steel tumbler is shared by everyone - which is not good.” (Staff of a government DOTS centre, Erode)
<i>Need for clean atmosphere</i>	“The atmosphere [at DOTS center] should be clean, as people tend to vomit because of tablet. If the surroundings are not good then people get irritated and do not want to come back.” (Staff of a government DOTS centre, KII, Erode)
Perceived negative attitude among healthcare providers	
<i>Keeping distance - literally</i>	“They did not want to be near me saying TB is airborne. They want us a bit further away from them. They will ask us to ‘go sit there’, ‘at that distance’.” (A male IDU, FGD, Imphal)
<i>Perceived discrimination against drug users</i>	“Since we are mostly drug users, they treat us a bit harshly if not totally negatively. There are ways I can ascertain from the way they look at us, their body language etc. It is visible in a subtle way.” (A male IDU, FGD, Imphal)
<i>Looked down upon due to TB and or HIV status</i>	<p>“Some people like the guard [lower rank staff/ non-clinical staff] over there knew that patients in the [name of the ward] are either HIV-positive or TB patient. They look down on us and treat us badly. I felt bad but the doctors treated us well.” (A caregiver, FGD, Imphal)</p> <p>“When I went to [DOTS center], [a staff] scolded me for missing some TB doses. They could have told it in a calm manner. Hence, I lost interest in taking medicines from there.” (A patient who is in now on Category-II DOTS regimen, Erode)</p>
Insurgency situation in Manipur and connection to TB treatment adherence	
<i>Not able to take DOTS due to bandhs/ Strike</i>	<p>“There was a recent general strike and curfew for three consecutive days, and the day of medicine collection fall into these days and DOTS centre was closed so he had to go without medicine for three days.” (An NGO staff, Imphal)</p> <p>“Had they [government DOTS centres] kept the centre open even during bandh or strike, we would not have defaulted.” (A man living with HIV, FGD, Imphal)</p> <p>“Whenever I go there [government hospital] during bandhs it is usually closed and they told me it is not possible to be open during bandhs. They [government health care providers] also told me that a few missed doses will not affect me. I am worried if I relapse again.” (A man living with HIV who was on TB medications, FGD, Imphal)</p>
<i>Need to buy from private facility as DOTS centres are closed during bandhs/strike</i>	“Sometimes when our medicine-collection day from the DOTS center falls on the day of bandh or curfew, then the center [DOT center] would be closed and we would have no other alternative but to buy them from a pharmacy if it is open.” (A male IDU, FGD, Imphal)
<i>Need for alternatives to ensure adherence during bandhs/ strike</i>	“Since the situation in Manipur can lead to curfews and bandhs anytime, I am afraid that I may miss taking some doses. In such situations [bandhs], either they [providers] should come to our house or they should hand some extra stock to us.” (A man living with HIV, FGD, Imphal)
<i>To give or not to give: Provider’s dilemma in giving extra tablets to cover bandh periods</i>	“The prevailing situation of bandhs, blockades, curfews do not help at all. It’s a dilemma regarding handing out medicines. If we give, how much would we give? If we don’t give, what would happen.” (An NGO DOTS provider, KII, Imphal)
<i>Police interruption</i>	“Earlier a man [an IDU] was bringing me my TB medicines. One day, the police detained him. They suspected that to be ‘drugs’. [NGO] staff had to come and explain and only then he was let off. I did not get medications for some days.” (A female living with HIV, FGD, Imphal)

Lack of family support and Social stigma associated with HIV/TB	
<i>Non-disclosure about HIV and TB status to family</i>	<p>“My elder son and I live in separate houses. I am on both ART [antiretroviral treatment] and TB treatment [DOTS]. I have not told anyone else – except my elder son.” (A man living with HIV, FGD, Erode)</p> <p>“Some want us not to tell their wife they have TB – let alone HIV.” (Staff of a government DOTS centre, Erode)</p>
<i>Negative consequence of disclosure of HIV status</i>	<p>“My wife left me once she knew I have [HIV]. Now I have no one to ask whether I took medicines or not.” (A man living with HIV on TB medications, FGD, Erode)</p>
<i>Perceived stigma associated with HIV</i>	<p>“[PLHIV] can get support for tests from us [NGOs] but some of them don’t want to disclose their [HIV] status and approach us only after a long period of time.” (An NGO staff, Imphal)</p>
<i>Not disclosing about TB status to outsiders</i>	<p>“With my family members, I did not hide that I have TB. But I have not yet revealed to outsiders.” (A male TB patient, FGD, Erode)</p> <p>“Most of the people with TB are not willing to take medicine at nearby DOTS centers since they do not want their neighbors to know they have TB.” (Staff of a government DOTS centre, Erode)</p>



RECOMMENDATIONS

1. Address psychological and other individual level barriers to TB treatment access and adherence

- **Provide training to healthcare providers to address individual level barriers:** Psychological barriers such as fear of side-effects and fatalism prevent some from initiating TB treatment. Hence outreach workers, counsellors, and doctors should be trained to be competent in eliciting and providing tailored counselling to address the various psychological barriers.
- **Create linkages with other services:** IDUs with TB who are dependent on alcohol and/or drug use need to be linked with drug dependence treatment and harm reduction services (needle/syringe programs, OST, residential rehabilitation, etc.).
- **Link IDUs with OST programs:** IDUs have difficulty accessing TB diagnostic facilities and TB treatment initiation because their priority is on drug use (due to severity of withdrawal symptoms). Hence, IDUs need to be linked with OST programs to help them attain a stable lifestyle and to assist them in adhering to TB treatment (and ART).
- **DOTS providers** need to be provided with the skills for managing repeated defaulters by training them on identifying factors for defaulting and addressing them appropriately.
- **Health Care providers** need to be sensitized about the sexual orientation of the patients and sensitize them on non-discriminatory behavior towards them.

2. Address structural barriers to TB treatment access and adherence

- Develop programmes to **increase support from family and society** through education (mass media) and counselling (one-to-one) to provide accurate information about TB and reduce stigma and discrimination.
- Develop mechanisms to **address the financial barriers** faced by a proportion of patients with TB. These could be provision of travel allowance for appointment-related trips to clinics and not charging for lab tests in the government centres. Another mechanism could be strengthening referrals with income-generation initiatives (government and non-government) for needy and willing PLHIV, IDUs and FSWs.
- Ensure that **TB drug resistance testing** is available (in strategic locations in Manipur) for patients - especially PLHIV, who require treatment for relapse to identify early diagnosis and treatment of Multi-drug resistant (MDR) and Extreme drug-resistant (XDR) TB.

3. Provide TB treatment and prevention education to marginalized groups, including those living with HIV

- **Provide TB education to PLHIV and marginalized groups through multiple avenues:** Provide and reinforce prevention and treatment messages to PLHIV, FSWs, IDUs, and MSM - in different forms and through different providers (peers, outreach workers, doctors, and counsellors).

- **Provide ongoing adherence counselling** – throughout the TB treatment course - tailored to the needs and circumstances of the patients with TB.
- **Educate all members of marginalized groups about TB (irrespective of HIV status):** Treatment messages should not be restricted only to those who are diagnosed with TB. Giving TB-related treatment messages to all (irrespective of their HIV status) helps diffusion of this information among the community. These messages should address commonly held misconceptions related to severity of side-effects (to reduce the risk of not taking TB medications when experiencing side effects) and quality of drugs provided in the government centres (to overcome the mistrust in government’s free TB medications); and emphasize the importance of completing the full course of TB treatment even if they feel well before completing the entire course.
- **Intensify awareness campaigns on TB treatment availability and information about symptoms of non-pulmonary forms of TB:** Publicize accurate information about TB treatment and its availability in selected government hospitals through mass media and innovative communication campaigns that appeal to and reach out to marginalized groups, including those living with HIV. Education on the symptoms of extra-pulmonary symptoms (e.g., swelling of lymph glands) needs to be provided especially for PLHIV and IDUs.
- **Strengthen the capacity of PLHIV networks and marginalized groups:** Capacity of the PLHIV networks and CBOs working with marginalized groups needs to be strengthened to provide TB treatment education/counselling (through in-centre counselling, support groups, and outreach) and to follow-up TB-infected clients to ensure adherence.

4. Ensure availability of quality TB counselling and treatment services

- **Ensure people-friendly environment and quality services:** Ensure that government DOTS centres are friendly and healthcare providers (doctors and counsellors) offer competent, non-judgmental, non-discriminatory and quality counselling and treatment services to TB patients irrespective of their HIV status and being from marginalized communities (IDUs, FSWs, and MSM).
- **Ensure screening of all PLHIV for HBV/HCV:** Ensure that standard clinical guidelines are followed in screening people living with HIV and IDUs (irrespective of HIV status) for HBV/HCV before starting TB treatment
- **Support treatment of HCV/HBV co-infections among TB patients including those who are HIV-positive:** Develop mechanisms to support treatment for HCV and HBV infections in IDUs (including those living with HIV) with TB.
- **Consider ‘smart cards’ for easy access to TB treatment irrespective of the native place of TB patients:** Similar to the initiative in the national ART program, consider providing ‘smart cards’ (electronic) for TB patients to ensure uninterrupted and easy access to TB treatment from any government (and non-government) DOTS centre. Availability such cards can help TB patients who frequently travel from one place to another.

5. Develop and implement an action plan to ensure equity in TB treatment access for PLHIV and marginalized groups such as IDUs and FSWs

- **Ensure that the specific TB prevention and treatment-related needs of PLHIV and marginalized groups are not overlooked on the assumption that they are not of substantial size that warrants specific attention.** Ensure that the current TB/HIV coordination mechanisms (policy and program levels) address their needs.
- Develop mechanisms to **monitor inequalities in TB treatment adherence:** Collect disaggregated data according to marginalized group status (PLHIV, IDUs, FSWs, MSM) in DOTS centres, and quantify inequity information on TB treatment access and adherence.
- **PLHIV networks and marginalized groups should be actively involved** at all levels to make effective use of their experience-based expertise in monitoring and review of TB programs to ensure equitable access to TB treatment and improve adherence. State and district TB/HIV coordination committees should involve representatives of PLHIV networks and marginalized groups.



REFERENCES

- 1 Chauhan LS. (2009). Status report on RNTCP [Revised National Tuberculosis Control Programme].
Indian J Tuberc. Apr;56(2):91-4.
- 2 Corbett EL, Marston B, Churchyard CJ, De Cock KM. (2006) Tuberculosis in sub-Saharan Africa:
Opportunities, challenges, and change in the era of antiretroviral treatment. *Lancet* 367: 926–937.
- 3 Dye C. (2006) Global epidemiology of tuberculosis. *Lancet* 367: 938–939.
- 4 Revised National Tuberculosis Control Programme (RNTCP) Status Report. (2009).
<http://www.tbcindia.org/pdfs/TB%20India%202009.pdf>
- 5 Cuneo WD, Snider DE. (1989). Enhancing patient compliance with tuberculosis therapy.
Clin Chest Med 10: 375–380.
- 6 Volmink J, Garner P. (2006). Directly observed therapy for treating tuberculosis. *Cochrane Database Syst*
Rev 2: CD003343. doi:10.1002/14651858.CD003343.pub2
- 7 Dhingra VK, Rajpal S, Taneja DK, Kalra D, Malhotra R. (2002). Health care seeking pattern of
tuberculosis patients attending an urban TB clinic in Delhi. *J Commun Dis. Sep;34(3):185-92.*
- 8 Jha UM, Satyanarayana S, Dewan PK, Chadha S, Wares F, Sahu S, Gupta D, Chauhan LS. (2010).
Risk factors for treatment default among re-treatment tuberculosis patients in India, 2006. *PLoS One.*
Jan 25;5(1):e8873
- 9 Dandona R, Dandona L, Mishra A, Dhingra S, Venkatagopalakrishna K, Chauhan LS. (2004). Utilization
of and barriers to public sector tuberculosis services in India. *Natl Med J India. Nov-Dec;17(6):292-9.*
- 10 Dhingra VK, Lall D, Aggarwal N, Vashist RP. (2008). DOTS in drug addicts with TB: Delhi experience.
Indian J Tuberc. Jul; 55(3):122-6.
- 11 Rowe KA, Makhubele B, Hargreaves JR, Porter JD, Hausler HP, et al. (2005). Adherence to TB preventive
therapy for HIV-positive patients in rural South Africa: implications for antiretroviral delivery in resource-
poor settings? *Int J Tuberc Lung Dis* 9: 263–269.
- 12 Ngamvithayapong J, Uthairavit W, Yanai H, Akarasewi P, Sawanpanyalert P. (1997) Adherence to
tuberculosis preventive therapy among HIVinfected persons in Chiang Rai Thailand. *AIDS* 11: 107–112.
- 13 Ngamvithayapong J, Winkvist A, Diwan V (2000) High AIDS awareness may cause tuberculosis patient
delay: Results from an HIV epidemic area Thailand. *AIDS* 14: 1413–1419.
- 14 Storla, D. G., Yimer, S., Bjune, G. A. A systematic review of delay in the diagnosis and treatment of
tuberculosis. *BMC Public Health.* 2008 Jan 14;8:15
- 15 Vermeire E, Hearnshaw H, van Royen P, Denekens J. (2001). Patient adherence to treatment: Three
decades of research. A comprehensive review. *J Clin Pharmacol Ther* 26: 331–342.
- 16 Munro, S. A, Lewin S. A., Smith, H. J., Engel, M. E., Fretheim, A., et al. (2007). Patient Adherence to
Tuberculosis Treatment: A Systematic Review of Qualitative Research. *PLoS Med* 4(7): e238.
doi:10.1371/journal.pmed.0040238
- 17 WHO. (2002). An expanded DOTS framework for effective tuberculosis control. WHO/CDS/TB/2002.297.
Geneva: World Health Organization. 23 p. Available at:
http://whqlibdoc.who.int/hq/2002/WHO_CDS_TB_2002.297.pdf
- 18 Orem, D. (1991). *Nursing: Concepts of practice.* St. Louis, MO: Mosby.
- 19 DiMatteo, M., & DiNicola, D. (1982). *Achieving patient compliance: The psychology of the medical
practitioner's role.* New York: Pergamon Press.
- 20 Gritz, E., DiMatteo, M., & Hays, R. (1989). Methodological issues in adherence to cancer control
regimens. *Preventive Medicine*, 18, 711–720.
- 21 McDonnell M, Turner J, Weaver MT. Antecedents of adherence to antituberculosis therapy. *Public Health*
Nurs. 2001 Nov-Dec;18(6):392-400.
- 22 Creswell, J. (1998). *Qualitative Inquiry and Research Design; Choosing Among Five Traditions.* London,
New Delhi, Thousand Oaks, Sage Publications.
- 23 Ritchie J, Spencer E. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG,
eds. *Analyzing Qualitative Data.* London: Routledge, 1994, pp. 172–194.
- 24 Green J. Analysing qualitative data. In: Green J, Browne J, eds. *Principles of Social Research.*
Maidenhead, United Kingdom: McGraw-Hill (Open University Press), 2005, pp. 75–89.
- 25 Aday LA, Andersen R. A framework for the study of access to medical care.
Health Serv Res 1974;9:208–220.
- 26 Lincoln, Y.S., & Guba, E. (1985). *Naturalistic enquiry.* Newbury Park, CA: Sage.
- 27 Raizada N, Chauhan LS, Babu BS, Thakur R, Khera A, Wares DF, Sahu S, Bachani D, Rewari BB, Dewan
PK. Linking HIV-infected TB patients to cotrimoxazole prophylaxis and antiretroviral treatment in India.
PLoS One. 2009 Jun 22;4(6):e5999







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