TB Stigma Assessment among Vulnerable Communities Susceptible to TB Infection in Selected Districts of Assam and Karnataka

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Disclaimer

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Contents

LIST OF TABLES

LIST OF FIGURES

ACRONYMS

AIDS	Acquired Immuno-Deficiency Syndrome
ASHA	Accredited Social Health Activist
DBT	Direct Benefit Transfer
DMC	Designated Microscopy Centre
DOTS	Directly Observed Treatment Short course
FGD	Focus Group Discussion
FLW	Frontline worker
FSW	Female Sex Worker
HCW	Healthcare Worker
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interview
KNP+	Karnataka Network for Positive People
LT	Lab Technician
MDR-TB	Multi-Drug-Resistant TB
MO	Medical Officer
MSM	Men who have Sex with Men
NGO	Non-Governmental Organisation
NSP	National Strategic Plan
NTEP	National TB Elimination Programme
OBC	Other Backward Class
PLHIV	Person Living with HIV
PwTB	Person with Tuberculosis
PwhTB	People who had Tuberculosis
SC	Scheduled Caste
ST	Scheduled Tribe
STS	Senior Technical Supervisor
TB	Tuberculosis
TBHV	TB Health Visitor
TDC	TB Detection Centre
TG	Transgender
TGW	Tea Garden Worker
UV	Urban Vulnerable
KHPT	Karnataka Health Promotion Trust
WHO	World Health Organization

OPERATIONAL DEFINITIONS

Bisexual	Gender identity where the person is attracted to and may form sexual and romantic relationships with someone regardless of that person's gender identity
Community	People residing in the same neighbourhood
Discrimination	Treating someone in a different, unjust, unfair or prejudicial manner, often based on his/her belonging or perceived belonging to a particular group. Discrimination is viewed as the result of the process of stigmatisation
Experienced stigma	Actual instances of discrimination or rejection that a person with TB may face
Hamam	A hierarchically organised fictive household where transgenders live as a family and work as well
Kothi	Biological male who takes on the 'effeminate' role in same-sex relationships
Perceived stigma	The fear of being discriminated against, devalued or rejected by others for having TB
Public or observed stigma	Negative attitudes, beliefs, and behaviours of the community or general public
Secondary stigma	Stigma that is directly experienced and observed by the family members and caregivers of people diagnosed with TB
Self-stigma	Negative attitudes, internalised shame, and self-blaming due to a TB diagnosis
Significant Others	Includes friends, relatives, and co-workers
Stigma	A process of devaluation, whereby a person is discredited, seen as a disgrace, or is perceived to have less value or worth in the eyes of others. Stigma is often associated with discrimination
Structural stigma	The laws, policies, media, and institutional architecture that may be stigmatising or, alternatively, protecting against stigma. This includes societal-level conditions, cultural norms, and institutional practices that constrain the opportunities, resources, and well-being of stigmatised populations
Transgender	People whose gender identity and expression does not conform to the norms and expectations traditionally associated with their sex at birth

EXECUTIVE SUMMARY

Tuberculosis (TB) is one of the foremost public health challenges in India today. India has the highest prevalence of TB, contributing 26% of the total deaths caused by TB worldwide (GTB Report, 2023). The National Strategic Plan for Tuberculosis Elimination (NSP) (2017–2025) initiated by the Government of India offers a roadmap to reduce the burden of TB by minimising the incidence and prevalence of and mortality from the disease by the year 2025. The vision is for a TB-free India with zero deaths, disease, and poverty due to TB, and the goal is to achieve a rapid decline in the burden of TB morbidity and mortality while working towards the elimination of TB in India by 2025. However, an array of social factors - such as poverty, unfavourable living and working environments, stigma and discrimination, and cultural norms - are strong barriers to the detection, treatment, and prevention of and successful outcomes for TB. The Stop TB Partnership funded KHPT to assess the levels and probable determinants of stigma among vulnerable communities, such as tea garden workers (TGWs) and urban vulnerable (UV) populations. The study also explored the experiences of people living with HIV (PLHIV), female sex workers (FWSs), men who have sex with men (MSM), and transgender (TG) individuals in relation to the stigma and its influences on their treatment of TB.

The study employed a mixed-methods approach. A cross-sectional quantitative design was used to collect information from persons with TB or persons who had TB (PwTB/PwhTB), their family members and caregivers, community members, and healthcare providers from two broad populations comprising the UV and TGWs. The qualitative study employed in-depth interviews (IDIs) and focus group discussions (FGDs) using pre-tested, semi-structured interview guides and collected information from vulnerable populations like FSWs, TGs, MSM, and PLHIV. A desk review was also undertaken to understand existing policies, laws, and programmes on TB and their role in addressing the associated stigma.

Within the UV sample, 85% of PWTB/PWHTB (N=400), 57% of family members (N=400), 86% of community members (N=400), and 100% of healthcare workers (HCWs) reported perceived stigma (N=200). Additionally, 16% of PwTB/PwhTB, 17% of family members, 35% of community members, and 6% of HCWs reported observing stigma. Direct experiences of stigma were reported by 41% of PwTB/PwhTB, 15% of family members, and 5% of HCWs among the UV group. Notably, UV PwTB/PwhTB with higher education levels (12 years and above) reported the lowest perceived stigma compared to the other categories. UV PWTB/PWHTB belonging to other castes (general caste) experienced the least stigma (28%) compared to scheduled castes (47%), scheduled tribes (48%), and other backward classes (42%). Perceived stigma was higher among the community members of the UV group than those from the TGW community. For example, around 66% of community members from the UV sample agreed that some people did not want PwTB playing with their children, and they kept their distance from people with TB, even avoiding the sharing of food and drinks with friends who were PwTB.

In the TGW sample, 83% of PwTB/PwhTB, 32% of family members, 87% of community members, and 99% of HCWs reported perceived stigma. Observed stigma was reported by 5% of PwTB/PwhTB, 3% of family members, 6.2% of community members, and 6% of HCWs. Additionally, 11% of PwTB/PwhTB, 6% of family members, and 6% of HCWs had experienced stigma. Perceived stigma among the TGW was significantly associated with caste. TGWs who were from a scheduled caste exhibited higher perceived stigma than other caste groups. Female PwTB/PwhTB experienced double the stigma (16%) compared to males (7%). However, high or moderate social support led to almost four times less stigma than did low support. Additionally, social support and comprehensive TB knowledge were associated with lower stigma (whether perceived or experienced).

Among the family members of UV PwTB/PwhTB, a larger proportion reported behaviours indicative of secondary stigma compared to the family members of TGWs. For instance, around a third of UV individuals (34%) said their family members had requested them to keep the TB diagnosis a secret, whereas only a small percentage of TGWs (4%) reported the same. Despite these differences, both groups exhibited low agreement with statements suggesting personal shame or fear of being seen at healthcare clinics.

Public or community stigma was reportedly higher in the UV group. For example, 50% of community members from the UV sample agreed that some people felt uncomfortable being near PwTB, preferring to keep their distance from PwTB and not even sharing food and drinks with their friends who were PwTB. A significant proportion of HCWs (around 70%) agreed that 'some HCWs feel pity for TB patients'. Around 56% of the HCWs who were working with TGWs agreed that some of their peers believed in isolating the patient during the intensive phase of the treatment. Meanwhile, 49% of HCWs from the UV group agreed that some HCWs had considered forcing TB treatment if necessary. Around 17% of them agreed that some HCWs were nervous about treating TB patients.

The participants of the qualitative study were already stigmatised due to their non-conformity with societal gender norms (TGs/MSM/bisexuals), profession (sex work), and illness (HIV), and they had negligible family and social support. The TB infection added a further layer of stigma. TB stigma intersected with the stigma resulting from their gender identity (being TG or MSM), profession (being a sex worker), or disease (HIV infection) and affected their mental health, adherence to treatment, work, disclosure of disease, interpersonal connections, and more.

The initial responses to the illness were fear and sadness, both fuelled by the misconceptions and myths surrounding TB. The participants added that their knowledge and awareness of TB increased after their treatment began. Perceived stigma was the most common form of stigma they faced. The participants perceived they would be stigmatised by not only their community and co-workers but also their friends, relatives, and family. Experienced stigma was common too. PwTB/PwhTB faced discriminatory attitudes such as overprotective behaviour and comments on their physical appearance by members of the community, their co-workers, and even people in public places.

Individuals from the more vulnerable groups (FSWs, PLHIV, TGs, and MSM) had different experiences with TB. Stigmatised attributes such as race (seen through dress, mannerisms, profession, etc.) can be easily identified and are hard to conceal, allowing society to differentiate and stigmatise because the person is so visible (Ahmedani, 2011). This is why TGs were more vulnerable to stigma as well.

The extensive treatment duration, the associated stigma, and the physical and mental impacts of the illness often led to increased social isolation and financial insecurity, eventually resulting in self-stigma as well. Owing to the lack of awareness in villages, many believed TB was the result of wrongdoing or morally questionable behaviour, but awareness about the disease as well as its curability, symptoms, and treatment facilities increased over time. Fear of infection turned out to be the leading reason behind the stigma surrounding TB, and it led to the non-disclosure of disease, affecting medication adherence behaviour, personal and social cohesion, and mental health, sometimes leading to suicidal ideation as well.

This study concludes that creating awareness about TB can be a powerful tool in combating the stigma around the disease. In this regard, utilising information, education, and communication (IEC) strategies could play a significant role in enhancing TB awareness among people (including patients, the general population, and HCWs). In addition, policy interventions such as implementing equitable treatment frameworks, ensuring patient privacy, and adopting a patient-centric approach to TB treatment could play crucial roles in mitigating TB stigma.

BACKGROUND

1.1 Understanding Stigma

Many scholars identify stigma as a social determinant of health (Goldberg, 2017; Hejinders & Van Der Meji, 2006; Craig et al., 2017). Stigma is a process that begins when a particular attribute of an individual is identified as being undesirable or disvalued and that individual is deeply discredited and rejected by society because of that attribute (Link & Phelan, 2001; Goffman, 1963). It is a process by which the reactions of others affect their identity and disqualify the individual from full social acceptance. The World Health Organization (WHO) defines stigma as a mark of shame, disgrace, or disapproval, which results in an individual being rejected, discriminated against, and excluded from participating in different areas of society. Whereas Goffman (1963) discussed stigma as a social construct based on identity, Link and Phelan (2001) presented the framework through which the process of stigmatisation takes place, elucidating how social, economic, and political factors shape and manifest stigma (Kleinman & Hall-Clifford, 2009). Stigma is not a natural process and exercising stigma requires power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination (Link & Phelan, 2001). Stigma also involves 'fear' as a necessary component, which further regulates the process of stigmatisation, the severity of the process, and its impact.

The stigma and discrimination associated with tuberculosis (TB) exacerbate all aspects of an individual's life—social, personal, financial, and of course, their health. In the context of health, stigma is the negative association between a person (and a group of people who share certain characteristics) and a specific disease, which leads to people being labelled, stereotyped, discriminated against, treated separately, and/or experiencing a loss of status because of their link with a disease. Such treatment affects not only the infected individual but also their caregivers, family, and friends (WHO, 2020).

TB is probably the third-most stigmatised disease after leprosy and HIV (van Brakel & Miranda Galarza, 2014). TB stigma is often assessed and studied because of its adverse impact on TB control programmes, though it has also been addressed in terms of the emotional and social well-being of the individual (Macq et al., 2006).

Based on the nature of stigma and the pathway of stigmatisation, TB stigma can be further divided into various sub-categories (Central TB Division, 2021):

Internalised or self-stigma: This captures the idea that TB-affected individuals may come to absorb or endorse negative stereotypes.

Anticipated stigma (perceived stigma): This refers to 'the worry that one will be devalued after a TB diagnosis. For the person with a TB diagnosis, this is the fear (often the result of observing others being stigmatised) that the stigma against the person will be so bad that it will affect access to TB services.'

Observed stigma (public and community stigma): This refers to the negative attitudes and behaviours towards people with TB.

Enacted or experienced stigma: This reflects the range of stigmatising behaviours, messages, and effects that are either directly experienced by the person with TB or by their families and/or that drive others to acts of discrimination, rejection, or isolation in different settings (family, community, healthcare, and workplace, in particular).

Secondary stigma: This refers to stigma that is directly experienced and observed by the family members and caregivers of PwTB.

Structural stigma: This describes the laws, policies, media, and institutional architecture that may be stigmatising or, alternatively, protecting against stigma. It includes societal-level conditions, cultural norms, and institutional practices that constrain the opportunities, resources, and well-being of stigmatised populations.

These dimensions of stigma can operate at various levels, including (1) family, (2) significant others, such as friends and colleagues, (3) community or neighbourhood, and (3) healthcare facility. All spaces—whether the home, workplace, public places like buses, trains, temples, mosques, and churches, or any community gathering - could become spaces where a person is stigmatised, called out, and devalued because of their disease.

1.2 Tuberculosis in India

TB is one of the foremost public health challenges in India, and the country has the highest prevalence of the disease, contributing 26% of the total deaths caused by TB worldwide (GTB Report, 2023). The National Strategic Plan for Tuberculosis Elimination (NSP) (2017–2025) initiated by the Government of India offers a roadmap to reduce the disease burden by minimising the incidence and prevalence of and mortality from TB by 2025. The vision is for a TB-free India with zero deaths, disease, and poverty due to TB, and the goal is to achieve a rapid decline in the burden of TB morbidity and mortality while working towards the elimination of TB in India by 2025. An array of social factors—such as poverty, living and working environments, stigma and discrimination, and cultural factors—are strong influencers for the detection, treatment, prevention, and successful outcomes of TB (Thomas and Stephen, 2021).

Owing to the lack of awareness and knowledge about TB, both the community and persons with TB or persons who had TB (PwTB/PwhTB) are less supported, negatively perceived, and stigmatised. The stigma primarily stems from a fear of TB and of the disastrous health, financial, personal, and social consequences of the disease for those affected and their families. Furthermore, several types of stigma are associated with TB. It may be perceived (or anticipated) or experienced (or enacted) as operating on various levels—individual, family, community, and health system. These determinants of TB are linked to the vulnerability of certain groups of people who are at increased risk of TB infection. Therefore, India's National TB Elimination Programme (NTEP) recognises the need for targeted interventions to address the stigma.

1.3 Rationale and Objectives

As India moves towards TB elimination, it is essential to detect, treat, and prevent TB among vulnerable populations, which India's NSP for TB Elimination (2017–25) identifies as persons at risk of developing TB due to 'underlying determinants of health' and having reduced access to medical services. Drawing on the Stop TB Partnership guidelines, the NSP identifies vulnerable populations as those who are at an increased risk of exposure to TB because of where they live and work, including sex workers. Furthermore, despite transgender (TG) individuals being a high-risk group for TB, the India TB Report 2023 shows that only 747 cases of a projected 847 cases in 2022 were notified to the national registry, and 147 of them were either lost to follow-up or their treatment outcomes were unknown. There was no disaggregation of female sex workers (FSWs) and men who have sex with men (MSM) within the high-risk groups reported by the NTEP in the annual India TB Report.

In this context, the Karnataka Health Promotion Trust (KHPT), Bangalore, with support from the Stop TB Partnership, implemented the Challenge Facility for Civil Society (CFCS) in alignment with the United Nations' political declaration on TB and the global plan to end TB. The objective of the intervention was to empower vulnerable communities through better awareness, demand generation, mitigation of stigma for TB, and community lead monitoring of TB services, eventually extending this to all health-related services in selected districts of the states of Assam and Karnataka in India. The target population comprised high-risk groups such as tea garden workers (TGWs), urban vulnerable (UV) groups, FSWs, people living with HIV (PLHIV), TGs, and MSM, and the survey was conducted over 18 months (from 1 January 2023 to 30 June 2024). As part of the intervention, the study aimed to assess how and to what extent self-stigma manifests among persons with TB in communities and healthcare facilities, as well as how TB stigma acts as a barrier to accessing and providing services.

Key Objectives	
	To measure the level and dimensions of stigma among persons diagnosed with TB and by the family members and caregivers of PwTB, community members, and healthcare providers
	To estimate the settings and stages of care in which TB stigma is being experienced and observed by persons diagnosed with TB and by the family members and caregivers of PwTB.
	To understand TB-related stigma and discrimination among FSWs, MSMs, and the PLHIV community, and build awareness of health rights
	To understand the extent to which structural stigma (any existing laws or policies, the enforcement of those laws or policies, and the corresponding media coverage) could harm or protect PwTB
	To develop recommendations to address TB stigma in order to reduce peoples' vulnerability to TB infection, increase peoples' access to TB services, and improve treatment outcomes.

1.4 Methodology

Study design

The study employs a mixed-methods approach using phenomenological qualitative and cross-sectional quantitative designs. Structured questionnaires were used for the quantitative interviews. In-depth interviews (IDIs) and focus group discussions (FGDs) were conducted using interview guidelines.

Study area

The quantitative survey was conducted in Bengaluru (urban metro population, including garment factory workers) in Karnataka as well as in Dibrugarh (TGWs) and Sonitpur (TGWs) in Assam using a structured questionnaire. The qualitative interviews took place in Bengaluru alone.

Sample: Target group and size

A sample size of 400 was selected for each group based on the assumption that 50% to 60% of the PwTB, their families, and the community had perceived stigma. We assumed that around 10% of the HCWs would have high perceived stigma and, accordingly, a sample of a minimum of 160 HCWs, was selected for the interview. The sample sizes were based on a confidence level of 95% and an error margin of 5%. The sample size and criteria for selecting participants are outlined below:

1. The proposed sample for the study was 400 PwTB/PwhTB.
2. For the family level, the total sample was 400 from each population group. One family member or caregiver (aged 18 years and above) residing in the same household as each of the PwTB was selected.
3. For the community level, 400 neighbours (aged 18 years and above) of the PwTB/PwhTB were randomly selected for the study from each population group.
4. For the health system level, 80 personnel of the NTEP from the cadres of medical officer (MO), lab technician (LT), senior treatment supervisor (STS)/senior treatment and lab supervisor (STLS), TB health visitor (TBHV) and Accredited Social Health Activist (ASHA) were selected from the TB detection centres (TDCs) or designated microscopy centres (DMCs) for each state.
5. For the law and policy environment, a desk review of current laws and policies, current opportunities, and actual dissemination was conducted.
6. Additionally, to explore the role of stigma among specific vulnerable and hard-to-reach groups, such as FSWs, LGBTQIA, and PLHIV aged 18 or above, a series of qualitative interviews was conducted through IDIs and FGDs.

Table 1: Study sample distribution

Sample Distribution	Urban Vulnerable	Tea Garden Workers
Quantitative Study		
PwTB	400	385
Family member or caregiver of PwTB	400	385
Community level (general population or neighbours)	400	385
Health system level (NTEP staff or frontline workers)	80	86
TOTAL	**1280**	**1241**
Qualitative Study (PwhTB)*		
	IDI/FGD	
FSWs	8	
MSM and TG	8	
PLHIV	8	
TOTAL	**24**	

Note: *IDIs and FGDs were conducted only in Bengaluru urban district.

Inclusion criteria for participants in the quantitative and qualitative studies

- Adult population aged 18 years and above
- Person with TB or with a history of TB in the past one year

- Persons who were mentally sound and capable of providing consent to participate in the interviews
- Family members or caregivers who have offered or are offering support to PwTB/PwhTB
- Neighbours or community members residing in the neighbourhood of PwTB/PwhTB
- HCWs from NTEP who have been working for no less than six months
- For the qualitative study, the study focused on persons who were engaged in the specific occupation for at least the past six to eight years and who currently had TB or had a history of the disease
- All those who provided informed consent to participate in the study

Data collection process

The data collection was carried out between November 2023 and January 2024 in all the districts. A ratio of 1:1:1 was applied (one PwTB, one family member, and one community representative). The detailed recruitment process is explained below:

- At PwTB/PwhTB level: First, 20 high-burden TDCs (previously, DMCs) were selected from each geography in consultation with NTEP staff, and a list of all PwTB (name, address, and contact details) who were receiving treatment or had a history of TB in the last one year was obtained. Initial screenings were conducted over phone calls to determine eligibility and ensure the availability of the PwTB/PwhTB. Post screening, 20 consenting PwTB/PwhTB from each TDC were interviewed at either their house or any place that was convenient for them.

- **At family level:** The PwTB/PwhTB were asked to identify a family member or caregiver who resided with them and either was supporting or had supported them during their TB treatment journey.

- **At community level:** One community member residing in the same locality as the PwTB/PwhTB was randomly identified and invited to participate in the study.

- **At health system level:** HCWs who offered TB care services to PwTB at the health facilities were identified from the respective treatment units.

- **For qualitative interviews:** Local NGOs working with the specific vulnerable and hard-to-reach groups (viz. FSW, MSM, TG and PLHIV) were contacted to get access to the desired participants. Individuals who either were currently suffering from TB or had a history of TB and who satisfied the inclusion criteria were selected for the interviews.

Survey instruments

For the quantitative survey, structured questionnaires from the TB Stigma Assessment data collection instruments developed by Stop TB Partnership were used. The instruments included four major sections on stigma: stigma scale (five-point Likert scale), experienced stigma or discrimination, observed stigma or discrimination, and demographic characteristics. In addition, certain aspects like socio-demographic characteristics, knowledge and attitude towards TB, and social support were added for the purpose of a detailed understanding and analysis. Separate tools were developed for each of the four target groups—PwTB/PwhTB, family members and primary caregivers of people diagnosed with TB, community representatives or neighbours living in the same community as PwTB/PwhTB, and HCWs.

For the qualitative survey, a separate interview guideline was prepared to enquire about different aspects, such as the participants' socio-economic conditions, general health, TB-related stigma and discrimination, social support, and human rights.

Training and pre-test

The survey instruments, both quantitative and qualitative, were translated into the local languages - Kannada and Assamese. The survey instruments were digitised and data collection was done using computer-assisted personal interviewing (CAPI). Three investigators and a supervisor were appointed in each district. The teams were extensively trained on the objective of the study, target groups, inclusion and exclusion criteria, and survey instruments. Following the training, mock interviews and pre-testing of the tools were conducted. The necessary rectifications were made to the tools based on the pre-test.

For the qualitative data collection and translation, one qualitative researcher was appointed and trained on the guidelines. The local KHPT team in each state extended support in identifying TDCs, line-listing PwTB/PwhTB, and planning and mobilising the participants for the entire study.

Ethical considerations

The required ethical protocols were followed and the necessary approvals were sought from the respective stakeholders. As the study involves human subjects, ethical approval was obtained from Shetty's Hospital Ethics Committee. The purpose of the study, along with the risks and benefits, were read out clearly to each of the participants and interviews were conducted after obtaining voluntary and written informed consent from each participant. For illiterate respondents, thumb impressions were obtained. In scenarios where the participants refused to provide written consent or thumb impressions, verbal consent was taken. The field investigators ensured complete confidentiality and privacy during the interview process.

Data management and analysis

Quantitative: Data collection was carried out by a team of trained field investigators and supervisors in each district. The state-level M&E coordinator was responsible for data quality assurance and monitoring. Periodic field visits were conducted by the state-level M&E manager for supportive supervision. Once each interview had been approved by the field supervisor and the state-level M&E manager, the data was stored securely on the organisation server. Post data collection, data cleaning was carried out by the state-level M&E coordinator. Data analysis was conducted by the research team using STATA version-16, based on the pre-decided analysis plan.

Qualitative: All the qualitative interviews were audio-recorded after obtaining informed consent from each participant and archived at the organisation's head office. A trained research team had prepared a pre-coded analysis matrix based on the research objectives and the interview guide. The audio files and field notes were transcribed and translated into the pre-coded matrix. A team of trained researchers used a deductive approach to analyse and code the data in order to maintain objectivity and ensure quality.

Various themes had emerged through the process of deductive analysis for each of the solutions, ranging from 'Experiencing TB' to 'Impact of TB stigma'. In view of the array of themes and sub-themes emerging out of the analysis, the findings have been structured under four broad domains and all the themes have been grouped under each domain.

At the end, a detailed discussion focusing on the key objectives of the study, including the various dimensions of stigma and its implications have been explained.

Description of outcome indicators

The main outcome of this study was to explore different types of stigma, such as experienced stigma, observed stigma, and perceived and self-stigma. There was a direct question about experienced stigma and observed stigma for PwTB/PwhTB. We did not measure self-stigma separately in a quantitative analysis but included it with perceived stigma. We used the STOP TB 'Stigma and Discrimination' metrics for PwTB/PwhTB: a five-point Likert scale with 12 components, which included questions on perceived stigma and certain aspects of self-stigma. Those who agreed to at least one of the 12 components were considered as cases for this study.

Other information such as the impact of stigma on treatment was sought directly from the participants who reported instances of any stigma (experienced, observed, and/or perceived and self-stigma). In addition to the socio-demographic indicators, we created two indices: 1) a social support index and 2) an index for comprehensive knowledge on TB. A similar procedure was followed to create indicators for family members, community members, and HCWs.

Information on social support was obtained using a seven-point (very strongly disagree to very strongly agree), 12-component scale, which was further divided into three groups (low social support, moderate social support, and high social support) following the methodology of Zimet et al. (1988). Information on knowledge of TB was sought directly from the participants. Comprehensive knowledge was assessed using three components: (A) TB is curable, (B) TB spreads through air droplets, and (C) Cough is the most common symptom. Those who reported 'yes' for all these three components were considered to have comprehensive knowledge of TB.

Section 1

Stigma among Vulnerable Community (Urban Vulnerable and Tea Garden Workers)

1. Persons with TB or with History of TB (PwTB/PwhTB)

1.1 Profile of the Survey Population

This study collected information on TB stigma from 785 PwTB/PwhTB individuals, including 400 samples from UV populations and 385 samples from TGWs. The study samples skewed 41% female and 59% male with median ages of 31 years and 44 years respectively for the two genders.

Other socio-demographic characteristics varied across both groups. In the UV group, 50% of the respondents belonged to other backward classes (OBCs), while this was the case for 75% of the TGWs. The level of education varied - only 14% of the UV participants had no formal education as compared to 32.7% of the TGWs. Marital and work composition was similar for each group. (Annexure: Table 1)

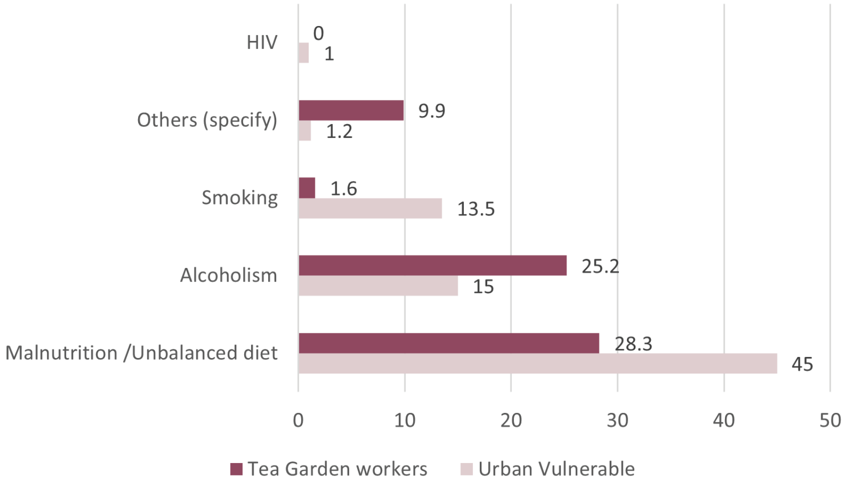
1.2 Knowledge of TB among PwTB/PwhTB (Causes, Symptoms, Transmission, Treatment, and Prevention)

To understand the level of knowledge about TB among the study population, we collected information on different components, such as risk factors for TB, symptoms of TB, the mode of transmission of TB, and preventive and curative care for TB. The levels of knowledge of the surveyed groups are presented in Figure 1 to Figure 5.

1.2.1 Knowledge of major risk factors for TB among PwTB/PwhTB

(Figure 1.1) presents the varying levels of awareness among the UV and TGW communities regarding the major risk factors for TB. Both groups recognised malnutrition and alcoholism as the major risk factors for TB. However, knowledge of HIV as a risk for TB was extremely low in the surveyed population, with less than 1% of urban respondents acknowledging it.

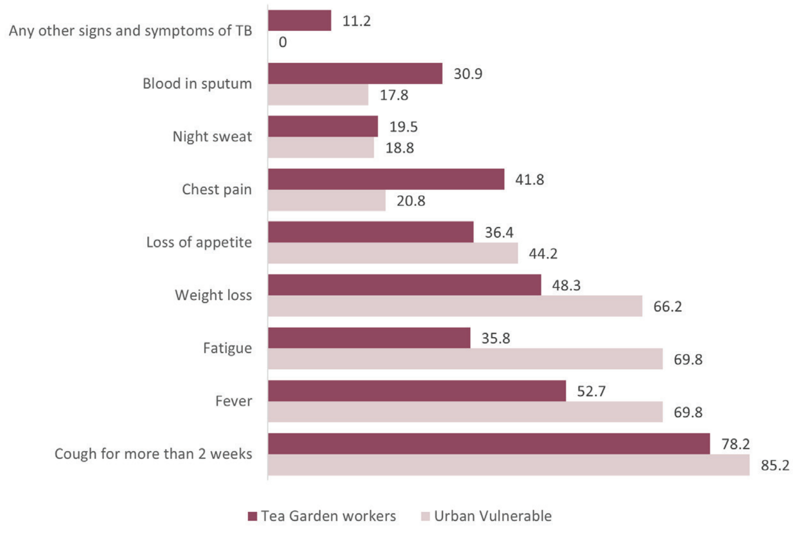
Figure 1.1: Major risk factor for TB as per PwTB/PwhTB



1.2.2 Knowledge of symptoms of TB among PwTB/PwhTB

(Figure 1.2) provides insights into the awareness of TB symptoms among the UV and TGW communities. 'Cough for more than two weeks' was the most recognised symptom of TB among both groups. PwTB/PwhTB from the UV group reported higher awareness across most symptoms compared to the TGWs. Other symptoms like fever, fatigue, and weight loss were more widely acknowledged by the UV participants. The TGWs showed better recognition of symptoms like chest pain and blood in sputum.

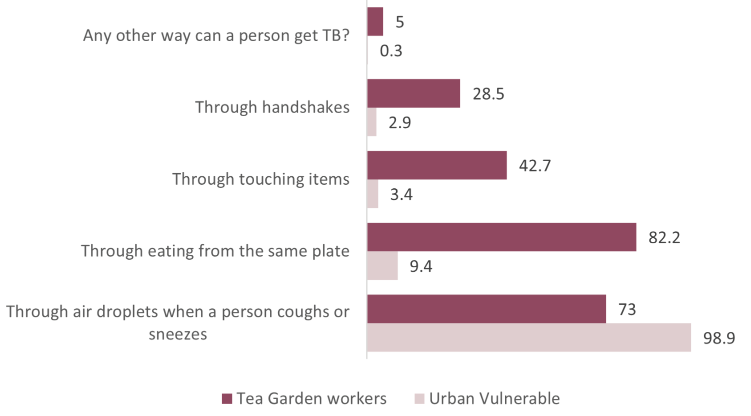
Fig 1.2: Signs and symptoms of TB as per PwTB/PwhTB



1.2.3 Knowledge of TB transmission among PwTB/PwhTB

(Figure 1.3) summarises the understanding of TB transmission among the respondents, highlighting significant disparities in knowledge. Notably, the majority of urban PwTB/PwhTB (99%) identified the primary mode of transmission of TB - through air droplets when a person coughs or sneezes. Conversely, among the TGWs, while a substantial proportion (73%) recognised this as a mode of transmission, the level was lower than among the UV population. Furthermore, the survey delved into additional misconceptions regarding the transmission of the disease. A considerable proportion of TGWs (82%) believed TB could spread through eating from the same plate, but only a small fraction of UV individuals (9%) had this misconception. Similarly, more respondents among the TGW group perceived that TB could be transmitted by touching common items and through handshakes, as compared to the UV population.

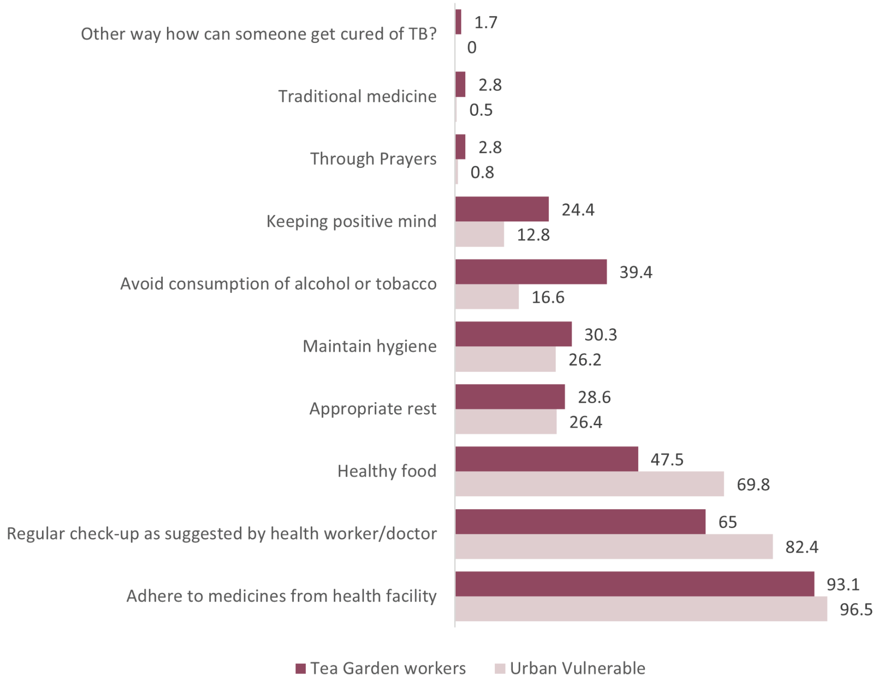
Figure 1.3: Spread of TB as per PwTB/PwhTB



1.2.4 Knowledge of curative measures of TB among PwTB/PwhTB

The majority of the respondents from both population groups were aware that TB was a curable disease (UV: 100%; TGW: 97%). These participants were also asked about their awareness of treatment options to get cured of TB. A significant proportion from both groups reported the importance of adhering to medicines, with 97% of the UV individuals and 93% of TGWs acknowledging its significance in treatment. Regular check-ups and maintaining a nutritious diet were also recognised as crucial factors, although to a lesser extent among TGWs than among UV individuals. Thus, treatment adherence, regular follow-up, proper nutrition, and avoiding substance use emerged as the key factors that were emphasised by both groups, albeit to varying degrees **(Figure 1.4).**

Fig 1.4: Measures to get cured of TB as per PwTB/PwhTB



1.2.5 Knowledge of preventive measures of TB among PwTB/PwhTB

Comprehensive knowledge of TB was found to be 77% among UV PwTB and 45% among TGWs with TB. Around 95% of UV PwTB/PwhTB reported knowing some measures to prevent TB. Covering the mouth while sneezing or coughing and good nutrition are the crucial preventive measures for TB. A significant population (UV: 88%; TGW: 79%) acknowledged the importance of covering the mouth while coughing or sneezing as an important preventive measure. However, there was less awareness of good nutrition as a significant factor in TB prevention (UV: 47%; TGW: 33%). Misconceptions about preventive measures were also prevalent, particularly among the TGWs. For instance, a substantial proportion (81%) believed that avoiding sharing plates with PwTB was a preventive measure. Similarly, a significant percentage of TGWs who were PwTB/PwhTB (47%) believed that not shaking hands with PwTB could prevent transmission, thus reflecting a misunderstanding of how TB is transmitte.

Figure 1.5: Comrehensive knowledge of TB among PwTB

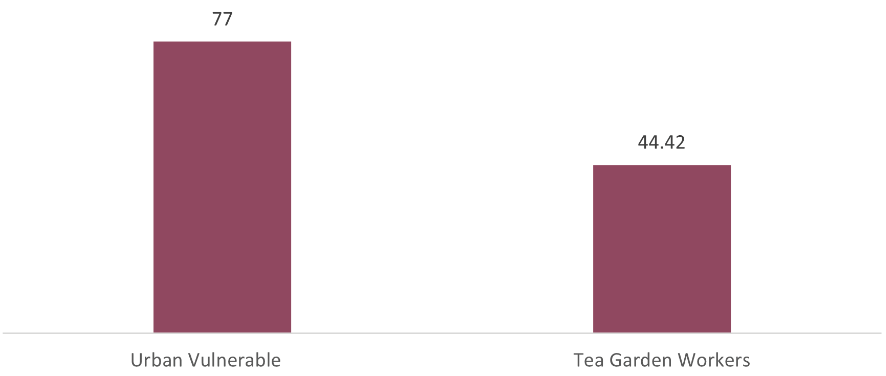
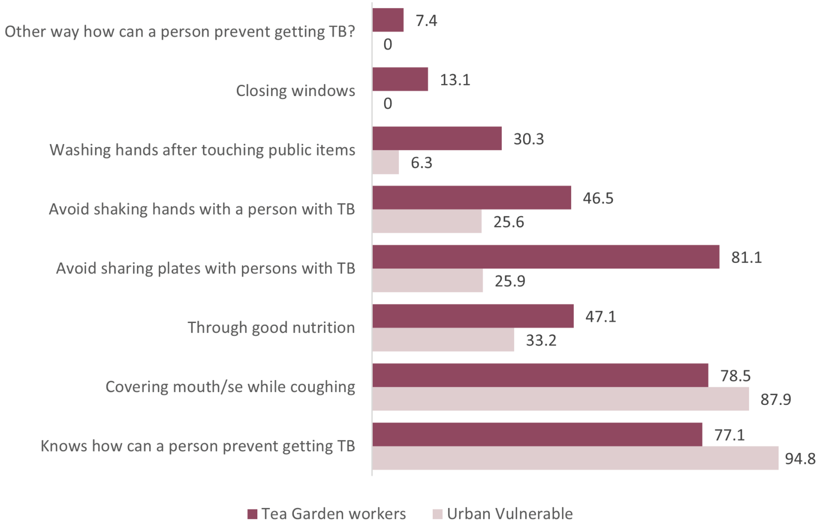


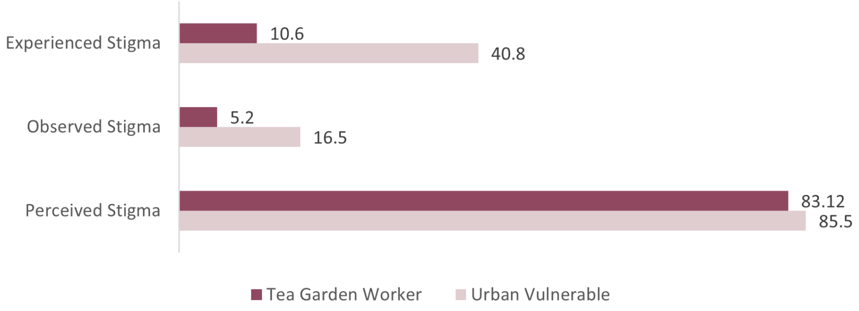
Figure 1.6: Measures to prevent TB as per PwTB/PwhTB



1.3 Reporting of Stigma by PwTB/PwhTB

The study captured various dimensions of perceived, observed, and experienced stigma. The results revealed considerable variations between the two population groups in terms of the reporting of stigma **(Figure 1.7).** While perceived stigma was high in both groups, observed stigma and experienced stigma were considerably higher among UV individuals than TGWs.

Figure 1.7: Dimensions of stigma as reported by PwTB



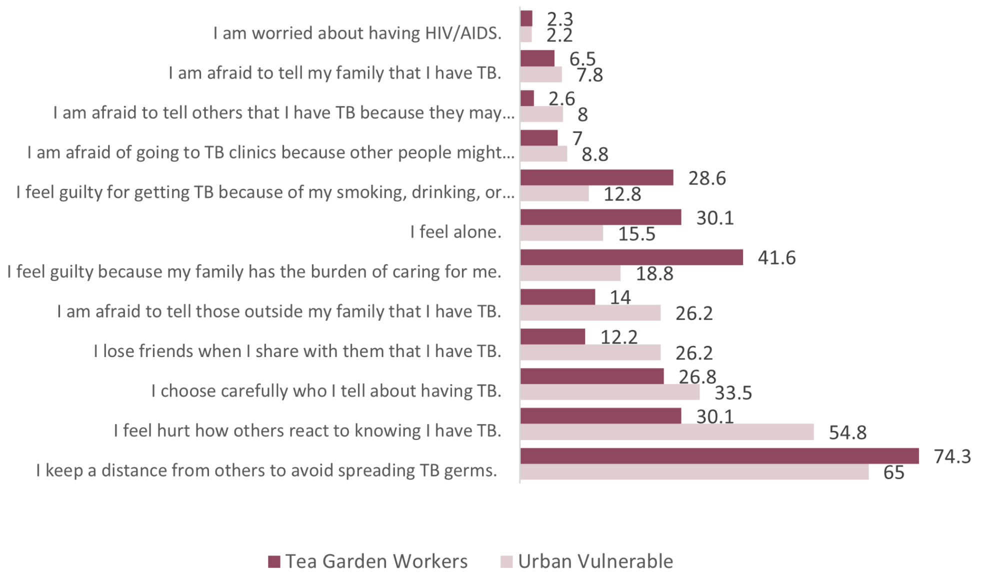
1.4 Stigma among PwTB/PwhTB Based on Background Characteristics

Exploring the association between stigma and socio-demographic characteristics helped to understand the stigma associated with TB and its determinants. Using descriptive and bivariate analysis (chi-square test), we explored whether the stigma was associated with socio-demographic characteristics.

1.4.1 Perceived and self-stigma metrics for PwTB/PwhTB

Figure 8 reports various components of perceived and self-stigma among the PwTB/PwhTB. Across the five-point stigma scale, the majority of the surveyed population (UV: 65%; TGW: 74%) admitted that they keep a distance from others to avoid spreading TB germs, and 70.1% reported choosing carefully whom they tell about their TB status. In addition, 50.4% reported feeling hurt by the reactions of others upon learning they have TB.

Figure 1.8: Stigma metrics among PwTB/PwhTB



1.4.2 Perceived and self-stigma among PwTB

Age and education were significantly associated with perceived stigma among UV PwTB/PwhTB. Notably, the UV group with higher education (12 years and above) reported the lowest perceived stigma compared to other groups. For the TGWs, significant associations with perceived stigma were noted for caste, education, social support, and comprehensive knowledge of TB. TGWs belonging to scheduled tribes (STs) exhibited higher perceived stigma compared to other caste groups. Notably, social support was significantly associated with perceived stigma. Individuals with high social support reported less perceived stigma (80%) compared to others who received low social support (100%) or medium social support (95%).

Furthermore, those with knowledge of TB (knowledge about the medium of transmission and comprehensive knowledge) reported lower perceived stigma than those who lacked such knowledge.

Table 2: Association between different individual characteristics and perceived and self-stigma

	Perceived and Self-stigma			
Characteristics	**Urban Vulnerable (N=400)**	**P Value**	**Tea Garden Worker (N=385)**	**P Value**
Age		**0.034**		**0.407**
18–29	90.0		83.9	
30–39	79.5		88.1	
40–49	90.9		81.8	
50 and above	80.5		78.6	
Gender		**0.852**		**0.437**
Male	85.2		84.4	
Female	85.9		81.4	
Religion		**0.083**		**0.222**
Hindu	86.7		82.2	
Others*	77.8		88.9	
Caste		**0.639**		**0.001**
SC	89.2		59.1	
ST	87.5		100	
OBC	84.8		83.6	
Others	82.5		84.2	
Education Level*		**0.006**		**0.0**
No schooling	89.3		90.5	
Primary	90.6		73.7	
Secondary	86.8		93.9	
Higher	73.0		100	
Marital Status		**0.671**		**0.858**
Never married	84.3		82.6	
Currently married	100		100	
Divorced/Separated	90.0		82.6	
Widowed	88.5		84.6	
Working Status		**0.331**		**0.226**
Currently working	87.2		80.7	
Currently not working	83.3		85.3	
Social Support		**0.498**		**0.005**
Low	75.0		100	
Medium	89.3		95.0	
High	84.7		80.1	

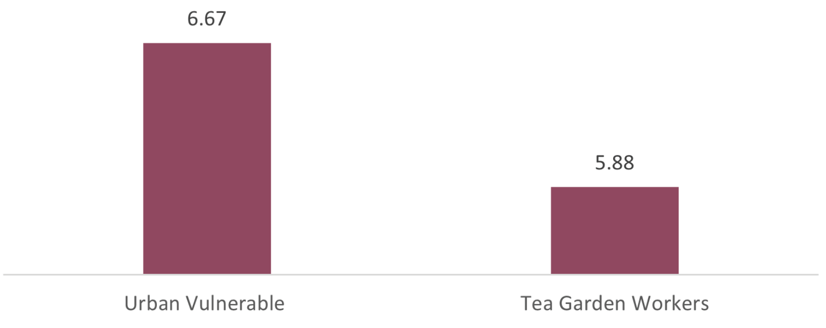
Knowledge of TB				
TB is fully curable		**0.559**		**0.531**
Yes	85.4		82.9	
No	100		80.0	
TB spreads through air droplets		**0.725**		**0.033**
Yes	86.1		76.1	
No	100		84.8	
Cough is the most common symptom		**0.247**		**0.711**
Yes	85.6		82.7	
No	90.0		83.9	
Comprehensive knowledge		**0.575**		**0**
Yes	86.0		74.9	
No	83.7		89.7	

Note: P values <0.05 denote a significant association as observed in the chi-square test.
*Others include Muslim, Christian, and other religions.

1.4.3 Perceived and self-stigma as a barrier to seeking TB services

(Figure 1.9) indicates how perceived stigma can act as a barrier to seeking TB care services as reported by the respondents. Notably, despite reporting a high level of perceived stigma **(Figure 6)**, the respondents did not report its impact on health-seeking as much. Only around 7% and 6% of PwTB/PwhTB from the UV and TGW groups reported that perceived stigma inhibited them from seeking and accessing TB-related services.

Figure 1.9: Perceived stigma as a barrier to seeking TB services



1.5 Experienced Stigma among PwTB/PwhTB Based on Background Characteristics

The social hierarchy (caste system) within Indian society was also observed in the context of TB stigma. The association between experienced stigma and caste among UV PwTB/PwhTB was found to be significant. UV PwTB/PwhTB belonging to other castes experienced less stigma (27.5%) than those from scheduled castes (SCs) (47%), STs (47.5%) and OBCs (42.1%).

For PwTB/PwhTB from the TGW community, experiencing stigma was significantly associated with gender, social support, and knowledge of TB. Stigma experienced by female PwTB/PwhTB from the TGW group was double (15.5%) the stigma experienced by their male counterparts (7.1%). Again, social support was a mitigating factor in experiencing TB stigma. Our data suggests that individuals with high or moderate social support experienced almost four times less stigma than individuals with low social support. Moreover, those with comprehensive knowledge of TB reported lower experienced stigma than those who lacked such knowledge.

Table 3: Association between different individual characteristics and experienced stigma

	Perceived and Self-stigma			
Characteristics	**Urban Vulnerable (N=400)**	**P Value**	**Tea Garden Worker (N=385)**	**P Value**
Age (in years)		**0.163**		**0.133**
18–29	44.6		11.3	
30–39	45.2		15.5	
40–49	43.4		4.6	
50 and above	32.2		11.2	
Gender		**0.379**		**0.009**
Male	42.6		7.1	
Female	38.2		15.5	
Religion		**0.765**		**0.191**
Hindu	41.0		11.5	
Others*	38.9		5.6	
Caste		**0.045**		**0.682**
SC	47.0		44.6	
ST	47.5		45.8	
OBC	42.1		40.2	
Others	27.5		32.4	
Education Level		**0.318**		**0.055**
No schooling	44.6		10.3	
Primary	45.8		8.6	
Secondary	40.2		13.9	
Higher	32.4		37.5	
Marital Status		**0.312**		**0.754**
Never married	50.0		7.8	
Currently married	38.3		11.2	
Divorced/Separated	40.0		0.0	
Widowed	50.0		13.0	

Working Status		**0.098**		**0.673**
Currently working	44.9		9.9	
Currently not working	37.7		11.3	
Social Support		**0.080**		**0.004**
Low	50.0		38.5	
Medium	29.3		10	
High	43.3		9.6	
Knowledge of TB				
TB is fully curable		**0.087**		**0.150**
Yes	40.5		10.1	
No	100		20	
TB spreads through air droplets		**0.481**		**0.000**
Yes	42.2		4.9	
No	0		5.1	
Cough is the commonest symptom		**0.523**		**0.005**
Yes	40.5		9.6	
No	37.5		12.4	
Comprehensive knowledge		**0.547**		**0.001**
Yes	41.5		4.7	
No	38.0		15.4	

Note: P values <0.05 denote a significant association as observed in the chi-square test.
*Others include Muslim, Christian, and other religions.

1.6 Experienced Stigma as a Barrier to Treatment Journey

The total reported cases of observed stigma was 26% (UV: 41%; TGW: 11%). These respondents were asked whether their treatment seeking was affected by the stigma they experienced in different settings. To this, 94% of the participants (UV: 100%; TGW: 88%) who had observed stigma reported that it had an impact on their treatment-seeking behaviour. Stigma experienced within the community played a crucial role in restricting respondents from seeking TB treatment. For instance, stigma experienced by the UV group within their community inhibited approximately 59% of them from seeking care and getting treatment adherence support. Nearly half of the UV respondents reported that stigma experienced at the community level inhibited them from beginning treatment itself. Similarly, stigma within the home or family environment also created significant obstacles on their treatment journey.

For the TGWs, experienced stigma worked as a barrier at different stages of their treatment journey, though the impact of stigma on their treatment journey was comparatively milder than that experienced by UV PwTB/PwhTB.

These findings highlight how stigma at the community and familial levels can profoundly impact individuals' willingness and ability to seek TB treatment. Addressing and mitigating stigma within these social contexts is essential to ensure that PwTB can access timely and effective care without facing discrimination or barriers based on societal attitudes.

Figure 1.10.1 Stigma experienced by UV PwTB on their TB journey under different settings as a barrier to treatment journey (N=162)

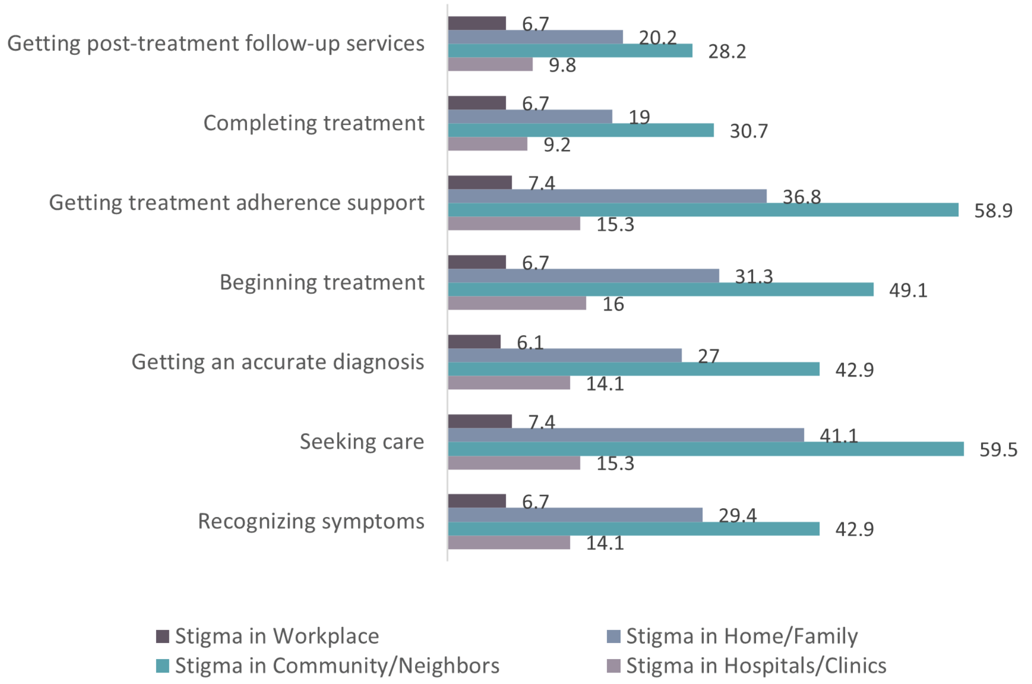
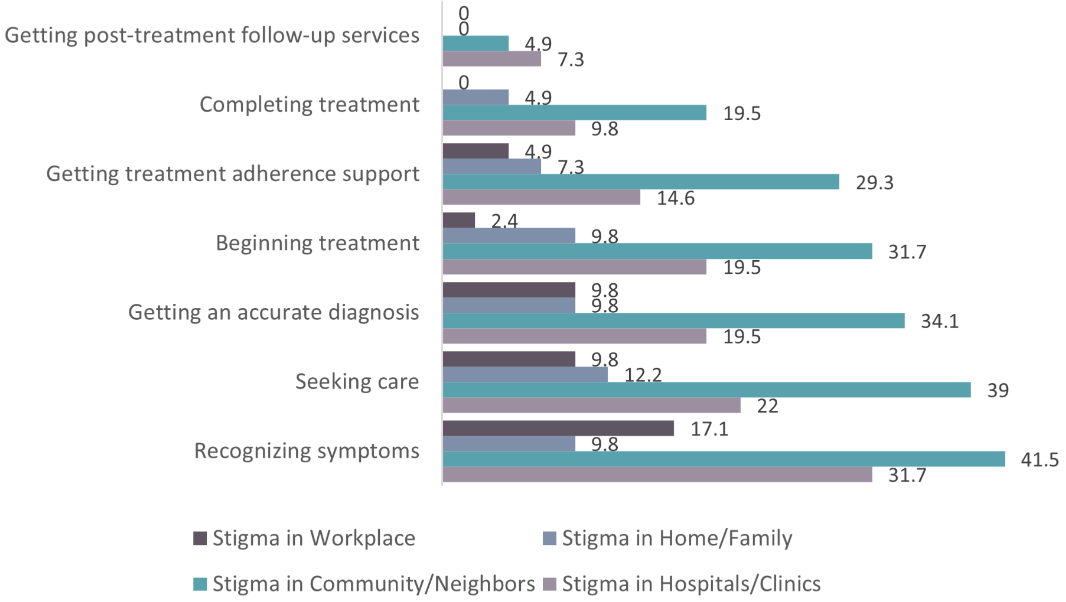


Figure 1.10.2 Stigma experienced by TGW who are PwTB under different settings as a barrier to treatment journey (N=36)



1.7 Observed Stigma for Other PwTB/PwhTB as a Barrier to Treatment Journey

About 11% of the participants (UV: 16%; TGW: 6%) reported cases of observed stigma. Further, these respondents were asked whether treatment seeking was affected by the stigma experienced at different places. To this, 90% respondents (UV: 100%; TGW: 82%) who had observed stigma reported that it had an impact on their treatment-seeking behaviour.

It was evident that stigma acted as a significant barrier inhibiting the treatment-seeking process for TB patients. Stigma observed within the community played a crucial role in hindering individuals from seeking treatment. For instance, stigma observed by UV PwTB/PwhTB within their community inhibited approximately 80% of them in seeking care and getting treatment adherence support. For 62% of UV PwTB/PwhTB, stigma observed at the community level inhibited them from beginning the treatment itself. Similarly, stigma within the home or family environment also created significant obstacles on their treatment journey.

For PwTB/PwhTB from the TGW community, observed stigma worked as a barrier at different stages of their treatment journey, though the impact of stigma on the treatment journey was comparatively milder than for UV PwTB/PwhTB.

Fig 1.11.1 Stigma experienced by other UV PwTB on their TB journey under different settings as a barrier in treatment journey, as observed by PwTB/PwhTB (N=66)

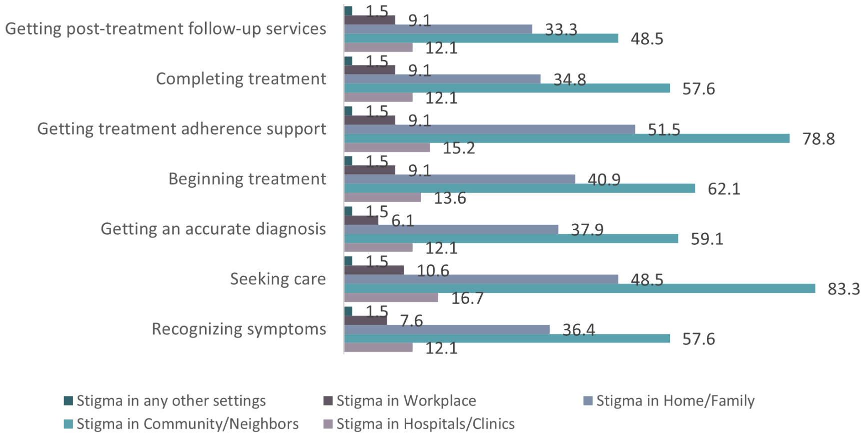
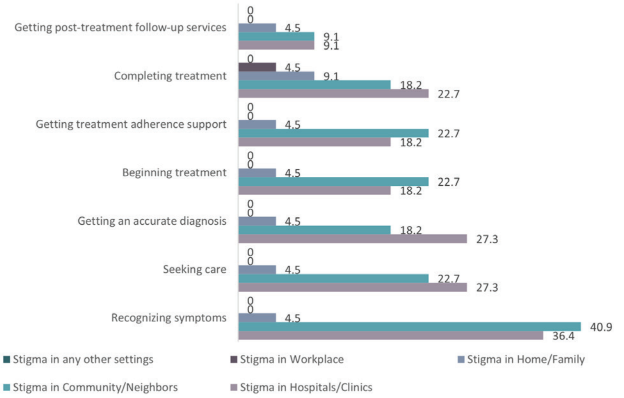


Fig 1.11.2 Stigma experienced by other TGW PwTB on their TB journey under different settings as a barrier in treatment journey, as observed by PwTB/PwhTB (N=18)



2. Family Members and Caregivers of PwTB/PwhTB: Secondary Stigma

2.1 Profile of the Survey Population

Family members and caregivers are an integral part of the TB treatment journey. They too face secondary stigma due to their family member's TB infection. A total of 785 family members and caregivers (400 from the UV group and 385 from the TGW community) of PwTB/PwhTB were included in this study. The family members or caregivers interviewed in this study were mostly spouses of the PwTB/PwhTB, followed by parents and children. **(Annexure: Table 2)**

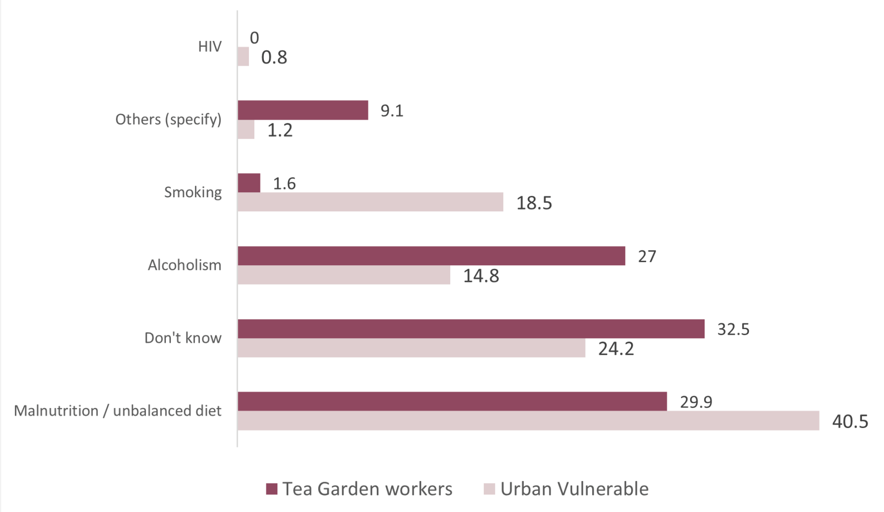
2.2 Knowledge of TB among Family Members and Caregivers (Causes, Symptoms, Transmission, Treatment, and Prevention)

The present study collected information on the knowledge of TB among family members and caregivers.

2.2.1: Knowledge of major risk factors for TB among family members and caregivers

Malnutrition, alcoholism, and smoking were the major risk factors for TB as recognised by the family members and caregivers of PwTB in the UV and TGW groups. Notably, a considerable number of caregivers of TGWs (33%) and UV patients (24%) were reportedly unaware of the risk factors for TB **(Figure 2.1).**

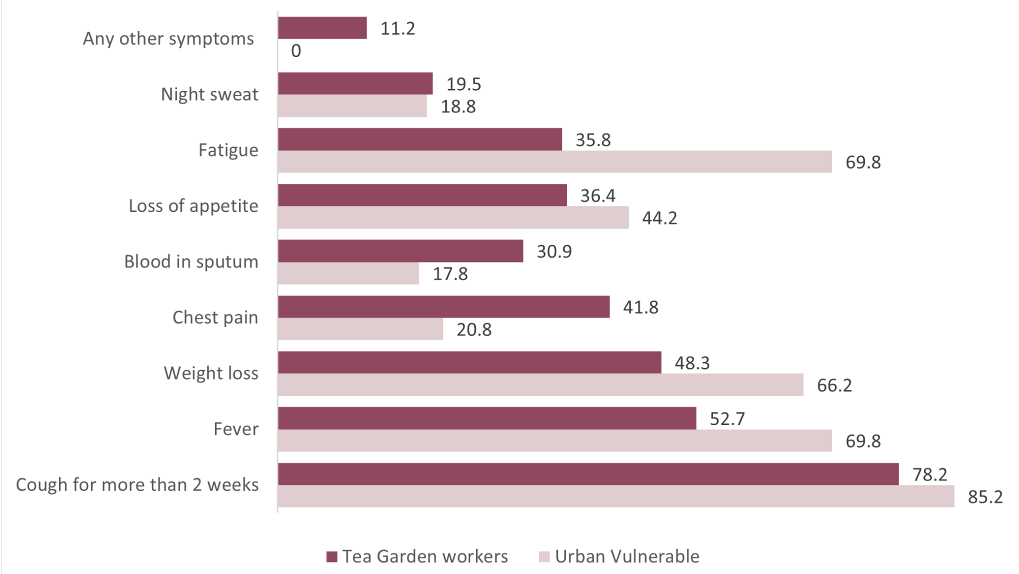
Figure 2.1: Knowledge of major risk factors for TB as per PwTB/PwhTB



2.2.2 Knowledge of symptoms of TB among family members and caregivers

To understand their awareness of TB symptoms, the study questioned the family members and caregivers on various symptoms of the disease. 'Cough for more than two weeks' was the most common symptom to be recognised by both groups. The UV group had better awareness across most symptoms compared to the TGW group. Other symptoms like fever, fatigue, and weight loss were more widely acknowledged by UV individuals. The family members and caregivers of the TGWs showed better recognition of symptoms like chest pain and blood in sputum.

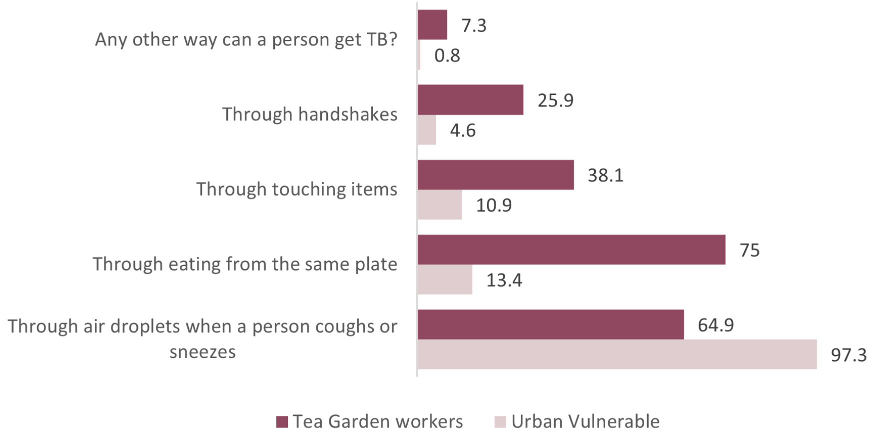
Figure 2.2: Signs and symptoms of TB as per PwTB/PwhTB



2.2.3 Knowledge of the transmission of TB among family members and caregivers

A significant proportion of the family members and caregivers (UV: 97%; TGW: 65%) acknowledged that TB is transmitted through air droplets. However, among the family members of the TGWs, misconceptions about the medium of transmission were prevalent: 75% believed TB could be transmitted by sharing food and 38% believed it could be transmitted through touch.

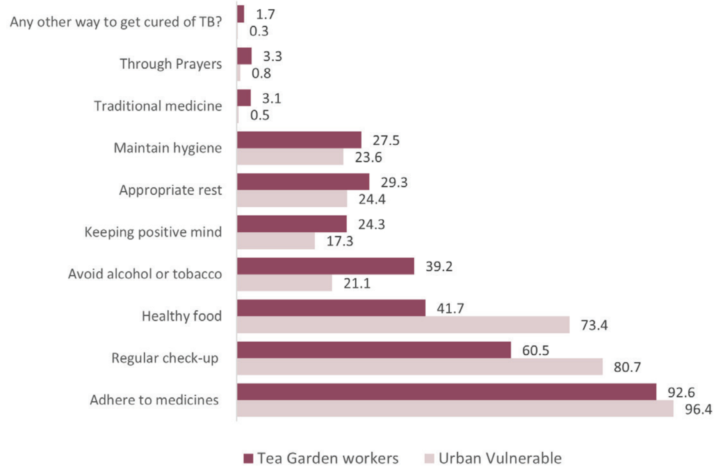
Figure 2.3: Knowledge of the transmission of TB among family members and caregivers of PwTB/PwhTB



2.2.4: Knowledge of curative measures for TB among family members and caregivers

Adherence to medicines was the most widely recognised method among the family members and caregivers of both the groups. They also considered regular check-ups and consumption of healthy and nutritious food to be important for getting cured of TB, though to varying degrees. Avoidance of alcohol and tobacco as a curative measure had comparatively moderate recognition, especially among the family members of PwTB/PwhTB from the UV population.

Figure 2.4: Knowledge of curative measures for TB among family members and caregivers of PwTB/PwhTB



2.2.5: Knowledge of preventive measures of TB among family members and caregivers

Comprehensive knowledge of TB was seen among 83% and 49% of the family members of the UV and TGW populations, respectively. The study also collected information on specific measures that the family members and caregivers of PwTB/PwhTB recognised as effective in preventing TB. We found that 'covering the mouth while sneezing or coughing' was the most recognised preventive measure; however, the recognition of good nutrition as a preventive measure was comparatively lower. Misconceptions about preventive measures were prevalent as well, particularly among the family members of PwTB/PwhTB from the TGW group. For instance, a substantial proportion of family members (80%) reported that TB can be prevented by avoiding shaking hands with PwTB and 46% believed that not sharing plates with patients was a preventive measure.

Figure 2.5: Comrehensive knowledge of TB among family members and caregivers of PwTB

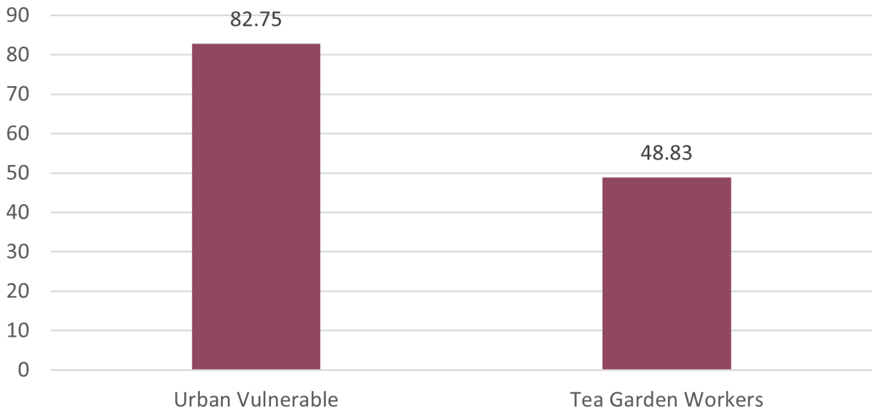
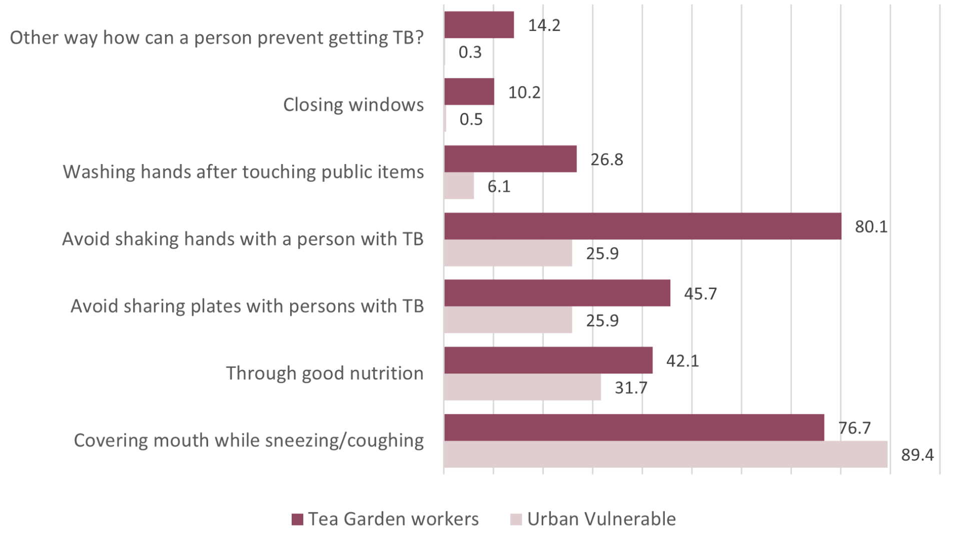


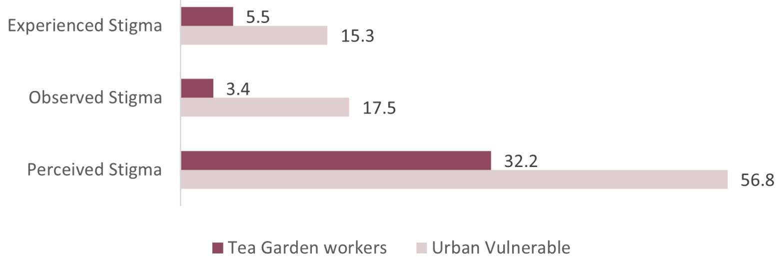
Figure 2.6: Knowledge of preventive measures of TB among family members and caregivers of PwTB/PwhTB



2.3 Secondary Stigma among Family Members and Caregivers

We found a huge variation in stigma reporting by the family members and caregivers of PwTB/PwhTB, as presented in **(Figure 2.7)** The family members of TGWs reported comparatively less stigma than the family members of the UV group.

Figure 2.7: Reporting of stigma by family members

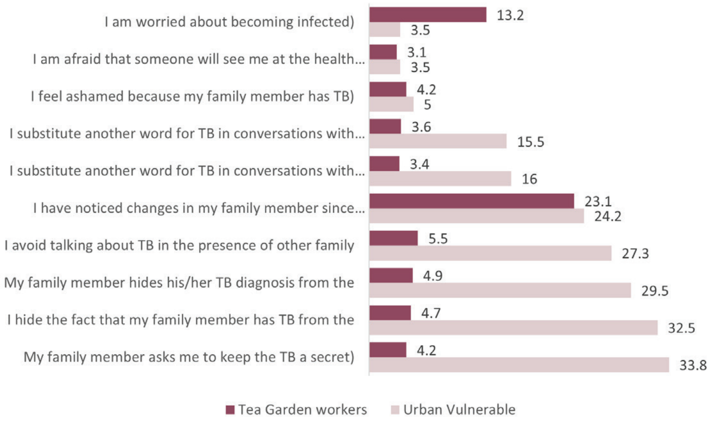


2.4 Dimensions of Secondary Stigma among Family Members and Caregivers

2.4.1 Perceived stigma metrics of family members and caregivers

Perceived stigma among the family members and caregivers of TB patients were measured on a five-point Likert scale, which showed varying responses. Among the UV respondents, a larger proportion reported behaviours indicative of secondary stigma, compared to the TGW group. For instance, around a third of the UV group (33.8%) indicated their family members had requested them to keep their TB diagnosis a secret, whereas only a small percentage of TGWs (4.2%) reported the same. UV individuals were also more likely to admit to hiding the TB diagnosis (32.5%) and avoiding TB-related discussions (27.3%) compared to TGWs (4.7% and 5.5%, respectively). Despite these differences, both groups exhibited low agreement with statements suggesting personal shame or fear of being seen at healthcare clinics. Overall, secondary stigma was prevalent to a greater extent in the UV group.

Figure 2.8: Perceived stigma metrics of family members and caregivers



2.4.2 Perceived stigma among family members and caregivers

This table summarises perceived stigma as reported by the family members and caregivers of PwTB/PwhTB. The perceived stigma reported by family members and caregivers was significantly associated with the relation they had with the PwTB/PwhTB.

For the TGW group, the working status and knowledge of TB of the family members and caregivers was significantly associated with their perceived stigma.

Table 4: Association between different individual characteristics of family members and their perceived stigma

	Perceived Stigma			
Characteristics	**Urban Vulnerable (N=227)**	**P Value**	**Tea Garden Worker (N=124)**	**P Value**
Age (in years)		**0.982**		**0.209**
18–29	56.4		38.8	
30–39	58.0		26.7	
40–49	57.3		28.6	
50 and above	55.2		32.8	
Gender		**0069**		**1.0**
Male	51.5		32.1	
Female	60.6		32.2	
Religion		**0.095**		**0.108**
Hindu	58.3		33.7	
Others	46.3		22.7	
Caste		**0.246**		**0.056**
SC	57.5		16.7	
ST	63.4		43.3	
OBC	52.2		34.0	
Others	64.1		20.6	

Education Level		**0.202**		**0.147**
No schooling	63.1		29.8	
Primary	52.6		29.4	
Secondary	60.1		42.4	
Higher	47.4		22.2	
Marital Status		**0.255**		**0.873**
Never married	51.3		29.4	
Currently married	57.0		32.7	
Divorced/Separated	0.0		0.00	
Widowed	71.4		33.3	
Working Status		**0.113**		**0.021**
Currently working	53.8		28.7	
Currently not working	61.9		40.9	
Relation with PwTB/PwhTB		**0.006**		**0.016**
Parent	58.0		25.0	
Grandparent	100.0		0.0	
Spouse	57.4		29.5	
Children	40.0		39.0	
Grandchildren	66.7		0.0	
Sibling	64.1		22.6	
Others	81.0		50.9	
Knowledge of TB				
TB is fully curable		**0.214**		**0.642**
Yes	56.3		31.9	
No	100.0		33.3	
TB spreads through air droplets when a person coughs or sneezes		**0.945**		**0.009**
Yes	57.0		26.8	
No	66.7		41.4	
Cough is the most common symptom		**0.299**		**0.004**
Yes	57.6		29.6	
No	40.9		39.7	
Comprehensive knowledge		**0.966**		**0.021**
Yes	56.8		26.6	
No	56.5		37.5	

Note: P values <0.05 denote a significant association as observed in the chi-square test.

*Others include Muslim, Christian, and other religions.

2.4.3 Experienced stigma among family members and caregivers

Stigma experienced by the family members and caregivers of UV PwTB/PwhTB was significantly associated with their education level. Such stigma was four times higher among those with no formal education (22%) compared to others with higher levels of education (12 years and above), who encountered only 5% stigma.

Table 5: Association between different individual characteristics of family members and their experienced stigma

	Experienced Stigma			
Characteristics	**Urban Vulnerable (N=400)**	**P Value**	**Tea Garden Worker (N=385)**	**P Value**
Age (in years)		**0.3**		**0.9**
18–29	10.0		4.7	
30–39	19.0		6.7	
40–49	16.5		6	
50 and above	16.1		4.5	
Gender		**0.1**		**0.5**
Male	11.2		6.4	
Female	18.3		4.9	
Religion		**0.2**		**0.9**
Hindu	16.1		5.4	
Others	9.2		5.6	
Caste		**0.1**		**0.2**
SC	18.8		3.3	
ST	26.8		0	
OBC	12.9		6.9	
Others	11.5		0	
Education Level		**0.053**		**0.7**
No schooling	21.5		6.9	
Primary	19.2		4.4	
Secondary	15.7		5.9	
Higher	5.1		0	
Marital Status		**0.1**		**0.7**
Never married	8.1		6.0	
Currently married	17.4		0	
Divorced/Separated	0		0	
Widowed	9.5		3.9	
Working Status		0.2		0.1
Currently working	17		6.5	
Currently not working	12.2		2.7	

Relation with PwTB/PwhTB		**0.1**		**1.0**
Parent	17.3		6.3	
Grandparent	0		0.0	
Spouse	19.6		6.4	
Children	6.3		3.4	
Grandchildren	0		0.0	
Sibling	17.2		6.5	
Others	9.52		3.8	
Knowledge of TB				
TB is fully curable		**0.3**		**0.0**
Yes	15.2		4.8	
No	0.00		0.00	
TB spreads through air droplets		**0.7**		**0.8**
Yes	15.7		3.3	
No	33.3		3.03	
Cough is the most common symptom		**0.3**		**0.1**
Yes	16		4.6	
No	4.5		8.2	
Comprehensive knowledge		**0.4**		**0.1**
Yes	16.0		3.2	
No	11.6		7.6	

Note: P values <0.05 denote a significant association as observed in the chi-square test.
*Others include Muslim, Christian, and other religions.

2.4.4 Experienced stigma for other family members as a barrier to treatment support

Around 10% (UV: 15%; TGW: 5%) had experienced stigma because of the TB status of a family member. Of those who experienced stigma, around 76% (UV: 100%; TGW: 52%) said that the experience inhibited them from providing treatment support to their PwTB family member.

Experienced stigma among family members and caregivers in different settings hindered them from supporting the treatment journey of their family member who had TB. Here as well, experienced stigma at the community level barred 73.8% of family members from supporting family members with TB in seeking TB care and getting treatment adherence support.

Figure 2.9a: Stigma experienced by family members of UV PwTB under different settings as a barrier to treatment support (N=61)

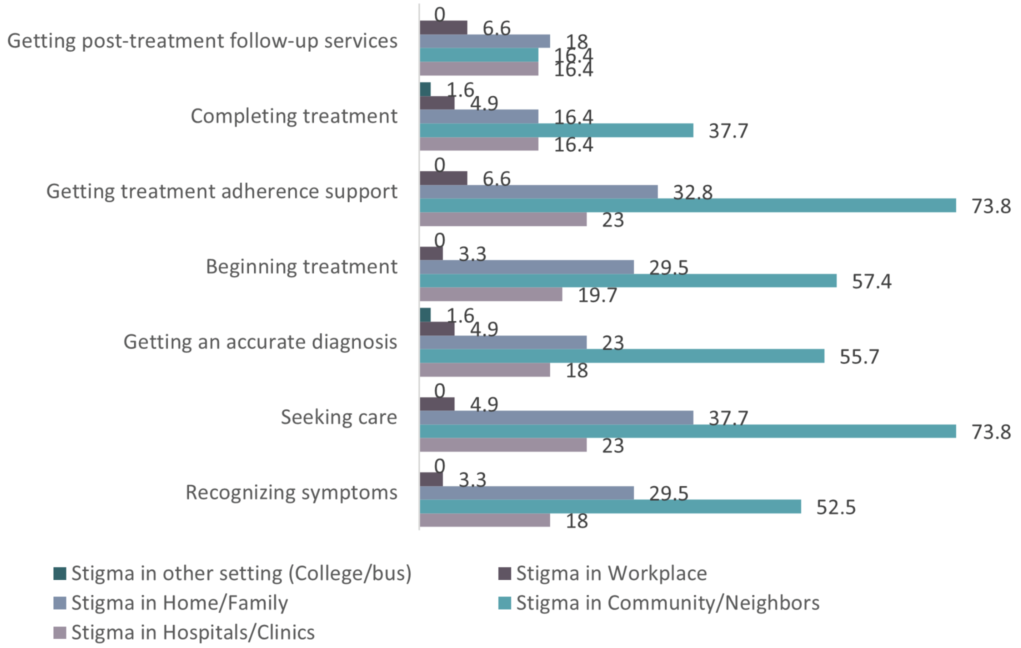
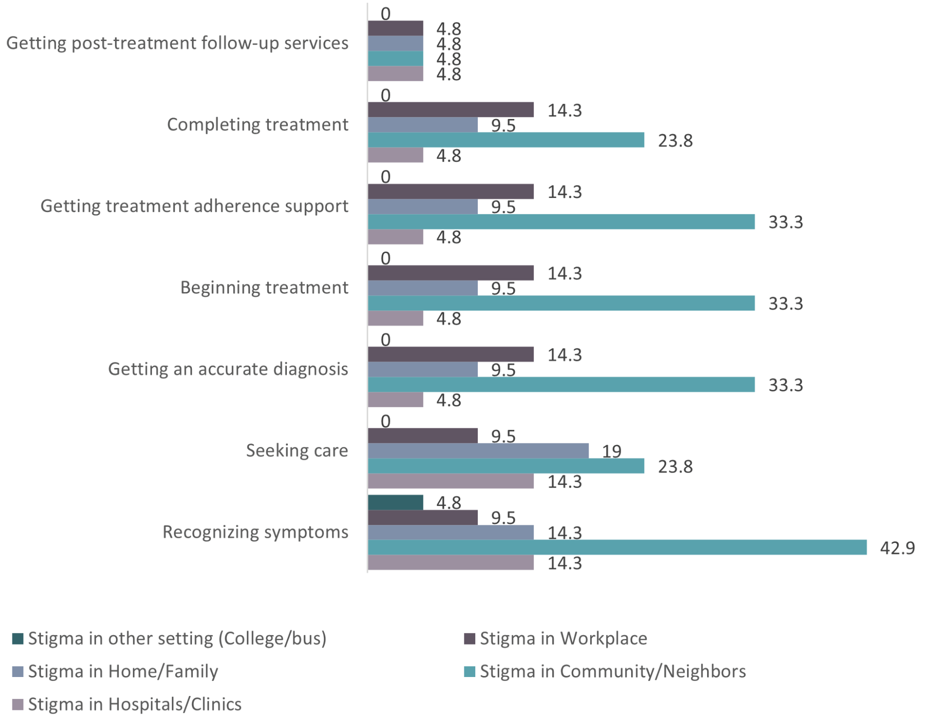


Figure 2.9b: Stigma experienced by family members of TGW who are PwTB under different settings as a barrier to treatment support (N=11)



2.4.5 Observed stigma for other family members as a barrier to treatment support

Around 11% of family members (UV: 18%; TGW: 3%) observed the families of other PwTB being stigmatised. About 98% of those who reported such cases (UV: 95%; TGW: 100%) said the stigma experienced by others inhibited them from providing treatment support to their own family members.

Figures 2.10a and **2.10b** show how the stigma was a significant barrier to support in the treatment-seeking process for TB. Stigma at the community level was especially crucial as it barred the family members from supporting the patient on their treatment journey, albeit to varying degrees,

As observed by the participants, stigma within the family was also important during the treatment process. Stigma within the family towards PwTB/PwhTB posed a challenge for family members in supporting the patient through different stages of the treatment journey.

Figure 2.10a: Stigma observed by family members of UV PwTB/PwhTB under different settings as a barrier to treatment support (N=70)

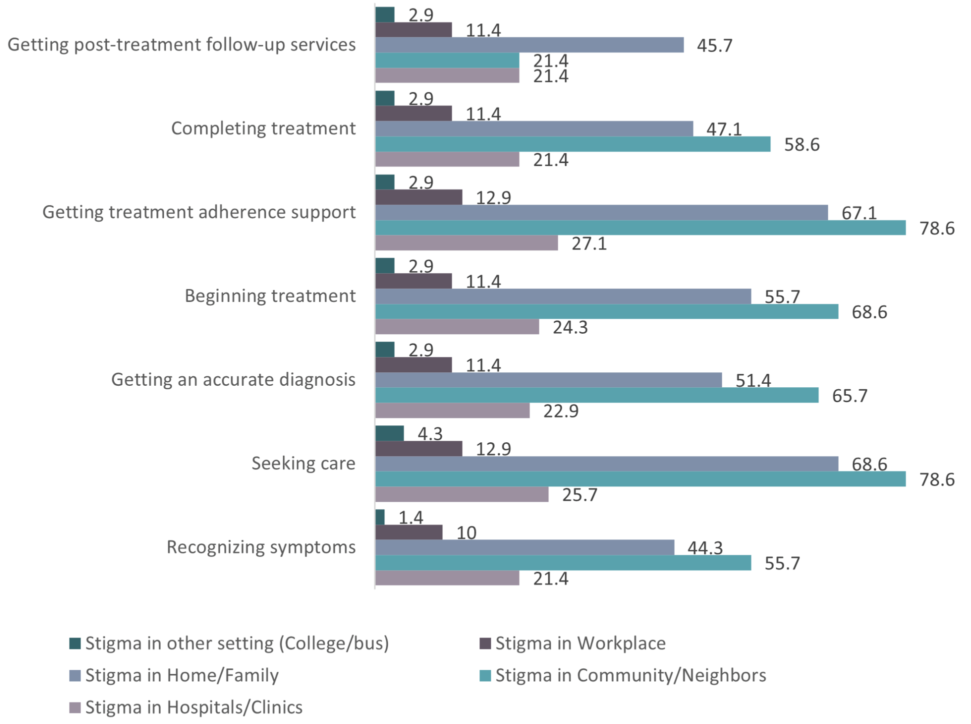
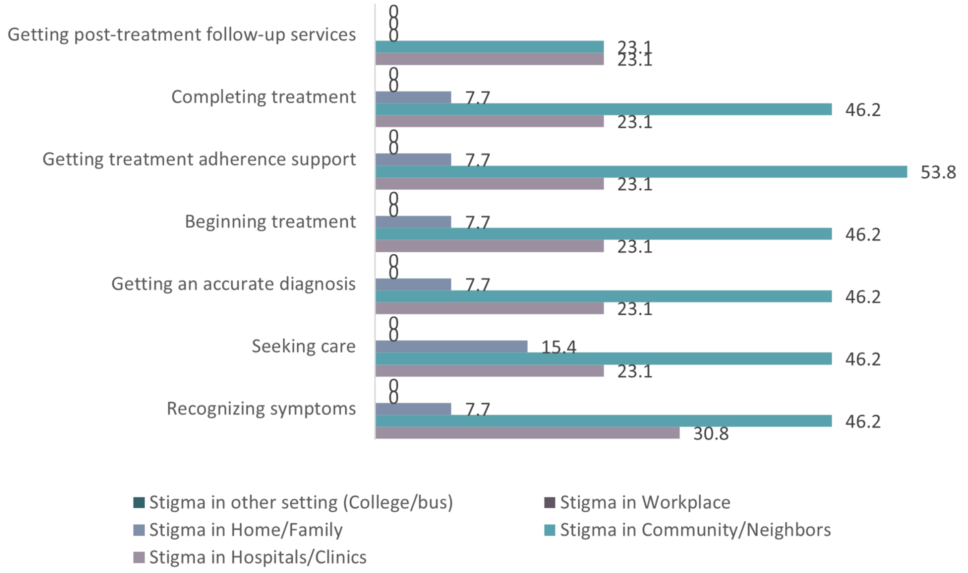


Figure 2.10b: Stigma observed by family members of TGW PwTB under different settings as a barrier to treatment support (N=13)



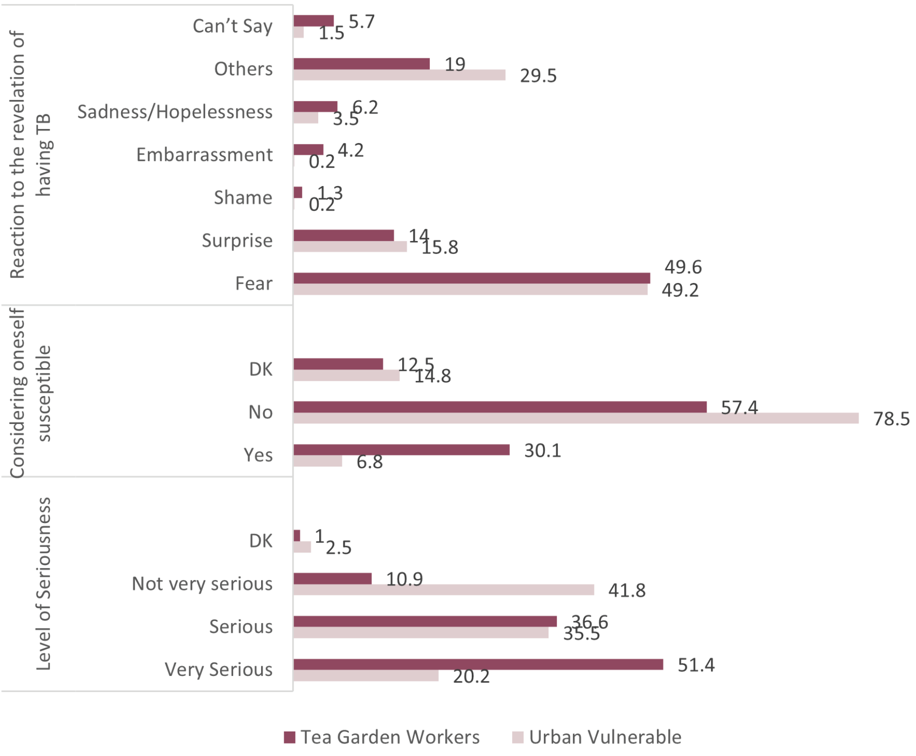
3.1 Profile of the Survey Population

We interviewed 785 community members and neighbours (400 from the UV community and 385 from the TGW community) of PwTB/PwhTB to understand TB-related stigma and its determinants. Around 65% and 44% of the UV and TGW community members, respectively, were female. There was a significant difference in educational attainment, with 33% of the respondents from the TGW community having no schooling, compared to just 11% among the UV group. A significant proportion of the respondents from the TGW community (57%) reported personally knowing two or more PwTB/PwhTB, compared to a much lower figure for UV individuals (10%). (**Annexure: Table 3)**

3.2 Attitude towards TB

A fifth of the UV community members and over half of the TGW community members considered TB to be a very serious disease. Those from the TGW group also reported a higher susceptibility to TB (30.1%) than their UV counterparts (6.8%). Almost 50% of the participants reported 'fear' as their primary reaction to a TB diagnosis.

Figure 3.1: Community members' attitudes towards TB

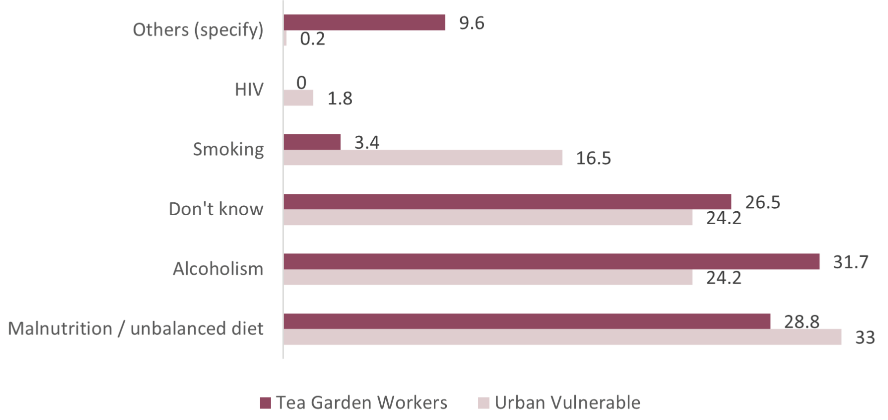


3.3 Knowledge of TB among Community Members of PwTB/PwhTB (Causes, Symptoms, Transmission, Treatment, and Prevention)

3.3.1 Knowledge of major risk factors for TB among community members

The community members of PwTB/PwhTB recognised malnutrition and alcoholism as the major risk factors for TB. However, a significant proportion of them (around 25%) reported not knowing about the risk factors of the disease **(Figure 3.2)**

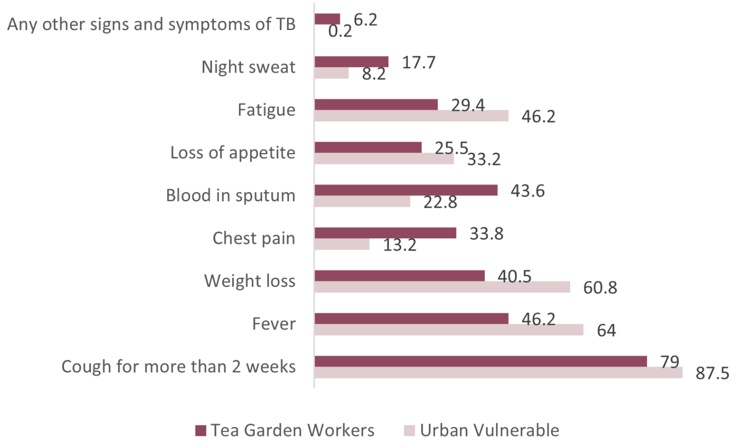
Figure 3.2: Knowledge of major risk factors for TB among community members



3.3.2 Knowledge of signs and symptoms of TB among community members

'Cough for more than two weeks' was the most recognised symptom of TB among the community members. UV individuals demonstrated higher awareness across most symptoms than did TGWs. Other symptoms like fever, fatigue, and weight loss were more widely acknowledged among the community members of UV PwTB/PwhTB. Those from the TGW community showed better recognition of symptoms like chest pain and blood in sputum **(Figure 3.3).**

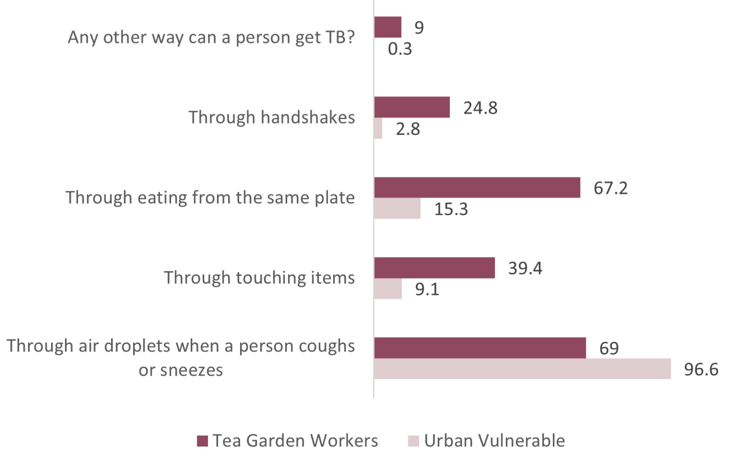
Figure 3.3: Knowledge of signs and symptoms of TB among community members



3.3.3 Knowledge of transmission of TB among community members

Around 88% of the community members from both groups reported knowing about the medium of transmission of TB. However, only 69% from the TGW community had the correct knowledge about the medium of transmission, whereas the figure was 96% for people from the UV community. Misinformation about the medium of transmission, such as that it spreads through handshakes and eating on the same utensils, was higher among the TGW community.

Figure 3.4: Knowledge of transmission of TB among community members

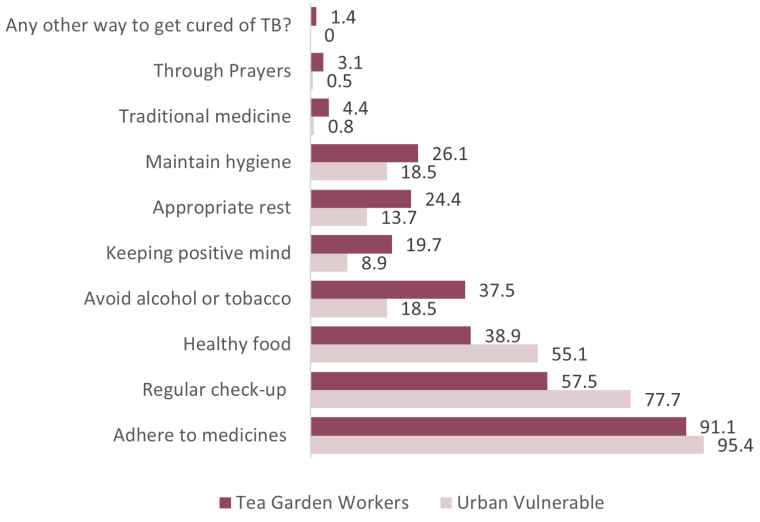


3.3.4 Knowledge of curative measures of TB among community members

A significant proportion of the community members confirmed that adherence to medicines was the most widely recognised curative measure, followed by regular check-ups and healthy and nutritious food. More emphasis on these measures came from the UV community members. The level of knowledge about curative care varied across the different survey groups.

Recognition that the avoidance of alcohol and tobacco, hygiene maintenance, getting the appropriate tests, and having a positive mindset throughout the treatment journey were curative measures was more common among members from the TGW community.

Figure 3.5: Knowledge of curative measures of TB among community members of PwTB/PwhTB



3.3.5 Knowledge of preventive measures of TB among community members

Almost all of the community members had comprehensive knowledge of TB. This study looked into the specific measures that they recognised as effective in preventing the disease. Covering the mouth while sneezing or coughing was the most recognised preventive measure among the community members (UV:

86%; TGW: 70%). However, recognition of good nutrition as a preventive measure was comparatively low in both groups (UV: 26%; TGW: 37%). Misconceptions about preventive measures were also prevalent, particularly among people from the TGW community. For instance, a substantial proportion of them reported that not sharing plates (79%) and not shaking hands with a PwTB (45%) could prevent transmission.

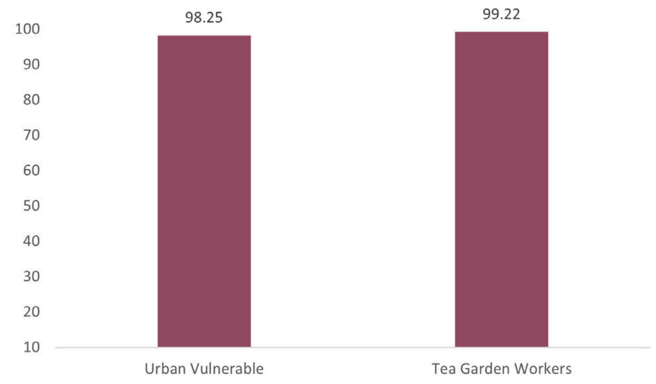


Figure 3.6: Comrehensive knowledge of TB among community members of PwTB

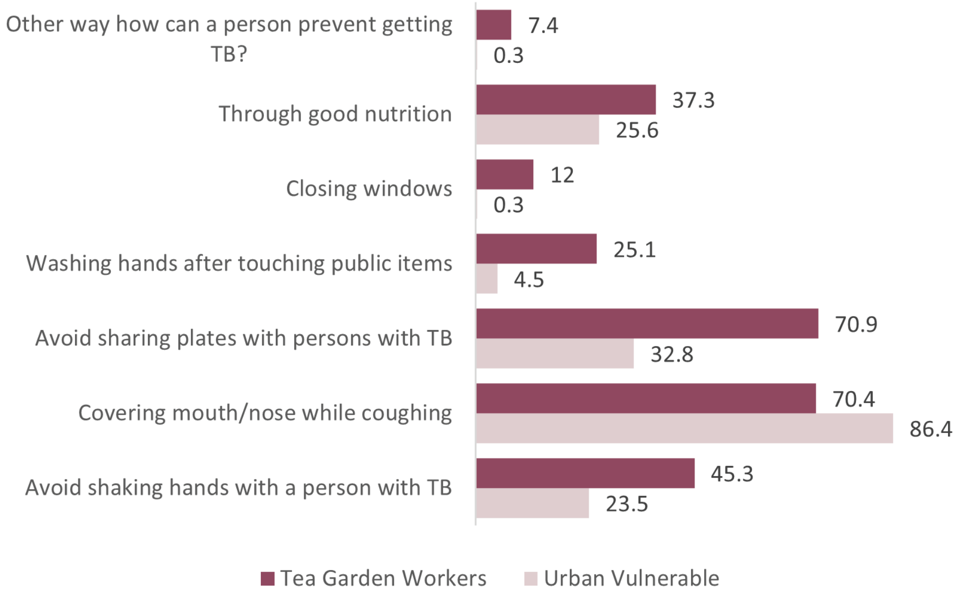


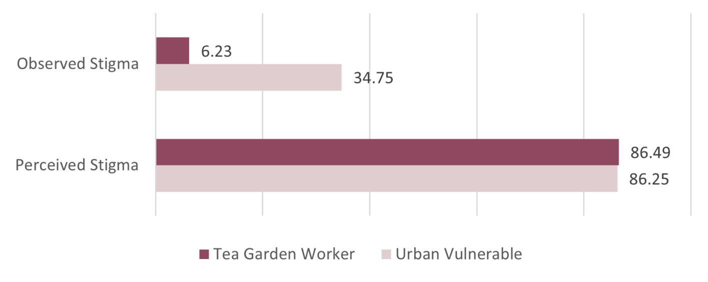
Figure 3.7: Knowledge of preventive measures of TB among community members of PwTB/PwhTB

3.5 TB-related Stigma

A five-point Likert scale was used to assess the stigma and discrimination towards PwTB/PwhTB. To assess the perceived stigma towards TB in the community, the participating community members were asked about their own and general attitudes towards PwTB/PwhTB,. Information on observed stigma was sought directly from the community members.

Although community members from the two groups had similar levels of perceived stigma (86%), the level of observed stigma was significantly lower (6%) in the TGW group than in the UV population (35%).

Figure 3.8: Reporting of stigma by community members

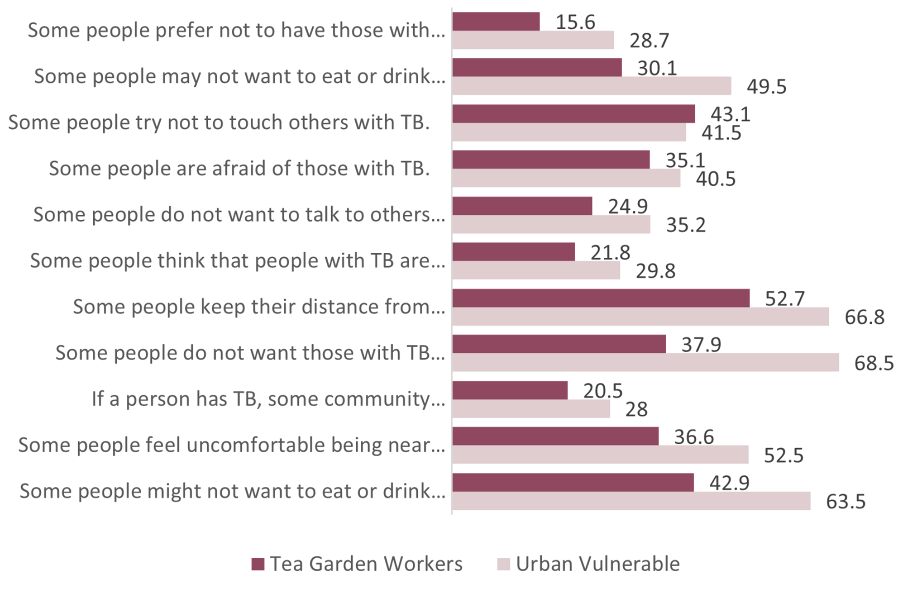


3.6 Dimensions of Stigma towards PwTB/PwhTB Reported by Community Members

3.6.1 Perceived stigma metrics towards PwTB/PwhTB

The data reveals that community members from the UV group reported higher perceived stigma than those from the TGW community. For example, around 66% of the community members of the UV community agreed that some people did not want PwTB playing with their children, and that they maintained distance from people with TB, not even sharing food and drinks with their PwTB friends **(Figure 3.9).**

Figure 3.9: Perceived stigma metrics towards PwTB/PwhTB



3.6.2 Perceived stigma by community members towards PwTB/PwhTB

The stigma perceived by community members was significantly associated with their acquaintance with PwTB/PwhTB and their knowledge of TB. Other factors were not significant in the context of the perceived stigma reported by community members.

Table 6: Association between different individual characteristics of community members and their perceived stigma

	Perceived Stigma			
Characteristics	**Urban Vulnerable (N=400)**	**P Value**	**Tea Garden Workers (N=385)**	**Numbers**
Age		**0.550**		**0.723**
18–29	82.0		84.3	
30–39	87.5		89.8	
40–49	88.5		84.6	
50 and above	87.1		87.0	
Gender		**0.673**		**0.058**
Male	87.2		89.4	
Female	85.7		82.7	
Religion		**0.576**		**0.854**
Hindu	86.6		86.6	
Others	83.6		85.7	
Caste		**0.224**		**0.751**
SC	88.8		93.1	
ST	92.69		86.21	
OBC	86.6		86.06	
Others	78.28		85	
Education Level		**0.428**		**0.210**
No schooling	79.1		84.8	
Primary	85.7		90.7	
Secondary	86.8		80.0	
Higher	90.0		88.9	
Marital Status		**0.358**		**0.084**
Never married	81.5		76.1	
Currently married	87.2		88.5	
Divorced/Separated	0		100	
Widowed	77.8		79.2	
Working Status		**0.819**		**0.064**
Currently working	86		88.7	
Currently not working	86.8		81.9	

Personally known number of people with PwTB/PwhTB		**0.004**		**0.021**
None	91.3		80.0	
One	83.9		79.3	
Two or more	87.8		90.9	
Don't know	74.3		87.5	
Knowledge of TB				
TB is fully curable		**0**		**0.090**
Yes	88.2		87	
No	88.9		50	
TB spreads through air droplets		**0.716**		**0.015**
Yes	88.3		88.7	
No	75		77.5	
Cough is the commonest symptom		**0.020**		**0.058**
Yes	73		88.5	
No	87.1		78.5	
Comprehensive knowledge		**< 0.001**		**0.313**
Yes	87.0		86.7	
No	42.9		66.7	

Note: P values <0.05 denote a significant association as observed in the chi-square test.
*Others include Muslims, Christians, and other religions.

3.6.3 Stigma experienced by PwTB community members as a barrier to treatment journey, as observed by community members

Around 21% of the community members (UV: 35%; TGW: 6%) reported observing other community members with TB being stigmatised. Around 88% of them (UV: 100%; TGW: 75%) said the stigma was a barrier to treatment seeking.

As presented in **(Figures 3.10a & 3.10b),** experienced stigma at the community level had the most detrimental impact on the TB treatment journey - for example, more than 50% community members of the UV group reported that experienced stigma at the community level affected each aspect of the treatment journey.

Figure 3.10a: Stigma experienced by UV PwTB/PwhTB under different settings as a barrier to treatment journey, as observed by the community members (N=139)

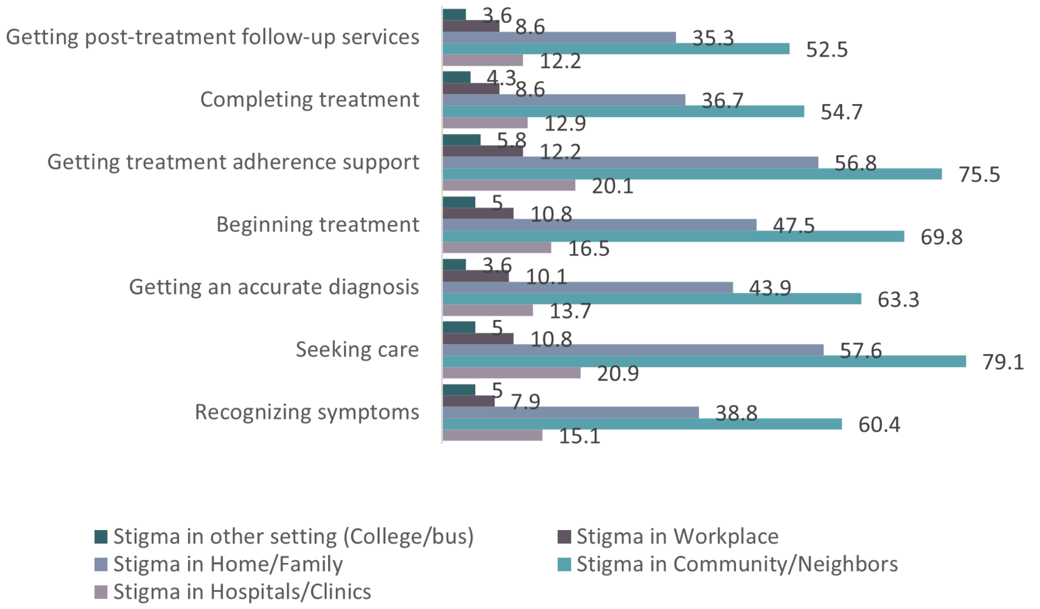
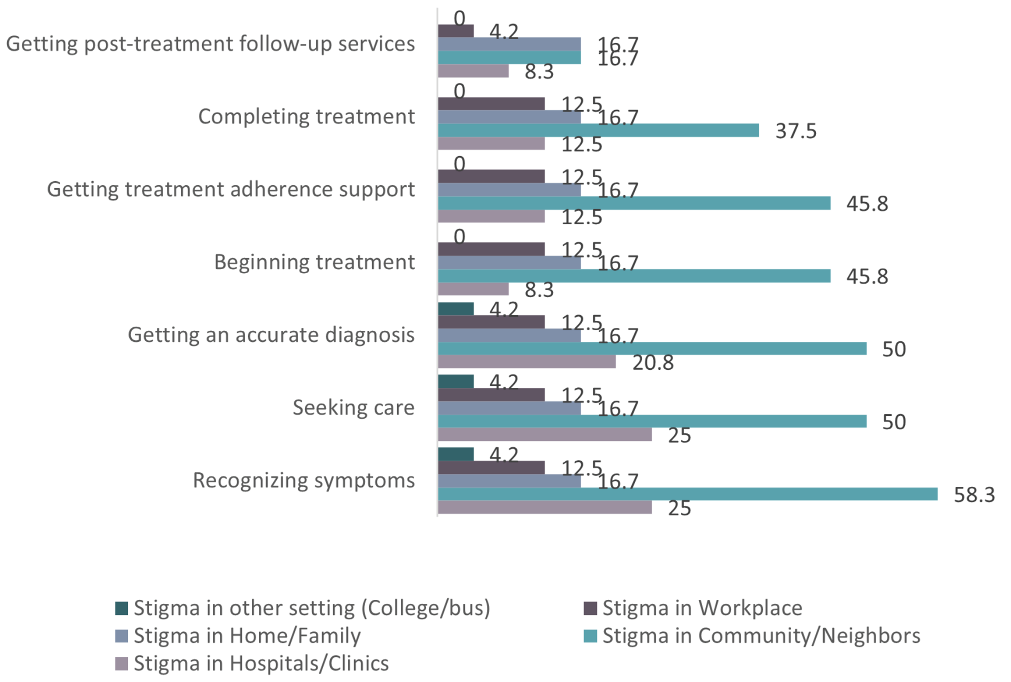


Figure 3.10b: Stigma experienced by TGW- PwTB/PwhTB under different settings as a barrier to treatment journey, as observed by the community members (N=18)



4. Healthcare Workers

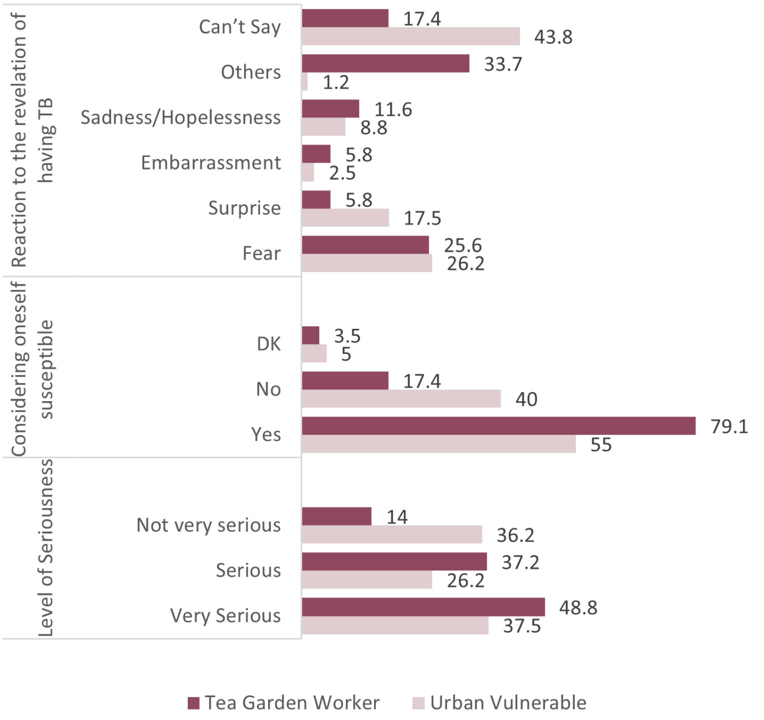
4.1 Profile of the Respondents

The study encompassed 80 and 86 HCWs who were serving the UV and TGW communities, respectively. Around 70% of the HCWs from both groups were aged between 30 and 50 years and around 64% of them were male. The predominant category of HCWs interviewed were ASHA workers (35%). **(Annexure: Table 4)**

4.2 Attitude towards TB

HCWs providing services to the UV group and TGWs showed differing attitudes towards TB. While 38% of HCWs for the UV group perceived TB as very serious, 49% of HCWs for TGWs shared this view. Moreover, 55% of HCWs working with the UV population considered themselves susceptible to TB, in contrast to 79% of HCWs working with TGWs. Fear was one of the predominant reactions to a TB diagnosis, as reported by approximately 26% of the HCWs working with the UV and TGW communities.

Figure 4.1: Health workers' attitudes towards TB



4.3 Knowledge of TB among HCWs (Causes, Symptoms, Transmission, Treatment, and Prevention)

4.3.1 Knowledge of major risk factors for TB

About 41% and 34% of the HCWs providing services to the UV and TGW groups, respectively, viewed malnutrition as a major risk factor for TB. However, only 1% of the HCWs providing services to TGWs considered smoking as a risk factor.

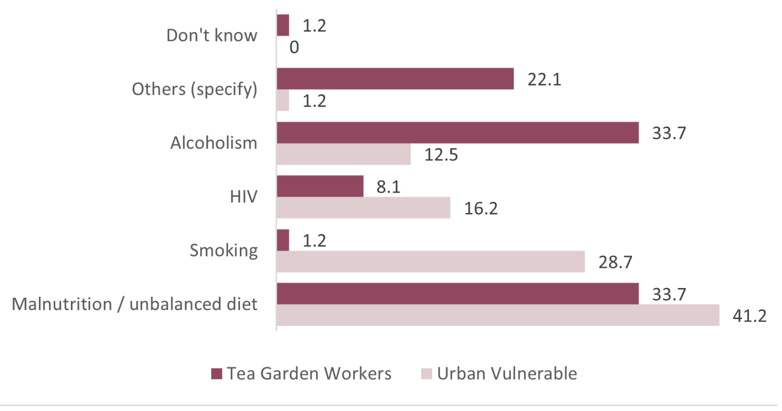


Figure 4.2: Knowledge of major risk factors for TB among HCWs

4.3.2 Knowledge about the signs and symptoms of TB

Recognition of the various signs and symptoms of TB was similar among the HCWs serving both groups, as shown in **(Figure 4.3).**

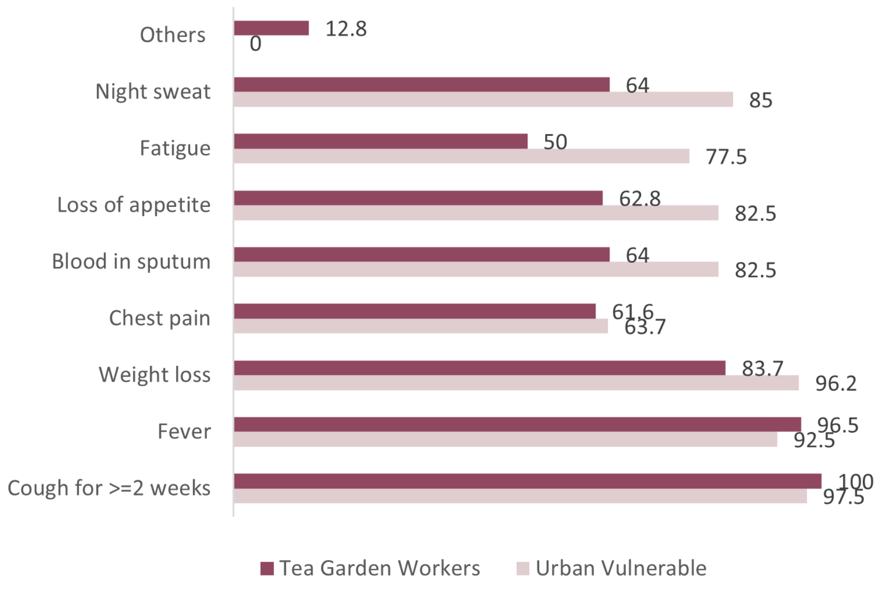
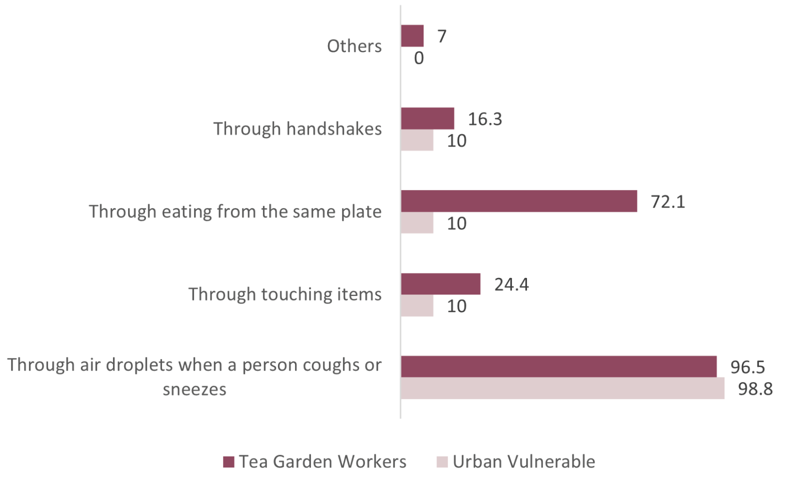


Figure 4.3: Knowledge of signs and symptoms of TB among HCWs

4.3.3 Knowledge of mode of transmission of TB

There were some reported misconceptions on the medium of transmission of TB among HCWs. For example, 72% of the HCWs working with TGWs reported that TB could be transmitted by eating on the same plate as a TB patient.

Figure 4.4: Medium of transmission of TB as per HCWs



4.4 TB-related Stigma Reported by HCWs

Data about the HCWs' perceived stigma towards PwTB/PwhTB was collected using a five-point Likert stigma dimension scale. If the participants' answers were 'Agree' or 'Strongly Agree' for any item of the scale, such as, 'Some healthcare workers are nervous about treating TB patients', then it was considered as the perceived stigma of the HCWs.

Almost all HCWs reported that they had perceived stigma of TB among their peers. We questioned them directly about their observed and experienced stigma. Around 6% of HCWs had observed stigma faced by other HCWs and only around 6% of HCWs had experienced stigma.

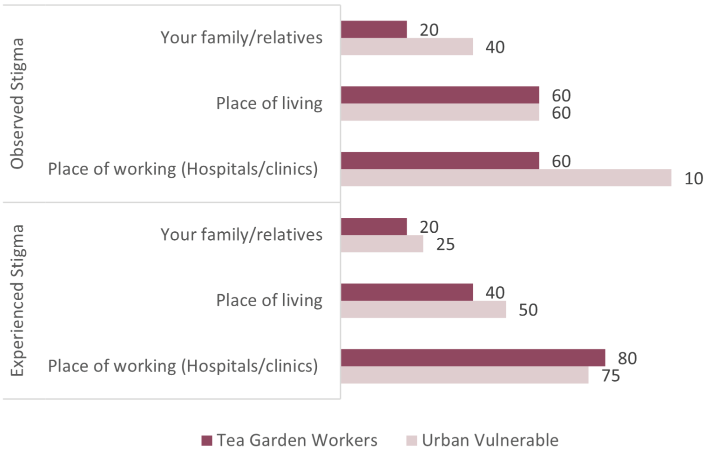
Table 7: Dimensions of stigma by vulnerable population groups

Dimension of Stigma	Urban Vulnerable	Tea Garden Workers
	Percentage (Sample)	Percentage (Sample)
Perceived Stigma	100 (80)	98.84 (85)
Observed Stigma	6.3 (5)	5.9(5)
Experienced Stigma	5 (4)	5.9 (5)

(Figure 4.5) presents the stigma experienced and observed by HCWs due to the nature of their work—i.e. working with TB patients. Of the total respondents who observed stigma, all HCWs providing services to the UV group were stigmatised at their workplace, whereas the figure was 60% for HCWs who served the TGW group. Around 60% of HCWs were stigmatised by their community members.

Similarly, more than 70% of HCWs experienced stigma at their workplace. More than 40% of them were stigmatised by people from their community and more than 20% of HCWs working with either group (UV or TGW) faced stigma from their family and relatives.

Figure 3.5: Stigmatisation among HCWs in different settings

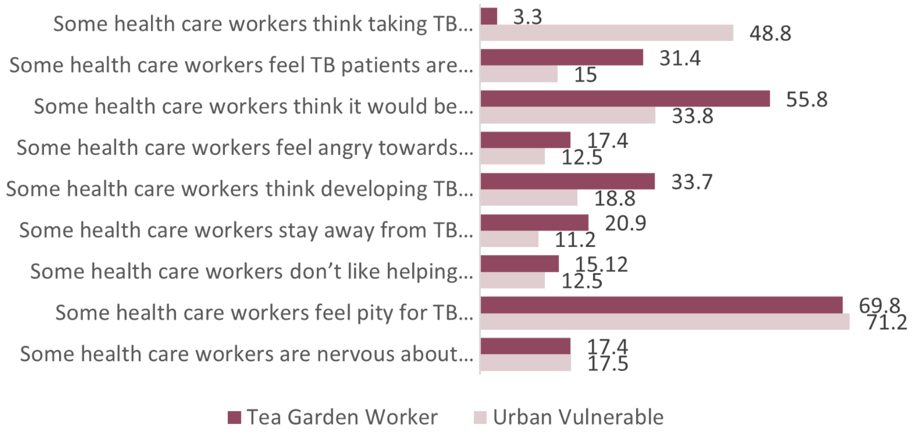


4.5 Dimensions of Stigma for HCWs

4.5.1 Stigma metrics towards PwTB/PwhTB by HCWs

(Figure 4.6) presents the various aspects of stigma exhibited by HCWs towards PwTB/PwhTB. A significant proportion of HCWs (around 70%) agreed that 'some healthcare workers feel pity for TB patients'. Further, 56% of HCWs working with TGWs agreed that some HCWs believed in isolating the patient during the intensive phase of the treatment, and 49% of HCWs working with the UV group agreed that some HCWs had considered forcing TB treatment if necessary. Around 17% agreed that some HCWs were nervous about treating TB patients.

Figure 4.6: Stigma towards PwTB/PwhTB by HCW



Section 2

Stigma among Vulnerable Communities (FSWs, PLHIV, TGs, and MSM)

1. Persons with TB or with History of TB (PwTB/PwhTB)

1.1 Characteristics of Participants during In-depth Interviews

The participants in the qualitative interviews consisted of female sex workers (FSWs), people living with HIV (PLHIV), as well as transgender individuals and men who have sex with men (TG-MSM), most of whom were below 50 years and spread across various social groups. Many of our participants had a recent history of TB (less than three years). In terms of education, there was diversity among the groups, with significant proportions having received no formal education or education up to the middle-school level. A smaller proportion of our participants held regular, salaried positions. Their living arrangements also varied - for example, while a majority of the FSWs (participants of the IDIs) lived with their families (seven out of eight), comparatively fewer PLHIVs and TG-MSMs did so. Most of the participants (19 out of 24) already had HIV.

Table 8: Characteristics of participants during IDIs

Characteristics		Groups		
		FSW	PLHIV	TG-MSM
Age (in years)	Below 30	1	3	2
	30–50	7	5	1
	Above 50			3
Gender	Male		6	3
	Female	8	2	
	TG		0	3
	Bisexual		0	1
	Kothi		0	1
Educational Level	No education	4	0	0
	Up to middle school (0–8)	2	3	1
	Secondary to pre-university	2	2	3
	Other courses	0	3	3
Type of Work	Regular job (salaried)	2	3	3
	Other jobs (sex work, daily wage, etc)	4	4	5
	Not working	1	1	0

Living Arrangements	Living alone/ Deserted or separated	1	3	2
	Spouse and/or children	7	5	5
	With other family members	0	0	1
Caste	SC/ST	2	6	2
	OBC	1	1	2
	Others	1	0	0
Religion	Hindu	5	6	5
	Muslim	0	0	0
	Christian	0	1	1
HIV Status	Yes	4	8	7
	No	2		1
Year of Infection with TB	Less than 5 years	4	8	5
	5+ years	4	0	3

Note: Some of the participants were not comfortable about disclosing their age.

2. Experiencing Tuberculosis

2.1 Knowledge, Understanding, and Stigma of TB

Most of our participants had never heard of TB before their own experience with the disease. However, some of the participants reported knowing about TB prior to their own diagnosis. Their knowledge and understanding of the illness were drawn from the experiences of other people, such as family members and acquaintances. Some participants had acquired significant knowledge about TB not only via their personal experiences but also through work.

Their initial response to the disease was predominantly characterised by fear and sadness. Some participants expressed fear, assuming they would die of the infection. One participant fell into depression after her maternal uncle succumbed to TB. Such fear was often fuelled by the misconceptions and myths surrounding the disease. One participant noted that people in her village believed anyone who contracted TB would die. These misconceptions and myths influenced the participants and spread fear among others who lacked any experience and awareness of the disease.

> I was young, and people would say TB was a major disease… that a person who got this disease would not survive. That led me to develop a negative opinion.’
> **- Female (FSW), Age 50**
>
> After the doctor told me (about the TB diagnosis), I felt scared. I was more afraid of it than of HIV.’
> **- TG (PLHIV), Age 28**
>
> I felt very sad thinking it might spread to the children.’
> **- FSW (FGD)**

The respondents' understanding and awareness of TB were very limited. Their lack of experience with the disease coloured how they viewed and understood the condition. They associated TB with visible symptoms like weight loss and extreme thinness; consequently, if someone appeared very lean and thin, it was commonly assumed that the person had TB. This perception reflects a prevailing misconception among the communities, as highlighted by one of the participants:

> If you are very lean and thin, you have TB. They do not know how TB is contracted, isn't it?'
> **- Female (FSW), Age 45**

After undergoing treatment, their knowledge and understanding of the illness increased significantly, and the fear and misconceptions eventually disappeared. Reflecting on their personal experiences, the participants noted a shift in their perspective. Some took the initiative to help spread awareness among other TB patients, motivating them and even accompanying them to the health facilities.

> Initially I felt sad to have got TB but now I am not scared. I will be taking others to get them admitted and cured.
> **- Male (MSM), Age 65**
>
> Earlier, they would say TB is not curable. Later, when they spread awareness that TB is curable, ASHA workers and Anganwadi workers would give tablets for TB.
> **- Male (MSM), Age 65**

From the narratives of our participants, we inferred that attitudes towards TB were better in the cities than in the villages, which is a credit to increasing levels of awareness and education. Our participants mentioned that people were educated and had more awareness in the cities, whereas people in the villages were uneducated and lacked awareness about the disease.

> The people's experience of the disease is limited, be it any disease. In the cities, people are educated and know about it (disease), whereas people in the villages many are uneducated and lack awareness.
> **- Bisexual (TG-MSM), Age 58**

Our participants mentioned that people from the cities were more aware of TB because they were exposed to awareness programmes, such as television advertisements on TB. This might be why there was less TB-related discrimination in cities than in villages.

> It (the attitude towards TB) is better in the cities because they have been showing it on TV and there is awareness. But in the village, even today and up to this moment, the old mentality prevails.'
> **- Female (FSW), Age 45**

The lack of awareness in the villages led people to believe TB resulted from wrongdoing and morally questionable behaviour, which led them to speculate about the patient's actions and pass judgment without understanding the mechanism of TB transmission. This extended beyond common stigma practices like avoidance and desertion, also manifesting as taunts and comments on the patient's character. The female participants highlighted this in the FGD. We inferred that the behaviour of the villagers was more nuanced than their simply questioning the moral integrity of the PwTB. Being female with an HIV infection would have certainly put female patients in situations where they were viewed as inferior and morally questionable.

> They say, "She has got that disease, don't know what she has done." And they do not think that it may have come through the blood. Many people think in the wrong way. I haven't done any such wrong things. However, people see us as inferior. They say, "She might have done wrong things, so she has got this disease." When they insult others, we feel they may insult and taunt us in the same way. In the village, they talk… They say, "She has gone somewhere and got this.
> **- Female (PLHIV)**

There were reported instances where the villagers had embraced the notion that individuals with TB had a limited lifespan, which led them to pity the patients and leave them alone. Family members, friends, and others in the village often adhered to this belief. This attitude of resignation and abandonment stemmed from misconceptions about the disease because they believed TB was incurable. Such misconceptions perpetuated a sense of hopelessness, and the patients were left on their own without proper support or access to treatment.

> They will give up on the patient saying "Aiyyo! That person has this disease. How long will he survive? Let him eat and drink whatever he wants for however many days he is alive." And they will leave the person like that. I have seen two to three cases in my village where this happened.
> **- Bisexual (TG-MSM), Age 58**

One participant said that even when someone attempted to intervene and offer guidance on the importance of proper care and treatment, their efforts were often met with resistance. Our inference is that people resist initially because they think all their efforts towards PwTB would be in vain. Despite brief moments of receptiveness, the prevailing belief in the inevitability of the disease's outcome returns and they again resign themselves to fate and to the patient's wishes.

> 'If we tell the family members, they say, "This person will advise us and go. Will he stay here and look after us? He will be in Bangalore." They will follow the advice for one or two days.'
> **- Bisexual (TG-MSM), Age 58**

2.2 Experiencing TB at Different Periods

Our participants highlighted that earlier there used to be a lack of awareness about the cause and mode of transmission of TB, which led to more stigma around the disease. People were hesitant to interact with TB patients, fearing potential transmission of the illness through physical contact or proximity. This fear of contagion resulted in TB patients facing social isolation and discrimination, and therefore preferring not to disclose the illness.

> 'In those days people would treat TB patients differently. They hesitated to touch them, to touch their clothes. They used to think "If we go near them we may also get it". So keeping this in mind, I thought why should I reveal my condition? I did not reveal it to anyone.'
> **- Male (TG-MSM), Age 55**

Gradually, the stigma and myths surrounding TB are decreasing thanks to increasing awareness about the illness. As highlighted by one of the participants, despite the prevalent stigma about the illness, the understanding that TB is a curable disease, along with awareness of its symptoms and where one should go for treatment, has increased over time, leading to a change in people’s attitudes.

> When my brother was infected, nobody - neither his wife nor his children - would do anything for him. Nobody behaves like that anymore. They might maintain a distance while speaking and they might keep their plates separate, but there is a lot of awareness now. Now if the cough does not reduce even after 15 days, then they go and get the sputum test done. They were not doing this earlier.
>
> **- Female (FSW), Age 50**

> Now I know where they give medicines for TB. I know it can be cured and that it is not the worst disease. I have the mental strength now. Earlier I was scared of hospitals, but now I do not have fear of TB or cancer, I am not even scared of HIV because there are medicines for all diseases.
>
> **- Female (FSW), Age 42**

2.3 Treatment Adherence

The treatment for TB requires the necessary adherence behaviour, which includes adhering to the full course of medication and healthy behaviours such as abstaining from alcohol consumption and consuming nutritious food. Adherence was a challenge during the course of treatment. However, most of our participants adhered to the prescribed treatment even though they struggled and faced challenges in accessing and consuming the medicines.

Earlier, TB medicines were provided only to the patient. Family members could not collect the medicine on the patient’s behalf. This was another challenge for the patient in terms of medication adherence. If the patient started working again while on medication, accessing and consuming the medicines became a problem. One participant, who had TB in 2012, shared his struggle to collect medicines, especially while working. First, owing to the stigma attached to the disease, an individual could not reveal their condition at their workplace as they might lose their job. Additionally, working while infected took a physical toll, making the individual feel very weak, and persistent coughing caused others to look at them in an insulting way. Second, while at work, they had to take leave to go and collect the tablets. This proved difficult as the person needed to come up with excuses to visit the health facility and collect the tablets every month.

> When I went every month to take the tablets they would ask, “Why are you going every month? What is the matter?” I somehow managed by saying there was some function like a naming ceremony or that someone had died. In this way, I would create excuses for two hours at my workplace. I would say I have important work and return to work after collecting the tablets.
>
> **- Bisexual (TG-MSM), Age 58**

TB weakened the patients both physically and mentally, which was why they could not always go to the hospital to get the medicine on their own and sometimes would even forget to take the medicines. Later, family members were permitted to collect the medicines on behalf of the patient, which helped them adhere to the medication course.

> I became weak. I would get tired. My mother would go once or twice a week and bring the tablets. I had not taken it for around two days as I was feeling exhausted and had become very weak. Then my mother reminded me and gave me the tablets.
> **- Female (FSW), Age 30**

There were follow-ups by healthcare staff who visited patients at their homes to administer medication and provide other relevant instructions. However, the patients believed this could have led to other problems for them and their families. Owing to the stigma attached to the disease, the perceived fear of discrimination and stigmatisation led many PwTB to refrain from revealing their disease status to community members, friends, relatives, co-workers, and sometimes even their family members. They were afraid that if HCWs visited their homes, everyone would come to know about their illness, which would affect their social and personal lives. Therefore, they chose to go to the health facility and take the tablets there.

> I told the healthcare workers not come to my house, that if there were any problem I would contact them directly. If they come near my house do you know what will happen? If they come when my relatives are there, if they say "We have come from such and such hospital or NGO to meet this person," they (my relatives) will ask all kinds of questions.
> **- Bisexual (TG-MSM), Age 58**

There were instances where individuals were unable to consume the medicines because they needed to consume many tablets; their body had not yet adjusted to so many tablets. They would feel tired, dizzy, and sometimes vomit when they initially started the medication.

> While taking the tablets I felt an uncomfortable sensation in my stomach… We do not get good food. No one gave me good food.'
> **- Female (FSW), Age 40**
>
> I was feeling sad as I had to take seven to eight tablets each day. It (the medicine) was somewhat bitter.'
> **- Female (FSW), Age 30**

The span of the treatment and the side effects from the medicines led to sadness, emotional distress, and sometimes non-adherence as well. Patients would throw away the medicines rather than consume them due to the discomfort caused by the taste, quantity, and mental distress, which led to a worsening of the disease. The following accounts from our participants capture their plight very effectively:

> No human being should undergo such pain. I needed to take five tablets every morning. I could not be active the entire day because they made me so tired, but we have to take the tablets to be cured of TB. We feel very tired, there is nausea sometimes, and we feel like vomiting but are not able to vomit.
> **- Male (PLHIV), Age 30**

> I was mentally upset during my hospital stay. I did not sleep all night for six months. I had vomiting. I took the medicine every day for 15 days, and then I stopped taking it because I felt a lot of discomfort and my symptoms worsened. My daughter scolded me and made me swallow the tablets before going to work. I used to tell her, I won't take the tablets, I will throw them away. And I threw them too. If my daughter asked I said, yes, I took the tablets.
> **- Female (FSW), Age 34**

The relentless discomfort and emotional distress caused by their illness led to a deterioration in their mental health and sometimes to suicidal ideation. The medication and pain sometimes made them question the very meaning of their lives. Some of our participants expressed profound despair and questioned the necessity to continue living amidst this burden of medication, pain, and stigma surrounding their illness. Experiences of stigma, scrutiny, and gossip worsened their mental health. One participant spoke about how relatives and people from his community intruded upon his daily life with unsolicited questions and advice on his condition.

> I had given up on life. I felt, do I need this life? Should I live? Should I live taking so many tablets? Should I live bearing all this pain? Someone asks my family members, "Why is he like this?" Relatives ask, "Why is he like this? Is he not well? Why didn't you take him to the hospital?" We cannot share everything, isn't it?
> **- Bisexual (TG-MSM), Age 58**

The discomfort due to the medication, its side effects, and physical exhaustion were reported by the participants. We inferred that they faced challenges during their treatment which were not directly associated with stigma but that the stigma of TB restricted these participants from sharing their agony and what they were going through even with their close ones. In the absence of stigma, they would have shared their feelings, struggle, and pain with their friends and family, and that would have alleviated their hardship during the treatment process.

One participant noted that the daily struggle restricted their social life. The social isolation, desertion, and poor treatment by family and friends brought more sadness and led to thoughts of self-harm. Despite their personal struggle, their social and familial responsibilities compelled them to complete the treatment, underscoring their resilience and determination for the sake of their children.

> It hurts mentally. It hurts as much to die. Why did God give me this disease? I cannot touch anyone, cannot talk to anyone, and others do not eat the food left by me. I feel very sad. I wonder why we have to live. I want to harm myself and die but I have to live for the sake of my children.
> **- Female (FSW), Age 50**

Adherence was also affected by the discomfort and side effects of the medication. Non-adherence to medication and unhealthy behaviour during treatment can lead to death as well. One of the participants recalled that adherence was manageable when the patient received moral and emotional support, but when the support disappeared, the patient discontinued the treatment, returned to their regular working and drinking habits, and succumbed soon after.

> My friend had TB. He would say: I do not want this tablet. This happens, that happens. I would say: I will talk to you if you take this tablet; otherwise, I will not talk to you. Somehow, I made him take the tablets for three months. Then his family members said something to me so I left at that point. After that, he stopped the medicines and recovered a little. Then he went to work saying he felt fine and started drinking. Within one month of starting to drink, he expired.
> **- Transgender (TG-MSM), Age 37**

The data reveals that postponement, discontinuation, and delaying medication could increase the severity of the disease and sometimes lead to death. Similar findings have been documented in past literature as well.

2.4 Importance of Family and Social Support

Strong family and social support are crucial during TB treatment, which lasts for six months. While everyone who is infected with TB tends to struggle, the challenges become more pronounced among individuals from vulnerable groups. These groups are at a higher risk of TB infection due to the nature of their work. Although the level of vulnerability among these groups is similar, the support they receive from family and social networks varies. As a result, individuals within these groups experience TB differently from one another.

Our study participants consisted of eight members from vulnerable groups such as FSWs, PLHIV, and TG-MSM. Only one FSW, two TG-MSM, and three PLHIV participants were living alone.

> I have seen that when I was in Rajiv Gandhi Institute of Chest Diseases. Among non-community members, if the husband has TB, the wife takes care and if the wife has it, the husband will take care. Or their children will take care. They have their husband and wife and children and others who will take care of them. Who is there for us? Who will take care of us? We have to take care of ourselves.
> **- TG (TG-MSM), Age 37**

TB affects the physical, mental, and economic well-being of the individual. We found that all PwTB/PwhTB had suffered physically and mentally during their treatment. Since the treatment for TB is a six-month course, support systems become crucial, whether family support, social support, economic support, or even emotional support. The support system works parallel to the medication and has a strong positive influence on combating the disease and the stigma around it.

> Today I am alive only because of my wife taking care of me.
> **- Male (PLHIV), Age 49**

Family support had a very positive impact on TB treatment. However, in some cases, the patient's family members were not supportive. One of our participants, a transwoman, shared how family members sometimes hesitated to offer support, fearing the spread of the disease to others. Having a TG identity was already associated with social stigma. The person had already left their home because social and family norms at their native place did not accept their TG identity. There was also apathy among their family members towards them. Financial assistance or gestures of care were met with suspicion, which further isolated the individual with TB.

> If they would have gone and given money to their parents and said I have TB, then they would take the money and send him back saying, "You go, others will also get it." They will even say, "You gave the money, isn't it? You go now.
> **- Transwoman (TG-MSM), Age 30**

Patients with TB often faced discrimination and stigma, even from those they interacted with daily. People would appear friendly and polite in their presence, but once they left, the conversations would take a different turn. Remarks such as 'Be careful, he/she has TB' would be whispered behind their backs, adding to the stigma surrounding the disease. For marginalised communities, such as TG individuals, experiencing discrimination based on their self-identity exacerbates the challenges of dealing with illnesses like TB.

> 'When they (patient) are there, they will speak nicely. However, after they leave, they will say, "Aiyyo! Be careful. He/she has TB, this and that." If people like us get any disease, be it TB or HIV, it is more painful than it is for others, given our self-identity as TG.'
> **- Transwoman (TG-MSM), Age 30**

2.5 Economic Aspects of TB

The evidence from various research studies strongly suggests a close link between TB and poverty (Kaulagekar & Radkar, 2007). Most of our participants were working-class individuals who sought treatment from the government health facility. One participant who was working with HIV and TB patients through an organisation shared his observation:

> I have seen the clients in the hospitals. Those who have had a TB attack (are all from) very poor families only. Poor people can only do labour to earn their livelihood. Rich people are very few. That is because the rich have a good lifestyle. Only those who are poor and labourers come there.
> **- Male (TG-MSM), Age 58**

This observation is in line with what various studies have identified. Individuals with a history of TB were predominantly from impoverished backgrounds. The studies noted that such people typically engaged in labour-intensive work to sustain themselves due to financial constraints. In contrast, wealthy individuals were rare in hospital settings, as they generally led affluent lifestyles and were less likely to be afflicted with TB. Thus, the hospitals primarily served individuals from economically disadvantaged backgrounds who relied on manual labour for their livelihoods.

TB had a profound impact on the financial well-being of individuals. The extensive treatment duration meant that the affected individuals were unable to work due to the physical and mental toll of the illness. Furthermore, the stigma associated with TB exacerbated the situation, leading to increased social isolation and financial hardship. One participant recalled how the financial strain caused by TB left her vulnerable to desertion and social isolation, as community members feared she would request financial assistance. Many held the misconception that TB patients were constantly seeking financial aid, which resulted in their avoiding interactions with those affected. Such avoidance persisted even when tangible support, such as financial aid or emotional encouragement, could have significantly improved the patient's circumstances.

> ‘People think, “If we talk to her she will discuss her problem and ask us for money. Where will we get the money?” They think in this way and avoid me. When I was hospitalised for six months, not a single person came and gave me 50 rupees or 100 rupees and helped me. My daughter used to go hungry. I would eat the food given in the hospital, but not my daughter… We asked for money to pay the rent and so people avoided us thinking we will ask for money. They do not talk to me. They say, “She is always pestering us for money saying that she is sick.” They say this and avoid talking to me. Maybe the reason is that I had TB. They might have thought that they too may get TB, so maybe for this reason they did not come.
> **- Female (PLHIV), Age 34**

2.6 Knowledge and Benefits of Government Schemes for TB patients

To understand the participants’ knowledge and awareness of government initiatives addressing TB, the study enquired whether they had benefited from any such schemes or programmes.

We found a lack of awareness about government schemes such as Nikshay Poshan Yojana (a DBT scheme), particularly among FSWs. None of the FSWs were familiar with this and other government schemes. However, during the FGDs, three participants mentioned recently learning about DBT schemes that provide Rs 500 a month to TB patients.

Among the PLHIVs, six out of eight individuals had some knowledge about DBT schemes, and one participant had availed benefits from the Gruha Lakshmi Yojana, a state-sponsored scheme offering financial support to female-headed households. Five individuals, including two TG individuals from the TG-MSM group, had knowledge about such schemes and had availed the services as well.

Overall, 12 out of 24 participants had knowledge about schemes for people with TB, but only one participant claimed to have received money (Rs 500) through the DBT programme.

3. Interaction of Vulnerability and Stigma

Self-identity aggravates the stigma experienced by individuals. Here, stigma takes a different route to impact the individual’s social, economic, and personal lives. This was more visible in the context of stigma.

	No. of Participants	Perceived	Experienced	Observed
Female	10	7	5	6
Male	9	4	3	6
TG/MSM	5	5	3	3

The above table does not offer any rate or prevalence of stigma within these population groups but it is compiled from the narratives on TB and stigma. We found that the extent of stigma in the narratives of these groups varied significantly.

Seven out of 10 female participants talked about perceived stigma, five of them admitted to having some experience of stigma, and six of them had observed other PwTB being stigmatised. Out of a total of nine male participants, four spoke about perceived stigma, three shared their experienced stigma, and six had observed it in others. The rest of our five participants - two TGs, one transwoman, one bisexual male, and one kothi—spoke about perceived stigma. Three of them shared their experience of stigma and three had observed stigma expressed towards other PwTB. The reasons behind the differences in the reporting of stigma is more nuanced than it seems.

We observed that males (irrespective of being PLHIV or MSM) reported less experienced stigma than females, and females reported comparatively less stigma than TG/MSM.

TG individuals and MSM reported the highest levels of experienced stigma and perceived stigma, followed by females. These differences can be credited to 'visibility is vulnerability' narratives when it comes to social stigma. Stigmatised attributes such as race (presented through dressing, mannerisms, etc.) can be easily identified and are difficult to conceal, allowing society to differentiate and stigmatise based on the visibility of the person (Ahmedani, 2011).

3.1 Layers of Vulnerability, Economics, and Stigma

Experiencing stigma can be different for different groups of people. When stigma intersects with socio-economic factors such as caste, work, and education, individual factors such as sexuality and gender, living arrangements, and social support, and health factors such as HIV infection, it becomes more layered. One of our study participants, a TG person, remarked how TB would be a different experience for other people.

> In the non-community, they will (openly) say they have TB. They need not fear anything if anyone has TB. TB and HIV are common now. Some of them have forgotten about it (the stigma).
> **- TG (TG-MSM), Age 37**

3.1.1 Transgender and MSM

Even among the vulnerable groups, TG-MSM, and PLHIV have some distinctive features. One group can be more closeted than the other. For some groups, it is easier to maintain their profession in a less visible way than it is for others. Thus, the prospect of TB stigma, coupled with stigma due to their profession and their identity as FSWs, TGs, MSM, or PLHIV leads to variations among these vulnerable groups. We found that that FSWs, for example, were able to conceal their identity as sex workers to avoid discrimination. On the other hand, TG individuals and MSM often faced immediate judgment because of how they looked or who they were. People would have stereotyped images of TG individuals and MSM.

> Some of the FSWs maintain themselves in such a way that nobody will come to know about it (their profession). However, as soon as people see them (transgender), they think these people are for that purpose only. It is the same with MSM as well. What happens among MSM is that sometimes their identity is known and sometimes it is not. This is more because the clients will not go to them.
> **- Male (TG-MSM), Age 65**

Therefore, when TG individuals or MSM contracted TB, the stigma was greater. An FSW often has a family, is less visible to 'common' people, and has comparatively more social support from family and friends, but that is not the case for TGs and MSM. The TG individuals and MSM who participated in this study resided and worked in their own communities and groups, which provided them with social support and a community feeling. As one participant who was working in a restaurant said:

> Everybody there (workplace) is from my community. They help each other and share amongst one another, saying "You do this and I will do that," chatting and playing. Because of that, I did not realise how time went by.
> **- Transgender (TG-MSM), Age 37**

However, the communities they lived and worked in (such as the hamam, where TGs resided with their guru, a senior member of the community and a sort of patron) became discriminatory and less empathetic once someone was infected with TB. One participant, who was working as a counsellor, highlighted that gurus and colleagues would tell clients and others not to visit and/or socialise with the PwTB. They would inform clients that the person had TB or HIV, thus creating a cycle of exclusion and prejudice.

> When there is an organisation like a hamam, more discrimination will take place there. The gurus will start telling others "Do not go to her, do not sleep with her, and do not mingle with her." They will also tell the clients that she has TB, she has HIV.
> **- Male (TG-MSM), Age 65**

Most of the TG individuals who reside in hamams had left their parental homes and come to live with the community because they had no social support, faced discrimination at home, and did not have many friends. One participant said that if these people were sent back home during their TB infection, there would not be anyone to look after them.

> Sadly, there will be nobody to look after them at their home. They would have left their house and come here because of discrimination. They will not have many friends either and certainly not in the TG community.
> **- Bisexual (TG-MSM), Age 58**

Sometimes, separate accommodation was arranged for PwTB or they were sent back home till they recovered. Following their recovery, they were sent to a different hamam.

> They will not keep the people with TB there. They will either send the person home or arrange separate accommodation. Once their treatment is complete, they will send them to a different hamam.
> **- Kothi (TG-MSM), Age 43**

The TGs and MSM were thus compelled to change their living and working places even after recovery. Since the TGs did not have many friends, shifting to a new hamam also meant losing a peer group. Further, as reported by one participant, the new hamam was not informed about the person's disease history. That could bring a sense of insecurity as to what would happen if people at the new place came to know about their history of TB. Such inconveniences, especially after recovery, were not reported by other vulnerable groups such as FSWs and PLHIV.

> They will join different communities because people here know that this person has TB. But the others don't know that this person has TB. They think that this person was here all these days and they will take him.
> **- Kothi (TG-MSM), Age 43**

Further, if a client was attended to by one of the PwTB/PwhTB at a hamam, other workers would not attend to that client. In this way, other members at the hamam would discriminate against the client by limiting the number of attendees he had access to simply because he was attended to by a person with TB. This behaviour would further hinder the earning ability of PwTB for if their clients were discriminated against, it was very likely that they would not go to the infected person again.

> If I had attended to a client and he visited a second time, nobody else would attend to him. That is how they discriminate.
> **- Transgender (TG-MSM), Age 28**

TG individuals and MSM, often abandoned by their families, were vulnerable to contracting TB and HIV, much like FSWs and PLHIV. Furthermore, their living arrangements and challenging work conditions made them more susceptible to the disease. In particular, the intricately layered working and living conditions of TG individuals made them more vulnerable than FSWs and PLHIV, as the other groups did not go through such experiences.

3.1.2 Female sex workers

When FSWs were infected with TB, their experiences and struggle during treatment were different from those of other vulnerable groups. The major challenges for FSWs were in terms of financial support. A TB infection weakened their body, and clients asked why they had become so lean and thin. Since their body became weak, they could not work, and that affected their income.

> FSWs become weak when they have TB. Clients know how we were in the beginning and how we change physically if we fall ill. They ask us, "Do you have any disease? Why have you become like this?" They leave us and ask for another woman. FSWs fear that customers will leave them and go.
> **- Female (FSW), Age 50**

The physical toll of the illness made them visibly weak and thin, resulting in negative perceptions among their clients. Their body would become so weak that they could not perform sex work and, as a result, lost out on income. This posed threats to their livelihood, adding another layer of stress. Further, due to income loss, they were unable to eat nutritious food, which was necessary during a TB infection. Many FSWs were entirely dependent on their daily earnings, which left them vulnerable in times of illness like TB. Further, during the FGDs, our participants mentioned that FSWs often did not have any savings and they lacked financial stability, which was again a challenge.

The absence of a support system exacerbated their plight. Unlike FSWs with families that could provide care and assistance, those without familial ties faced isolation and neglect. Under such circumstances, managing TB became immensely difficult. An FSW who was already infected with HIV required healthy and nutritious food. However, if they were living alone, they often did not cook for themselves, consuming unhealthy food from outside instead. This had a negative impact on the ongoing treatment.

> It becomes very difficult if a FSW gets TB. Most of them do not have any savings. They will spend everything that they have earned on that day. Some of them would have left everyone and come on to the road. Life can be very difficult for such women.
> **- Female (FGD-PLHIV)**

> There will be no one to take care of her. She will have financial problems as well. If an FSW has a family, the family members will take care of her. They will not have to cook for themselves alone and eat unhealthy food from outside.
> **- Female (FGD-PLHIV)**

Stigma and discrimination due to TB at the workplace is prevalent and this study found similar results as well. Individuals who cough often face cautionary reactions from their colleagues. This caution extends to public transport, where people tend to move away from someone who is coughing. This phenomenon is more pronounced in domestic work settings compared to factory environments due to the close proximity to households and families. Domestic workers are primarily female, and many of our participants were engaged as domestic workers. FSWs who worked as domestic help encountered heightened stigma and precautionary measures at their workplace.

> If someone is coughing at their workplace, people get cautious. Even on public transport, people move away from you if you cough. This is more prominent in domestic work settings, rather than while working in factories. This aspect disproportionately affects women who are working as a domestic help.
> **- Female (FGD-FSW)**

3.1.3 People living with HIV

TB is closely associated with HIV. Published research has already covered how the presence of HIV makes TB stigma more severe as it gets linked to other disvalued characteristics of HIV. TB stigma may occur because an affected individual's community believes he or she must have done something to deserve to be infected (Courtwright & Turner, 2010; Mak et al., 2006). One of our participants, an FSW living with HIV, shared her experience of heightened stigma due to her dual status as a sex worker and an HIV-positive individual.

> They look down upon it. They look down more upon HIV. They say, "A sex worker has gone to everybody to have sex. They themselves have caused it (TB). She was not going to only one person. She has gone to several men and she has got the disease from everybody." They don't know how one gets TB, isn't it?'
> **- Female (FSW), Age 45**

Another participant shared a similar experience, explaining how difficult life becomes when an individual with HIV is infected with TB. When someone was diagnosed with both TB and HIV, there was a notable difference in how society treated them. Upon disclosing their dual diagnosis, many people tended to distance themselves and the patient lacked support.

> Those with HIV have more problems. Their immunity is compromised. There is a lot of difference in how people treat them when they have both TB and HIV. If they know that we have both TB and HIV, half the people go away. They do not support us.
> **- Male (PLHIV), Age 49**

The presence of HIV significantly altered perceptions of and treatment received by individuals, leading to differences in societal attitudes and support levels as well as to avoidance and desertion.

4. Stigma and Its Dimensions

The different dimensions of stigma (perceived, experienced, and observed) varied for each group. Perceived stigma was reported by PLHIV the most, followed by FSWs and TG-MSM. Seven out of the eight participants from the PLHIV group reported their perceived, experienced, and observed stigma. Only four out of eight participants from the TG-MSM group mentioned the perceived stigma related to TB. Furthermore, only one participant spoke about the experience of stigma, whereas six out of eight participants talked about their observation of stigma towards other PwTB. Six out of eight FSWs reported their perceived stigma related to TB, five out of eight FSWs talked about their experience of stigma, and five of them mentioned having observed stigma towards other PwTB.

Overall, PLHIV reported the highest levels of perceived, experienced, and observed stigma, followed by FSWs. The TG-MSM group reported relatively low TB stigma.

4.1 Observed Stigma

As our participants discussed the various dimensions of stigma, the pervasiveness of observed stigma became obvious. Observed stigma was responsible for shaping perceptions about how PwTB were treated by society in general. The individual had observed others being stigmatised and discriminated against because of their illness and this observation led them to believe that they would face the same fate if people came to know about their illness. Thus, this was the reason behind the perceived stigma.

One participant observed that if people did not know about their TB status, they would not stigmatise the person and would treat them normally; but as soon as they came to know about the person's TB diagnosis, their behaviour would change. The participant recounted how her neighbour, a migrant from a different state, was ostracised and forced to vacate his house due to his TB status. This observed stigma fuelled her apprehension about revealing her diagnosis. The community's attitude towards TB cases instilled a sense of dread in her. The fear of facing similar treatment if she were to disclose her own TB status weighed heavily on her mind, highlighting the profound impact of observed stigma on her perceived vulnerability and emotional well-being.

> “If people come to know that someone has TB they keep the person at a distance. They do not use the same plate to eat food. If they do not know, then they are silent and treat them like a normal person. My neighbour had the disease, he is a Hindi-speaking person, and people from the community made him vacate his house and sent him away. I feel sad that they may treat us in a similar way if I reveal my condition.
> **- Female (FGD-PLHIV)**”

Observed stigma led PwTB to maintain secrecy about their illness. One participant noted that due to the stigma, PwTB were motivated to maintain secrecy about their illness and, in order to maintain this secret, sometimes there was fear and hesitation to even start the treatment or follow up for medication because others would come to know about their illness once they visited the treatment facility. This highlighted a fear among individuals seeking TB treatment - that they might be seen by their neighbours. This fear often led to hesitation in accessing medication, with some individuals providing false reasons to conceal their true intentions. Despite their reluctance to disclose their motives, it is apparent that many sought treatment for TB. This observation underscores the significant impact of social stigma surrounding the disease, which can hinder individuals from seeking the necessary medical care.

> Some people are afraid to go and get tablets because they worry their neighbours may see them… A few hesitate to take treatment. I have seen most of the people, and if I ask them they give other answers, but I know that if they go to that room they have come for TB treatment only.
> **- Female (PLHIV), Age 30**

> My mother was not allowed inside the house; she was made to sit outside the house by my husband. She was given a separate plate; we did not eat on her plate. She had a separate glass, separate clothes. Even the bathroom was separate and a separate soap was provided. I thought similarly and did not allow my daughter to touch me but the doctor told me that TB was different. Now I feel sad for treating my mother like that. We were helpless; we had to listen to whatever my husband said.
> **- Female (PLHIV), Age 37**

One of our participants narrated how stigma could be practised covertly. Reflecting on her observation of healthcare facilities, she spoke about how healthcare personnel resorted to stigmatising behaviour. They did not say anything directly to the patient but once the patient left, they would tell others about their TB diagnosis and warn them to be 'careful because the patient has TB'.

> Discrimination definitely exists. It exists in my community. They (healthcare personnel) do a lot of discrimination. When the patient is there, they will speak nicely. However, after they leave, they will say, "Aiyyo! Be careful. He/she has TB, this and that.
> **- Transwoman (TG-MSM), Age 30**

Furthermore, in some scenarios, there was observed stigma and perceived self-stigma even as the PwTB internalised their fear and negative self-esteem due to the illness.

4.2 Perceived Stigma

Perceived stigma related to TB was the most prominent kind and it spread through every aspect of their lives. The participants perceived that they would be stigmatised not just by the community members and their co-workers but also by their friends, relatives, and family members. Gossiping, teasing, and verbal abuse were the most common forms of perceived stigma. The emotional and psychological toll of the stigma was even more debilitating than the physical effects of the disease.

Keeping one's illness secret was often a psychological trauma owing to the fear of facing social stigma and verbal abuse from others in the community and of perceived stigma related to TB. Our participants highlighted the significant impact of societal discrimination on individuals who were already struggling with illness.

> If they could get cured by taking medicines without revealing their condition to others, then it was good. If it was made public, that was it! People torture with words and kill. If the disease is one part, the torture makes it 10 parts.
> **- Female (FSW), Age 42**

Thus, while the disease itself might have posed challenges, the additional burden of social persecution amplified the suffering exponentially. This insight sheds light on the importance of fostering a compassionate and understanding community that supports individuals through their health struggles, rather than adding to their distress through judgment and mistreatment.

> I did not share with anyone because there are people in my friend circle who discriminate behind our backs. They crack knuckles, they make signs, and tease us. We feel insulted, but we do not care.
> **- Bisexual (TG-MSM), Age 58**

This fear of the spread of information about their disease status and the subsequent societal rejection was obvious from the participants' narratives.

> We must not tell our neighbours. If we light a small firecracker, it will go up into the sky and burst, will it not?
> **- Transgender (PLHIV), Age 37**

Perceived stigma manifested through gossip, teasing, verbal abuse, avoidance and desertion, and the absence of shared meals. People from the community, friends, and relatives would gossip about the infected individuals as well. PwTB also feared that people would tell others about their illness, thus exposing them to discriminatory treatment.

> If I tell my college friends, then the way they look at me will be totally different. Along with that, they might say, "Aiyyo! He has TB it seems.
> **- TG (TG-MSM), Age 28**

> If I say it in my friend circle, they will look at me in a discriminating way. (They will say) How did he get it? Even if I have TB, they will not hesitate to add some more things to it and tell others. They will say "Aiyyo! He has TB. Tomorrow he might even get HIV," and they will go away from me.
> **- Kothi (TG-MSM), Age 43**

The perceived stigma was so strong that sometimes individuals were hesitant to share information about their illness with not only their friends and community members but also their family and even their spouses. One participant explained why he did not tell his wife about his TB condition:

> I did not tell her (my wife) because then it will spread from one person to another. They will spread the news and speak tauntingly and in a hurtful manner. I am already very hurt and upset. It will be even more upsetting.
> **- Male (PLHIV), Age 34**

Fear of spreading the news about their illness thus prevented the patient from disclosing his illness status to even his spouse. He was afraid of being subjected to the stigma once others knew his status, which could increase his suffering and pain.

Stigma not only affected the PwTB but also their family members and caregivers. The participants mentioned how their family members did not reveal their illness status and that they forbade people from disclosing the diagnosis to anyone. This behaviour was deeply rooted in the perceived stigma around TB.

> My mother-in-law did not reveal it to anyone because if people come to know they may act differently and they will gossip about her having TB.
> **- Female (PLHIV), Age 30**

The discrimination as observed by one of our participants led him not to disclose his daughter's TB status to her husband's family. He highlighted that TB stigma attached to a patient throughout their life. People discriminated against PwTB even after their recovery. Since his daughter would be in her husband's house (in-law's) house, he did not reveal her condition and kept her with him throughout the treatment.

> We did not tell my daughter's family that she had TB because they would give her a separate plate and keep her clothes separately. They would do all this and the stigma would be there lifelong. Since my daughter lives in another's house, I did not reveal her TB status.
> **- Male (PLHIV), Age 65**

One of the participants shared how her daughter did not like her sharing the news of her illness with others, even with the other family members.

> My daughter told me not to reveal it to anyone. She scolded me if I did so. She said, "Why must you reveal it to others? What are we going to get by revealing it to others? Will they come and help us in difficult times?
> **- Female (PLHIV), Age 34**

A similar narrative was shared by another participant, who expressed fear that her sister would have avoided her had she come to know about the illness.

> If my sister had come to know, she definitely would not have come to my house thereafter. Nobody will give support. Nobody will allow us (PwTB/PwhTB) to come near them. There is a fear within, thinking that people might discriminate against me if they come to know that I have TB. If people come to know, then the patient could lose his/her honour.
> **- Female (FSW), Age 45**

4.3 Experienced Stigma

Experiencing stigma due to disease status is very common. Our participants reported witnessing discriminatory attitudes such as self-overprotective behaviour, along with comments and remarks on their physical appearance by people from their community, co-workers, and even by bystanders at public places and on public transport like buses.

> It could be a normal cough itself. But it will not stop. It might stop if we drink some water. But by that time… we feel like getting down from the bus because people on the bus are looking at us in that way.
> **- Male (PLHIV), Age 65**

> If we cough, they do not come near us. Rudely they say, “Hey, wear a mask or tie a handkerchief.” If we cough loudly, they signal with their eyes and mouth that he has TB and do not go near him.
> **- Bisexual (TG-MSM), Age 58**

The stigma does not go away even after being cured of the disease. Since people know that the person had TB, even if there was a normal cough, people would look at them differently.

> Though I am cured, that tag is still there that (she) had TB. Even though I am cured, that label will not go away. And if I cough, I look around me, and people will cover their faces and go away… I have experienced all these stigmas.
> **- Female (FGD-FSW)**

Many of our participants reported experiencing stigma in their families. The most common form of stigma in the family is the segregation of utensils and living arrangements. In addition, there were reported cases of withdrawing care and support from the infected individual during treatment.

> They discriminate because TB is an infectious disease. Some of them don’t accept the patient even at home. They will not take anything from our hands and eat. They will not allow us to cook. They keep us at a distance. Then if people in the neighbourhood come to know, it is even worse.
> **- Female (FGDFSW)**

> When I had fallen down, nobody… not even my mother or sisters or brothers took care of me. Only my friend took care of me.
> **- Transgender (PLHIV), Age 37**

Instances of stigma were also experienced at health facilities during the course of treatment. The stigma took the form of maintaining distance from PwTB and there was often too much emphasis on precautionary measures among the staff.

> They say rudely, “Whatever disease they may have we too may contract it.” Yes, most of the people have spoken rudely in front of us. When the mask accidentally rolled down and we coughed, then people close by would tell us rudely to wear the mask. They would say, “What you have may spread to us so wear the mask.” We cannot do anything, so we have to wear the mask.
> **- Female (FSW), Age 50**

> They will say, “See, she is working in this community and she herself became positive. They give us awareness and they themselves are not aware and they have not followed it (the precautions), isn’t it?
> **- TG (TG-MSM), Age 30**

Our participants highlighted the profound impact of stigma and how it hampered their adherence to treatment and affected their mental health and social wellbeing. Many of the participants shared that their motivation to complete the treatment despite facing emotional and social turmoil was their children and families. Initially, they were afraid of dying of TB and wondered what would happen to their children and family. In one case, our participant shared that her determination and resilience towards the treatment was because of the stigma she had faced due to this illness. Her resolve was fuelled by a profound desire to achieve full recovery and demonstrate to those who had discriminated against her that she would not succumb to the disease. A few have taken the experience of stigma as self-motivation and pushed themselves to adhere to the TB treatment and get cured. This sentiment underscored the impact of stigma on the individual's journey towards healing. Their determination to persevere and attain full health in the face of discrimination exemplified their resilience and strength in adversity.

> I am ready to take the tablet for another year. But I want to cure myself fully in front of those who have been discriminatory and show them that I am not dying from TB.
> **- TG (TG-MSM), Age 37**

5. Manifestation of Stigma

Based on the experiences shared by the participants, the table below outlines various means by which the stigma is perpetuated.

	Observed Stigma	Perceived Stigma	Experienced Stigma
Community/ Friends	Avoidance, unsolicited questions, separate living and eating arrangements, taunting (for TGs who live in the community)	Gossip, verbal abuse, avoidance and desertion in social interactions, spreading rumours, non-sharing of food	Gossip, avoidance and desertion in social interactions, non-sharing of food, verbal abuse, questioning morals and character of PwTB
Co-workers			Too much precautionary behaviour (avoidance, covering their faces with masks or handkerchiefs), asking the PwTB to wear a mask, eye-rolling, asking others not to mingle with the patient
Family	Separate living arrangements, separate utensils, restricted movements within the house, limited interactions with other members such as children, exclusion from daily household matters	Separate living arrangements, separate utensils, restricted movements within the house, limited interactions with other family members such as children, exclusion from daily household matters	Separate living arrangements, separate utensils, restricted movements within the house, limited interactions with other members such as children, exclusion from daily household matters
HCWs	Rude behaviour, improper care, disrespect, insensitivity to health needs		Rude behaviour, improper and insensitive care

6. Impact of Stigma

Stigma affects various aspects of the personal and professional lives of the individual as well as their treatment.

Stigma	Impact
Observed stigma	Non-disclosure of disease
Perceived stigma	Non-disclosure of disease, treatment non-adherence, self-stigma
Experienced stigma	Work, mental health, treatment non-adherence, weakened family and personal bonding, self-stigma

6.1 Stigma and Non-disclosure of Disease

Many of our participants talked about non-disclosure of the illness. From their narratives, we inferred that the reluctance to share information about their disease was deeply rooted in perceived and observed stigma. Very often, PwTB and PwhTB did not reveal their disease status to many out of a fear of discrimination and ill treatment. They would not reveal it to their neighbours, people from the community, co-workers, and sometimes friends, relatives, and even their family members.

> I did not tell her (my wife) because if I do it will spread from one person to another.
> **- Male (PLHIV), Age, 34**

> I did not share it with anyone because there are people in my friend circle who discriminate behind our backs. They crack knuckles, they make signs, and tease us. We feel insulted, but we do not care.
> **- Bisexual (MSM), Age 58**

> We must not tell our neighbours. If we light a small firecracker, it will go up into the sky and burst, will it not?
> **- Transgender (PLHIV), Age 37**

> I did not tell anybody because on hearing about my HIV itself everybody ran away from me. Thinking that they will run further away upon hearing about my TB, I did not tell anyone. My husband told me I was not to tell anybody.
> **- Female (FSW), Age 45**

Another reason for the non-disclosure of TB status was its impact on economic status. The participants' identity as FSWs, TGs, MSM, and PLHIV had already limited their economic opportunities. PwTB worried that if news of their TB illness spread, their opportunity to make a living would be affected.

> We do not reveal this to anyone. They talk in different ways. If they get to know, it will be problematic. Our work will be affected. They can remove us as well. If one person comes to know of it, all the staff will come to know about it, so I do not reveal it (my disease status) to anyone.'
> **- Participants (FGD-PLHIV)**

6.2 Stigma and Treatment Non-adherence

Stigma and discrimination had an impact on the treatment adherence of PwTB. The participants did not report any instances where TB stigma led to any kind of non-adherence. However, they shared their observations where the treatment seeking of other PwTB was affected by the stigma associated with TB.

One of the participants, who was working at the hospital as a sweeper, remembered how some chose to forego medication altogether to avoid revealing their condition to others, while others resorted to wearing masks or covering their faces with their saree pallu to conceal their identity while seeking treatment. Despite these efforts to mitigate the fear of judgment, the underlying apprehension persisted, influencing their decision-making processes.

> Some people don't go to collect the medicines because people will come to know. However, there will be others who wear a mask or wrap their saree pallu around their face so they cannot be identified. Even then, the fear will definitely be there. Despite this fear, they will go and collect the tablets and struggle to get cured. Some of them discontinue the medication as well.'
>
> **- Female (FSW), Age 45**

Uncertainty about how others would perceive their disclosure and concerns about the potential repercussions contributed to their reluctance to share their diagnosis with others. This fear extended to interactions with NGOs that offered support and referral services, as PwTB and TG individuals worried about the implications of accepting such assistance. As a result, many delayed seeking treatment, which led to further complications in managing their illness. In addition, the stigma associated with TB exacerbated their reluctance to engage with healthcare providers and support organisations. Some individuals reacted defensively or aggressively when approached about their condition, hindering any efforts to provide assistance. As one of our participants recalled:

> They may feel, "Today if I reveal it to one person, the news may spread and that person may reveal it to someone else." Somehow, they delay their treatment. If people see a healthy person they feel happy. If there is something wrong with a person, they have 108 questions and he faces many problems. So PwTB ask, "Who told you that I have this problem? Why did you come?" Some fight. They fight among themselves saying, "You did this. Nothing has happened to me. I am fine.
>
> **- Bisexual (TG-MSM), Age 58**

We found a few instances where patients (TGs infected with TB) had discontinued their treatment initially due to the behaviour they faced at the healthcare facility. When a patient visited the healthcare facility, the HCWs were rude to them, and other patients came to know about their disease status. As a result, other people started keeping distance from the person. The insensitive and rude behaviour of the HCWs made them feel bad, unworthy, and discriminated against, leading them to discontinue the treatment. Having felt such discrimination, they reported this to the authorities. Following an intervention, the HCWs were warned, and it was explained to them how difficult it would be for a TG person if they were discriminated against and treated badly at the healthcare facility itself.

> They had to discontinue the treatment in between because somebody treated them badly. They scolded the HIV-TB patients for something about their mask, and everybody came to know that the person had TB and started maintaining a distance. I visited that centre and told them that, see, first of all, we are transgender. Added to that, if we are discriminated against, then it becomes very difficult for us.
> **- Transwoman (TG-MSM), Age 30**

Another participant remarked on how strict rules and rude behaviour in some hospitals were inconvenient to patients.

> If I say I have a cough for one week and want to get the sputum test done, there is little space there to cough and collect the sputum and keep (the bottle) there. We have to go outside, cough and come.
> **- Kothi (TG-MSM), Age 43**

Such instances would have delayed the treatment process and caused further inconvenience to the patients. TB treatment requires a fixed course of six months. If there are delays, switching, or discontinuation, the treatment cycle is interrupted.

6.3 Stigma and Work

TB carries stigma into the workplace as well. The previous sections outlined how stigma affected the earning prospects of FSWs and how stigma disproportionally affected household workers (predominantly women) because of their proximity to working with a family compared to those who work in other settings.

6.4 Stigma and Mental Health of PwTB and PwhTB

Stigma left significant painful marks on the patients' social and personal lives. People would gossip about the health status of PwTB, speculating how they could have got the disease and even cooking up other details.

> When (anybody) talks lightly or lowly about my health, I feel sad.
> **- Female (FSW), Age 45**

Suicidal ideation and self-harm were also reported as resulting from isolation, discrimination, and discomfort due to TB and the associated stigma. As mentioned earlier, one of our respondents shared that the isolation pushed her to think about self-harm as well.

> Cannot touch anyone, cannot talk to anyone, and others do not eat the food left by me. I feel very sad. I feel why we do have to live. We want to harm ourselves and die (commit suicide).
> **- Female (FSW), Age 50**

> I was feeling suffocated and sad, and would sit alone. I felt like talking to others. But nobody would come and talk to me.
> **- Female (FSW), Age 30**

Perceived stigma also led to mental distress, which caused individuals to have panic attacks, and it left PwTB and their family members feeling helpless. In some cases, the inability to share their distress due to the perceived stigma would upset the individual as well.

> I wonder why it happened like this. I used to panic and then my husband consoled me, saying, “Don’t worry. Nothing can be done, leave it.
> **- Female (PLHIV), Age 30**

> If I tell others, they will add four things to that and they will gossip with others, so I did not tell them. I used to feel very upset. I used to think let me drink again and let me die. I used to feel very hurt. But if I die, there is no one there for my parents.
> **- Male (PLHIV), Age 34**

The prevalent stigma surrounding TB within social circles could be further deepened through the intersection of caste, colour, and gender identity. Individuals often hesitate to disclose their TB status due to the fear of discrimination and social rejection. The fear that revealing one’s TB status would result in stigmatising attitudes and gossip among friends was further compounded by the perceived association between TB and other factors, such as skin colour and caste status, which would subtly contribute to perceived stigma and lead to increased social isolation and marginalisation, as mentioned by one of our participants:

> I don’t know English. I am dark-skinned, belonging to the SC category. Everyone in my surroundings are Kannadigas and fair-skinned. They hesitate to include me with them. When we were in the quarters, there were more Gowdas and other people. I will mostly be alone. If I could reveal this in my friend circle, they will look at me in a discriminating way. (They will say) How did he get it? Even if I have TB, they will not hesitate to add some more things to it and tell others.
> **- Kothi, (TG-MSM), Age 43**

6.5 Stigma and Personal Connection

Our participants’ narratives shed light on the profound impact of the stigma surrounding TB. Such stigma has also severed family ties. Mistreatment in their families, avoidance, and desertion by family members and relatives were common.

> Had my sister come to know, she definitely would not have come to my house thereafter.
> **- Female (FSW), Age 45**

TB stigma affected not only social relations but also family ties. The reluctance to associate with individuals who are diagnosed with TB extends even to close family members, as one of the participants observed while recounting an incident involving their cousin brother. Despite the familial relation, relatives from the participant’s side refrained from visiting or offering support to their cousin, presumably due to the perceived risk of contracting the disease.

> I have a cousin brother who has TB. Nobody from my side goes (relatives) goes to their house.
> **- Female (FSW), Age 45**

> They just leave them… I have seen it. Even the wife will neglect the person, leave, and go.'
> **- Male (PLHIV), Age 30**

The experience of stigma embittered the individual as well. One of our participants' remarks exemplified the lasting effects of stigma on individuals affected by TB:

> When I had just come from the hospital, they would say, "She has TB, we will also get it." Many people did not even talk to me. Now that I have recovered, why will I care for those same people? I am staying in the same house and the same village.
> **- Female (FGD-FSW)**

6.6 Self-stigma

Stigma as practised by people from the community, co-workers, friends, and family did affect the social lives of PwTB. In addition, infected people also feared transmitting the disease to others, which prompted a profound change in their socialising and social interactions. Individuals diagnosed with TB consciously refrained from attending social gatherings and community events. The reluctance to mingle with others extended beyond mere precautionary measures:

> They fear that they too may get the disease. So we also maintain distance, we do not mingle with people, we do not go to functions, and we too have the fear that nothing should happen to them because of us.
> **- Male (FGD-PLHIV)**

The fear of infecting others, especially their family and friends, sometimes pushes PwTB to avoid interactions with them. This behaviour of limiting themselves in social interactions could also lead to social isolation.

> Not stigma but the precautionary measures taken by the patient to not to spread the disease to others took a toll on her personal life. She maintained a distance with her partner for a year so that he would not get infected by her. Her partner left her.
> **- Transwoman (TG-MSM), Age 30**

This self-imposed isolation was the outcome of concern, as well as social and personal responsibility, to safeguard the health and well-being of others. These narratives identified the profound impact of infection on not only the individuals' lives but also their social interactions and community dynamics.

7. The Fear Factor behind Stigma: Why Do People Stigmatise?

The fear of getting infected with TB is the most important factor for the manifestation of stigma. This fear is common among people without the illness, as they perceive they could get infected too. It is also prevalent among PwTB because their perceived fear and stigma have several implications as mentioned earlier.

The discriminatory attitude towards PwTB stemmed from a lack of personal experience with the disease among those who practised the stigma. The foremost reason for this, as highlighted by our participants, was the fear of getting infected. This fear was mainly associated with TB transmission, as uninfected people viewed TB as a contagious disease that could spread through the air if an infected person coughed.

> There will be others like that as well. They will think, “What if I too get TB, as it spreads through the air? It is a virus or bacteria, isn’t it?” Some people are fearful that if I talk to them they might get it. That is why they all treat me like that.
> **- Male (TG-MSM), Age 58**

This awareness of transmission modes instilled a pervasive fear among both TB-infected individuals and those who feared contracting the disease, which exacerbated the social stigma. When a person had knowledge, understanding, or any experience of the disease, they behaved differently from those who did not. TB stigma had its roots in the fear of transmission, coupled with unawareness and inexperience of the disease, and perceptions of health and happiness.

> They discriminate because they do not have any disease. They live happily, isn’t it? They fear getting the disease. There are many ways of getting HIV, but TB spreads through our breath while coughing. The bacteria spreads from one person to another person, and a healthy person can also be infected. For this reason, they do not come near us. Those who have TB do not behave like this.
> **- Bisexual (TG-MSM), Age 58**

> They have that fear, that “If I also get it, then something might happen to me. If I go near her, then I might also get it. Therefore, I must stay away from her.” That is their only concern.
> **- Female (FSW), Age 50**

Stigma related to TB as practised by community members, co-workers, friends, and family did affect the social life of infected patients. PwTB also had a fear of transmitting the disease to others, which prompted a profound change in how they socialised and interacted with others. Individuals diagnosed with TB consciously refrained from engaging in social gatherings and community events. The reluctance to mingle with others extended beyond mere precautionary measures:

> They fear that they too may get the disease. So we maintain a distance, we do not mingle with people, we do not go to functions, and we too have the fear that nothing should happen to them because of us.
> **- Male (FGD-PLHIV)**

Even HCWs and doctors adopted precautionary behaviour such as maintaining a certain distance with the patient during interactions. The patient did not feel offended and considered it a necessary measure to prioritise their health.

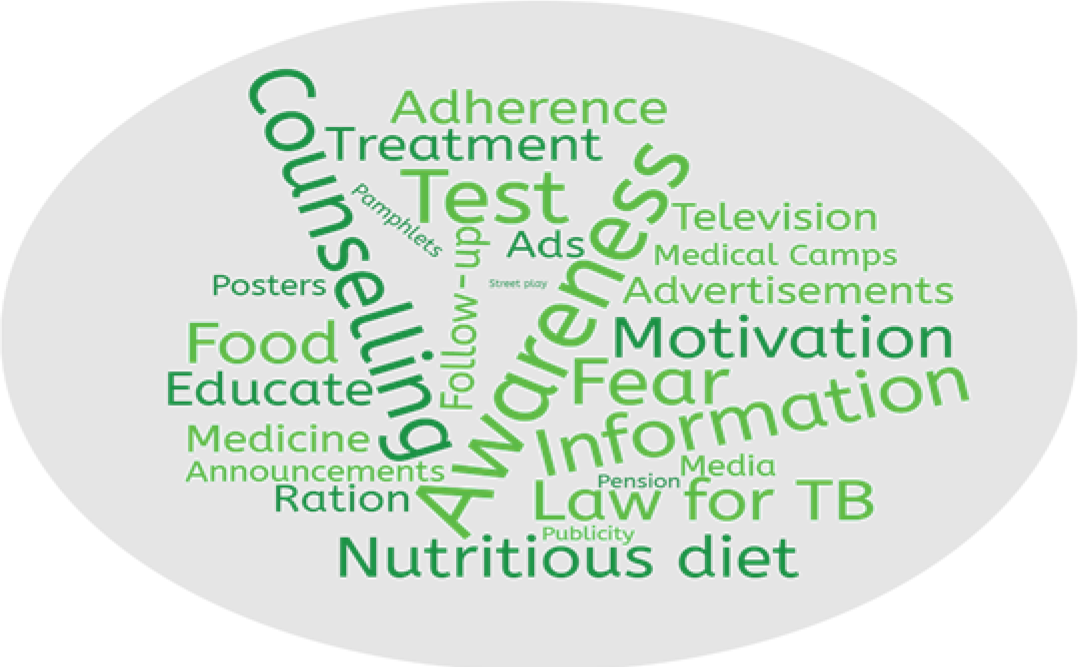
> The doctors sit very far away. Even when I had gone, I was sitting this far and only after my elder sister came and tied a mask on me did the doctor come near and speak to me. They also have that fear. Just because they are doctors, they cannot come and hug the patients.
> **- Kothi (TG-MSM), Age 43**

8. Addressing TB Stigma

8.1 Combating TB Stigma

Recommendations by PwTB

Stigma poses a significant challenge in combating TB in India. We asked our participants how to mitigate the stigma associated with TB. The following word cloud summarises the keywords from the participants' recommendations to challenge TB-related stigma.



The participants emphasised that only if awareness is spread to everyone will the stigma be mitigated.

> To avoid stigma, they (those who discriminate - people, family, and neighbours) should be brought to awareness. They are also like us; they are also human beings. If we create this awareness that's enough.
> **- Male (TG-MSM), Age 55**

People used to think TB was a major disease and knowledge about the disease was limited, so there were fears and misconceptions surrounding it.

> The government should take initiatives to spread awareness that it is not a major disease. There is medication, but it has to be continued.
> **- Female (FSW), Age 42**

> Everybody in society must be made aware. Then the stigma will decrease. Earlier, people were scared of HIV. But now, they are not that afraid. HIV was a major disease at the time. Similarly, if information regarding TB is given to all, it will be helpful for everyone.
> **- Female (FSW), Age 45**

The participants placed emphasis on using media such as television, movie theatres, posters, public announcements, and advertisements to spread awareness and educate people about TB. They said that if people were aware of the disease, the fear and stigma would reduce.

> Social media and movie theatres only talk about cancer and smoking. They must show ads about TB as well, highlighting that this is a curable disease. If that is done, outcomes will improve.
> **- Male (TG-MSM), Age 65**

> In schools, colleges, and panchayats, information on TB must be provided during functions and meetings. People could talk about TB for five minutes, rather than have unknown people speaking for hours together on irrelevant topics. It is enough if they give the information in just two minutes. If more information is available to the public, more advertisements are shown on TV, and awareness programmes are conducted in all the areas, people might start feeling less scared. Earlier, there used to be more TV advertisements about TB. Now, those are broadcast only in Hindi on the national channel. That's all. They don't show it on any other channel. If it is shown on all channels, then people will become more aware.
> **- Male (FGD- PLHIV)**

During the interview, one participant emphasised the importance of organising more medical camps as part of the effort to combat TB. They suggested that increasing the frequency of these camps, especially in remote areas, could contribute significantly to the detection and management of TB cases. By providing accessible healthcare services, particularly through sputum tests conducted during these camps, more individuals could be reached and diagnosed on time, thereby strengthening overall TB control efforts.

> If more camps are organised, it will be helpful. You can find more TB patients. If sputum tests are done in remote places, then patients will come for screening.
> **- Male (FGD-PLHIV)**

Stigma affects various aspects of a patient's life through mental health, fear, non-disclosure, and treatment behaviour. Our participants recommended motivation and counselling to counter stigma and fear due to TB.

> We can save a patient half with the treatment and half with motivation. Not only that, when following the treatment, the patient must take food accordingly, they should take care. Only when everything is done properly will the patient be cured and able to come out of it.
> **- Female (FSW), Age 50**

When one participant claimed that counselling was of key importance in combating stigma and the fear of TB, others agreed and showed their interest in counselling and motivating other PwTB. Other participants also underlined the importance of motivation and counselling.

> Counselling must be for everybody. It is not only for the TB patient. Even the family members must be given counselling.
> **- Male (TG-MSM), Age 65**

> If I have an option, I can come and counsel those who have this disease or if they have fears about this disease. I wish to talk about how to come out of the disease rather than disclose the disease status. Who does not get diseases? Everyone gets diseases. What type of disease is important, that's all.
> **- Male (PLHIV), Age 30**

Greater awareness would lessen the fear of TB and help mitigate the stigma associated with the disease. Family support was also recommended.

Such awareness, motivation and counselling, and increased family support would help reduce the fear of TB infection among people and help PwTB to fight the negative self-esteem that is caused by the disease and the associated stigma.

In the fight against TB, a nutritious diet is important. Owing to the physical weakness caused by the illness and the stigma attached, the participants reported that their income was affected. Owing to the loss of income, many participants suggested that the government should offer rations for TB patients.

> If they give more items… like instead of giving three items if they give five items in small quantities, it will be beneficial for poor people like us.
> **- Female (PLHIV), Age 34**

> Today, even if one has to buy one kilogram of rice, they must pay 40 or 50 rupees. So, it is difficult to consume that type of (nutritious) food. If people take the medicines but don't take nutritious food, they cannot survive. Their body (condition) will deteriorate further.
> **- Male (TG-MSM), Age 58**

Though the government offers Rs 500 as nutritional support through Nikshay Poshan Yojana, one participant highlighted that first of all, not everyone was availing of this scheme, and second, the amount was too low to meet the requirement.

> They say they give Rs 500 to somebody, but nothing happens with that money. It might be sufficient for only one day. If they eat properly or buy half a kilogram of mutton or something, it might be enough for that. That's all.
> **- Male (PLHIV), Age 65**

The pressing need for legislation to combat the stigma associated with TB was underscored by numerous voices within the community. The participants highlighted the discriminatory treatment faced by TB patients as akin to being treated as 'untouchables'. They emphasised the necessity of laws to deter such prejudicial attitudes, asserting that the fear of legal repercussions would dissuade individuals from viewing TB patients in an inferior light.

> A law is essential because people see them differently, like untouchables. They should enact laws to avoid this. If people have a fear of the law, they will not see TB patients in an inferior way.
> **- Male (PLHIV), Age 30**

Drawing parallels with HIV stigma, the participants articulated the potential efficacy of TB-specific laws in curbing discrimination.

> Similar to HIV, if there is a law for TB stigmatisation then people will fear and will not stigmatise or discriminate.
> **- Male (TG-MSM), Age 55**

They argued that legal measures would discourage stigmatised behaviours. Moreover, they advocated greater awareness efforts to complement legal initiatives, recognising the power of education in dispelling misconceptions and fostering acceptance.

Structural Stigma: Policy Framework for TB

The Russian Federation and the Philippines are the only two nations with TB-specific laws among the WHO's list of 30 high-burden TB countries. The majority of nations do not have laws specifically targeting TB. Instead, they address the issue of TB under the umbrella of public health laws and regulations. These legislations may be either public health-based laws or rights-based laws. Most countries have public health-based laws, and according to research from the O'Neill Institute at the Georgetown University Law Center supported by the Stop TB Partnership, disregarding human rights comes with several risks.

The United Nations Committee on the Elimination of Racial Discrimination has emphasised that India's SCs and STs, historically marginalised groups who are entitled to affirmative action, bear an inequitable burden of TB. The entitlement to health is firmly enshrined in Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR), affirming the 'right of everyone to the enjoyment of the highest attainable standard of physical and mental health'. This provision imposes an obligation on states to undertake the requisite measures for the 'prevention, treatment, and control of epidemic, endemic, occupational, and other diseases', while concurrently fostering conditions that ensure the provision of medical services and attention for all during periods of illness. States are mandated to uphold the right to health through the principles of respect, protection, and fulfilment—refraining from actions that hinder health rights, averting third-party interference, and implementing measures to fully actualise the right to health. Moreover, international law explicitly denounces discrimination in both access to healthcare and the underlying determinants of health, as well as in the procurement of the means and entitlements required for health maintenance.

While the Constitution of India does not overtly articulate the right to health, the judiciary, particularly the Supreme Court, has judiciously interpreted and inferred this right within the ambit of the right to life enshrined in Article 21.

The Tuberculosis (Treatment and Eradication) Bill, 2022 is a comprehensive TB bill. The endeavour to champion a comprehensive TB bill within the parliamentary domain is underpinned by an unwavering commitment to positioning TB care as an imperative facet of human rights, thereby expediting the nation's strides towards TB control. This legislative framework is poised to safeguard, uphold, and actualise the rights of individuals grappling with the disease throughout the spectrum of TB care delivery and associated services. Aligned with the tenets of the National Health Policy, the forthcoming TB policy is poised to be an intricate tapestry woven with crucial regulations. The policy also unequivocally champions the cause of non-stigmatisation for TB patients and their families, safeguarding their right to access public healthcare and seek redress through compensatory mechanisms.

The Tuberculosis Mukt Bharat Abhiyaan, launched by the Ministry of Health and Family Welfare (MoHFW) in 2021 under the comprehensive NSP India 2020–25 for TB Elimination, stands as a pivotal mission that is poised to curtail the TB epidemic by 2025. This ambitious initiative, conceived as a multi-dimensional approach, is dedicated to the detection of all TB patients, with a pronounced emphasis on those seeking care from private practitioners and addressing undiagnosed TB within high-risk populations. In tandem with the relentless pursuit of a TB Mukt Bharat (TB-free India), WHO India is gearing up to implement Project GATIMAN, a strategic initiative designed to bolster technical assistance across domains such as public-private partnerships, TB surveillance, knowledge management, implementation research, drug-resistant TB, laboratories, TB infection management, and advocacy and communications throughout states and Union Territories. Incentives of Rs 1,000 are bestowed upon the successful completion of treatment, complemented by an additional Rs 5,000 for each case of drug-resistant TB, provided to all treatment supporters during the course of treatment. Private providers receive Rs 1,000 for each notified TB case, while tribal areas receive Rs 750 as travel support for all TB patients in any tribal block. The MoHFW, in its commitment to address the multifaceted challenges of TB, introduced the Nikshay

Poshan Yojana scheme. This scheme provides a financial incentive of Rs 500 per month through DBT for each notified TB patient throughout the duration of their anti-TB treatment. The Pradhan Mantri TB Mukt Bharat Abhiyaan, launched on 9 September 2022 by the MoHFW, signifies a concerted effort to accelerate India's progress towards TB elimination by 2025. Under the aegis of the 'Community Support to TB Patients—Pradhan Mantri TB Mukt Bharat Abhiyaan', individuals and entities, including co-operative societies, corporate entities, elected representatives, NGOs, political parties, and partners, are encouraged to support the initiative. The initiative, operational under the NTEP, ensures free diagnostics and medicines for patients. Despite the laudable efforts of the government, achieving the goal of elimination seems impracticable without active community participation. This campaign encourages the community to adopt TB patients, offering support in the form of nutritional aid, supplements, additional investigations, and vocational support for a minimum of six months and a maximum of up to three years. On 9 September 2022, the Hon'ble President of India launched a nationwide campaign through the Pradhan Mantri TB Mukt Bharat Abhiyaan, urging individuals, NGOs, co-operative societies, faith-based organisations, corporate entities, political parties, and others to become Nikshay-Mitras. A Nikshay-Mitra can adopt a minimum of one consenting TB patient on treatment for a minimum period of six months, providing support tailored to the specific needs of the patient. This inclusive and innovative approach underscores the synergy between governmental initiatives and community-driven contributions towards the noble goal of TB elimination in India. This envisages eliminating TB stigma and normalising TB as a health issue.

The NTEP, Karnataka, is also initiating the Kshaya Mukta Grama Panchayat (TB-free Gram Panchayat) initiative as part of its ambitious Kshaya Mukta Karnataka (TB-free Karnataka) campaign. By involving the members of Gram Panchayats, they hope to ensure a better understanding of the disease from the community perspective, create an impetus for the early detection of cases and early initiation of treatment, build community support to enable adherence by reducing stigma, and provide support for nutrition and treatment completion to ensure better outcomes.

Kshaya Mukta Grama Panchayat Towards TB-Free Panchayats: Local decision-making bodies like Gram Panchayats (GPs), emerged as critical assets in driving TB policies. Through the Kshaya Mukta Grama Panchayat initiative, Karnataka embarked on a whole-of-government approach to TB elimination.

Convergence Model:

A) Integration with health centres: GPs aligned with primary health centres or health wellness centres, fostering collaboration to enhance TB services.

B) Capacity building: Over 16,000 GP members underwent orientation in Kannada, fostering awareness and understanding of TB activities.

C) Arogya Amrutha Abhiyaana: This is a ground-breaking initiative reaching rural households through GP leadership, with dedicated TB volunteers in 243 GPs.

D) Kshaya Nivarana Andolana: Active case-finding efforts resulted in screening 1,64,246 individuals and detecting 47 TB patients.

E) Kshaya Aasare: Providing holistic support, 158 GPs engaged in offering nutritional support and linking TB patients to social welfare programmes.

F) TB Sollisi GP Gellasi: Community engagement campaigns in 363 GPs, conducting 557 IEC sessions, aimed at reducing stigma and increasing awareness.

The Pradhan Mantri Nikshay Poshan Yojana scheme was launched in 2018 and is implemented by the MoHFW. All notified TB patients are beneficiaries of the scheme. All TB patients notified on or after 1 April 2018, including all existing TB patients under treatment, are eligible to receive incentives. DBT is the nutritional support plan for the on-treatment TB patients and every patient received Rs 500 for their nutritional benefit. The district of Sonitpur, Assam, paid the second highest DBT in the small state category of India.

Advancing Justice: A Human Rights Framework for TB Eradication

A profound shift in strategy becomes imperative, surpassing the conventional realms primarily governed by public health and biomedical models—frameworks that, by and large, falter in grappling with the intricate interplay of social, economic, and structural determinants steering the TB epidemic. At the crux of this transformative approach lies a human rights-centric paradigm, firmly rooted in both international and regional treaties, alongside the bedrock of national constitutions. These legal frameworks intricately outline the entitlements bestowed upon individuals ensnared by or susceptible to TB, encompassing the bedrock of fundamental rights. These rights span a spectrum including the sacrosanct entitlements to life, health, non-discrimination, privacy, active participation, unfettered access to information, freedom of movement, dignified housing, basic sustenance, potable water, and the enjoyment of benefits arising from scientific progress. Woven seamlessly into the fabric of human rights law are the corresponding legal obligations levied upon governments and the commensurate responsibilities ascribed to private entities. This dual framework not only fervently advocates for robust accountability mechanisms but also unfurls avenues for redressal in instances where rights stand violated. Furthermore, gleaned from the instructive tapestry of combating HIV, emerges a palpable truth: the unwavering commitment to championing and advancing the human rights of individuals grappling with TB bears the promise of nurturing interventions of enduring impact. This commitment extends its benevolent reach to fortifying outcomes in prevention and treatment modalities, thus decisively attenuating the spectre of emergent drug resistance. In essence, the elevation of TB from a mere health challenge to a human rights imperative not only signifies an intellectual evolution but also heralds a transformative trajectory in our collective approach to a global health crisis.

Embracing a human rights-based framework, the United Nations agencies have encapsulated the essence of such an approach in the acronym PANEL - Participation, Accountability, Non-discrimination, Empowerment, and Legality. This nuanced approach is pivotal in acknowledging the intricate interplay of the social, economic, and structural determinants propelling the TB epidemic. In one of her seminal scholarly works, Dr Dipika Jain meticulously enumerates recommendations that are commensurate with the intricacies posed by such a formidable issue.

A. Addressing socio-economic determinants of TB: Recognising malnutrition, overcrowding, poor sanitation, and their nexus with poverty as key contributors to TB, a robust strategy involves fortifying the Public Distribution System (PDS) to combat malnutrition effectively. Full implementation of the National Food Security Act, 2013, emerges as a critical step, ushering in essential reforms, improved grievance redressal mechanisms, and increased transparency in the distribution of food subsidies.

B. Providing adherence support: Instituting free or reduced-fare transport for TB patients accessing treatment aligns with prevailing practices for HIV patients, showcasing the government's commitment to reducing barriers to care. Implementing TB-specific pensions and integrating TB patients into existing social protection schemes underscore the government's endeavour to alleviate the economic burdens associated with TB treatment. This includes protection in the event of unemployment, disability, old age, or other situations in which they lose their means of subsistence, all without discrimination.

C. Ensuring quality treatment: Rigorous enforcement of the Clinical Establishments Act, 2010, is paramount in regulating both public and private health facilities, reinforcing adherence to standardised treatment guidelines for TB care. Amendments to the Act, introducing a dedicated implementation body and grievance redressal mechanisms, further enhance oversight and ensure quality in private health sectors.

D. Combating stigma: Recognising the pervasive stigma associated with TB, a comprehensive approach involves the full implementation of advocacy, communication, and social mobilisation guidelines formulated by the Central TB Division in 2014. International obligations necessitate that states address widespread stigmatisation and undertake targeted measures to eliminate discrimination, fostering a supportive environment for TB patients.

E. Providing adequate funding to TB programmes: Acknowledging the core obligation to provide essential drugs, states must maximise available resources to ensure sufficient funding for TB programmes, aligning with the 2012–2017 NSP targets.

F. Providing enforceable rights: Establishing enforceable rights for TB patients, such as legal aid provisions, reflects a commitment to accountability, empowering patients to claim their rights and seek remedies for violations.

G. Respecting patients' privacy: Scrutinising the notifiable disease status of TB and its implications on privacy, the government should justify the use of patient names in the notification system, considering alternatives like coded or unnamed notifications in alignment with international human rights standards. Based on a case study done in Kyrgyzstan in 2015, it has been observed that there has been a lack of focus on respecting the privacy of TB patients.

H. Incorporating explicit limitations on coercive measures: Explicitly articulating limitations on coercive measures within TB policies is imperative, guided by international principles emphasising strict necessity, proportionality, and adherence to scientific evidence. In essence, this multifaceted set of recommendations underscores a commitment to a human rights-based TB management paradigm, amalgamating legal, social, and ethical dimensions to foster enduring interventions and uphold the dignity and well-being of those affected by TB.

Discussion

This study assesses the levels and dimensions of stigma related to TB among vulnerable populations using a mixed-method approach, and is among the first to address TB-related stigma among vulnerable populations in India. The study used a quantitative approach to explore TB stigma among PwTB, family members, and caregivers, as well as in local communities and healthcare facilities, and to understand how TB stigma acts as a barrier to both accessing and providing services. Furthermore, to understand the manifestation, impact, and intricacies of vulnerability and stigma among FSWs, PLHIV, TGs, and MSM, a qualitative approach has been adopted. These two approaches offer distinct insights and perspectives on stigma, rather than merely complementing each other.

We found that the reporting of perceived and self-stigma was significantly high among PwTB (more than 80% in each group). Our finding is comparatively higher than what other scholars like Duko et al. (2010) and Baskaran et al. (2023) have reported. A possible reason for this overestimation could be the operational definition of perceived stigma.

The stigma experienced by UV PwTB/PwhTB was similar to the findings from other studies conducted in the same states of India (Shivapujimath et al., 2017). However, the stigma experienced by PwTB/PwhTB from the tea gardens was comparatively low. This variation in stigma reporting can be attributed to several factors such as knowledge, awareness, and understanding of stigma. Further, our experience during the field visits, especially among the TGWs of Assam, led us to believe there was more acceptance of PwTB in the tea gardens. This acceptance could be linked to the TGWs' exposure to and familiarity with TB patients over time, leading to the internalisation of TB as more acceptable compared to the UV population.

Stigma experienced at the community level has a more detrimental impact on the treatment journey. For instance, experience of stigma within the community plays a critical role in individuals seeking care. Among UV PwTB/PwhTB, approximately 60% reported that community-level stigma disrupts their treatment-seeking care and receiving treatment adherence support, while half of them stated that it deterred them from initiating treatment altogether. For PwTB/PwhTB among the TGWs, experienced stigma serves as a barrier at different stages of their treatment journey, although its impact appears to be milder than that experienced by the UV populations.

Secondary stigma perceived and observed by the family members of the UV group was high compared to among the family members of TGWs. For instance, around a third of the family members of the UV group indicated that their family had requested them to keep the TB diagnosis a secret, whereas only a small percentage from the TGW group (4%) reported the same. Stigma experienced by the family members of both groups was almost similar—around 5% of the family members reported facing stigma because of their family member's TB status. The secondary stigma of family members and caregivers was responsible for inhibiting the family members from supporting the treatment journey of TB patients. Stigma at the community level emerges as a significant obstacle to both UV populations and TGWs, albeit with varying degrees of severity. Dimensions of stigma and fear were prevalent among community members as well. For example, half of the community members of the UV group agreed that some people felt uncomfortable being near PwTB, or preferred to keep their distance from people with TB, not even sharing food and drinks with their PwTB friends.

There were some reported misconceptions about the medium of transmission of TB among HCWs as well. For example, among the HCWs working with TGWs, 72% reported that eating from the same plate could transmit TB. Further, a significant proportion of HCWs (around 70%) agreed that 'some healthcare workers feel pity for TB patients'. More than half of the HCWs working with TGWs agreed that some HCWs believed in isolating the patient during the intensive phase of the treatment. Also, almost half of the HCWs working with the UV population agreed that some HCWs had considered forcing TB treatment if necessary. Around 17% of them agreed that some of the HCWs were nervous about treating TB patients. The lack of knowledge and misconceptions about TB are also discussed by other researchers such as Alotaibi et al. (2019), Shreshtha et al. (2017), and Woith et al. (2010). This finding is particularly concerning as HCWs are expected to have accurate knowledge about disease transmission. Misconceptions about the medium of transmission can lead to stigma towards patients, which can negatively impact their care and treatment outcomes. Sadly, the stigma persists among HCWs, which can end up discouraging patients from seeking further help, as explained by a TB specialist during an interview with WHO, which highlights the impact of stigmatised attitudes among HCWs (WHO, 2022). Further, HCWs also face stigma due to their work with TB patients: 6% of HCWs had observed their peers being stigmatised and had themselves experienced stigma at their workplace, in the neighbourhood, and even from their family.

The role of social support in the mitigation of stigma is well-documented across various regions (Chen et al., 2021; Demissies et al., 2003; Li et al., 2009). This study also confirms the inverse association between social support and stigma. Education, awareness, and other social and economic factors are significant predictors of the stigma faced by the individual.

Effective stigmatisation requires a difference in power between the ‘stigmatised’ and the one who practices stigma (Major & O’Brien 2005). Link and Phelan (2001) (cited in Craig et al., 2018) use politicians as an example. In many societies, people attach negative attributes to ‘politicians’. However, few would consider them to be stigmatised because of the power they wield. In Indian society, this power primarily is held by the male-dominated hierarchical caste system. The social hierarchy channels the stigma experienced in the Indian context as is evident from our findings that UV PwTB/PwhTB belonging to lower caste groups experienced higher levels of stigma compared to those from other caste groups. We found that the stigma experienced by female PwTB/PwhTB of the TGW group was double (15.5%) the stigma experienced by males. Further, the social and power dynamics of TB stigma also emerge from our qualitative findings. TGs, MSM, FSWs, and PLHIV are groups that are vulnerable to TB infection. Among these groups, the most stigmatised would be the TGs, followed by MSM, given their ‘visible stigmatised attributes such as dressing and mannerism’. These groups are more vulnerable in terms of family and social support, less likely to conceal their self-identity, and have low socioeconomic positioning as compared to FSWs and PLHIV. We found an obvious pattern of TB stigma and heightened vulnerability to TB stigma where TG individuals and MSM faced more stigma.

Culturally, FSWs, TGs, MSM, and PLHIV are seen through a lens of societal stigma as they do not come within the ambit of societal norms and belong to what is seen as stigmatised professions, do not conform to the set gender binary, or indulge in practices which leave them infected by HIV. In such scenarios, social support from family, close friends, and community is negligible and when they are diagnosed with TB, they face double the stigma from not conforming to the norms of the society they live in and being infected by TB. Each of these vulnerable groups experiences different layers of stigma. The first layer is being an FSW, the second layer is being infected with HIV, and the third layer is being infected by TB. Similarly, with MSM/TG, the first layer is the lack of social acceptance of their sexuality and of their transitioning to either male or female from their biological sex, the second layer is being infected with HIV, and the third layer is being infected by TB. These layers of stigma affect their self-esteem and mental health and their ability to make their health a priority unless nudged by well-wishers from their circle and ASHAs.

Given the misinformation, myths, and lack of awareness about TB, the participants reported that they were initially afraid and sad to learn about their illness. The role of family and social support is important during TB treatment. The quantitative findings highlight the role of social support in the mitigation of stigma. Findings from the qualitative analysis also offer a similar understanding and further highlight the role of family and social support throughout the treatment journey.

Qualitative understanding provides in-depth details about TB stigma and how it intersects and affects the life of already-stigmatised groups. There is very little or no evidence on how TB stigma has an impact on the earnings of sex workers, hampers their personal and social connections (especially among TGs who live in hamams), leads to isolation and anxiety, and affects mental health, even leading to suicidal ideation among these vulnerable communities. There is literature discussing various aspects of stigma with results similar to ours. However, while these focus on the non-disclosure of disease, treatment non-adherence, work, mental health, and family and personal bonding among the non-stigmatised population (Lee et al., 2017; Mcarthur et al., 2016; Chang & Cataldo 2014), they do not address the multiple stigmas along with the TB stigma faced by vulnerable individuals.

Our findings on the impact of stigma on non-disclosure of the disease, non-adherence to treatment, self-stigma, mental health, etc. from this study align well with previous findings on the impact of different stigmas on individuals' lives. Observed stigma resulting in non-disclosure of disease is consistent with the findings of Corrigan and Watson (2002). We found that perceived stigma leads to non-disclosure of disease, treatment non-adherence, and self-stigma, corroborating the evidence provided by Earnshaw and Chaudoir (2009) and Rao et al. (2017). Experienced stigma does affect various aspects of individuals' lives, including work, mental health, and interpersonal relationships. Link and Phelan (2001) and Livingston and Boyd (2010) had similar findings on the impact of experienced stigma. Further, we found that experienced stigma leads to treatment non-adherence as well as weakened family and personal bonding, thus supporting the conclusions drawn by Ritsher et al. (2003) and Varni et al. (2012).

The manifestation of stigma includes avoidance, gossip, verbal abuse, rumours, precautionary behaviour, eye-rolling, separate living arrangements, segregation of utensils, restricted movements and interactions with other family members such as children, exclusion from daily household activities, and rude and insensitive care from HCWs. Similar mechanisms have been documented in other studies as well (Atre et al., 2011; Daftary et al., 2017; Mukerji & Turan, 2018).

The participants of the qualitative study were already facing stigma because of their chosen profession, sexuality and gender, and HIV status. However, the group of quantitative participants were from lower economic groups and not from the general public. The latter group may not have known what being stigmatised felt like until they became PwTB or family members of PwTB. Interestingly, during the interview process, it was necessary to explain to them what stigma was and only then did they relate it to TB stigma. Maybe this group had either normalised discrimination due to their lower economic status or normalised TB stigma as a way of life.

We find in this study that the fear of transmission is the major reason behind stigmatisation. Our findings are similar to other studies from different socio-demographic contexts (Courtwright & Turner, 2010; Mak et al., 2006; West et al., 2008). This fear of transmission is deeply rooted in the lack of awareness about how TB is transmitted. This lack of knowledge and even misinformation on TB transmission is also explored in our study. Not only the family members and community members but also more than 75% of HCWs who treated the TGW community believed that TB can be transmitted by eating on the same plate. A recent study added that in India, only about 24% of people have correct knowledge about how TB spreads.

Despite the prevalent stigma, all our participants continued their treatment and they further highlighted that things are improving with regard to TB stigma. Over time, there has been a notable increase in TB awareness within the community. The heightened awareness has translated into a greater understanding of where to seek treatment, recognition of TB symptoms, and a proactive approach towards seeking medical assistance. Such developments mark a significant shift in the attitudes and behaviours surrounding TB management. This collective increase in awareness signifies a positive transformation in the community's attitude towards TB and highlights the role of awareness Information Education Communication (IEC) in the mitigation of TB stigma.

Policy Gaps and Recommendations

After desk reviews of available literature, commentaries on policy, programmes and policy documents on TB, we identified some policy gaps, which could play a significant role in addressing TB stigma.

Policy Gaps

1) Necessity of equitable treatment framework

TB disproportionately affects marginalised communities and raises human rights concerns, especially in the light of the traumatic stigma associated with the medical condition, which can further isolate and marginalise groups such as the poor and sexual minorities who are at higher risk due to their living and working conditions and already subjected to discrimination. The United Nations Committee on the Elimination of Racial Discrimination has emphasised that India's SCs and STs, historically marginalised groups entitled to affirmative action, bear an inequitable burden of TB and are predisposed to healthcare infrastructure that is either inaccessible or markedly substandard, thereby exacerbating the health disparities they confront.

As India moves towards TB elimination, it becomes essential to detect, treat, and prevent TB among vulnerable populations, which India's NSP for TB Elimination (2017–2025) identifies as persons at risk of developing TB due to 'underlying determinants of health' and having reduced access to medical services. The NTEP acknowledges the interplay of TB stigma, gender, poverty, and HIV. The invisibility of these vulnerable groups, especially FSWs and MSM, omits the special attention that these groups require.

2) Privacy of the patient

The privacy of the patient is of the utmost importance, given the nature of the stigma carried by TB. As recommended by WHO, the state must adhere to non-consensual disclosure of a patient's TB status (Coleman et al., 2010). TB has been a notifiable disease where authorities have to be informed about the case. Given the stigma associated with the disease, some TB patients in India have refused treatment from DOTS providers due to the 'apprehension of disclosure'. Therefore, the government should explain and justify its use of patients' names in the notification system, given the possible alternatives of coded or unnamed notification (Jain & Tronic, 2018).

Further, due to the fear of identity disclosure, some patients opt for private care rather than the services offered by the government, which leads to catastrophic health expenditure.

3) Sensitisation of HCWs

HCWs must be trained to be sensitive and empathetic when treating TB patients, especially those from marginalised groups such as TG individuals, who already face significant discrimination due to their non-conformity to social norms. HCWs must recognise and rectify instances of discrimination to ensure inclusive and respectful care for all patients.

HCWs also need to be given timely training to increase their knowledge about TB, as we found a knowledge gap among HCWs in the literature as well as through our analysis.

4) Moving beyond a paternalistic approach to TB treatment (patient-centric approach to TB treatment)

As discussed by Daftary et al. (2017), PwTB or those presumed to have TB are frequently subjected to stigmatising language and practices within healthcare systems. This includes terms like 'TB suspects' and 'defaulters', which can perpetuate negative stereotypes and marginalisation. In addition, mandatory screening, testing, and disease notification systems often lack privacy, which further exacerbates feelings of isolation and discrimination (Daftary et al., 2015). Contact investigations may inadvertently label the patient, leading to increased social stigma. Measures such as airborne respiratory isolation, while intended to prevent transmission, can prolong social isolation and contribute to the social exclusion of individuals with TB. Furthermore, directly observed treatment (DOT), although designed to ensure medication adherence, might impede individual autonomy and infringe upon patient rights (Frick et al., 2016).

5) Lack of legal framework: Lesson from HIV discourse

India has a strong health rights jurisprudence since the 1980s, the outcome of HIV stigma which led to social change. These efforts offered and protected the rights of PLHIV, but it has yet to be meaningfully applied in the context of TB (Daftary et al., 2017; Duggal, 2001; Jain & Tronic, 2018). Our study participants also shared similar sentiments and emphasised the need for a law or policy that would discourage stigmatising behaviour.

Recommendations

1) Use of IEC in spreading awareness

This study revealed that the major reason behind TB stigma is rooted in the lack of awareness about TB. We also came across stories of participants where increasing awareness led to less stigma. Our participants recommended the use of media, such as television, movie theatres, posters, public announcements, and advertisements, to spread awareness and educate people about TB. Using IEC to spread awareness could be a game-changer.

2) Counselling services

Stigma affects the mental health of PwTB and leads to self-stigma. In this context, counselling could be a crucial tool for combating TB stigma by offering emotional support and dispelling misconceptions among patients. Promoting the mental well-being of the patients and addressing their misconceptions and fears through patient counselling could be helpful. Further, counsellors could provide vital information about TB, enhancing the community's awareness of TB and reducing community stigma. Importantly, counselling could address self-stigma by boosting self-awareness and acceptance, thereby mitigating feelings of shame and inferiority. Similar recommendations were made by the participants of the qualitative study as well.

3) Including HCWs beyond treatment to combat stigma

The testimonials provided by participants underscore the importance of awareness and education on TB. The treatment itself increased awareness and dispelled the fear and misconceptions surrounding TB. This highlights the transformative impact of interaction with HCWs in enhancing the knowledge and understanding of TB, showing how HCWs can ensure a significant shift in perspectives about TB. Apart from offering treatment, HCWs play an important role in educating people about illness and countering and challenging myths and misinformation about the disease. This becomes important in addressing stigma related to TB.

4) Effective implementation of the Tuberculosis (Treatment and Eradication) Bill, 2022

The TB Bill 2022 is a comprehensive national strategy that aligns with the NSP for TB elimination in India. It places emphasis on strengthening infrastructure and services, stakeholder involvement, and government responsibilities. The bill also prohibits discrimination on any grounds and highlights outreach activities to increase awareness, which is crucial for combating TB stigma and improving TB control efforts in the country. Effective implementation of this bill would strengthen the fight against TB and the associated stigma.

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Annexure-Tables and Figures

Table 1: Socio-demographic characteristics of survey population of PwTB/PwhTB

Characteristics	Urban Vulnerable (UV) (N=400)		Tea Garden Worker (TGW) (N=385)	
	Percentage	Numbers	Percentage	Numbers
Age (in years)				
18–29	27.5	110	32.2	124
30–39	18.2	73	21.8	84
40–49	24.8	99	22.9	88
50 and above	29.5	118	23.1	89
Gender				
Male	57.5	230	58.2	224
Female	42.5	170	41.8	161
Religion				
Hindu	86.5	346	86	331
Muslim	11.2	45	1	4
Christian	2.2	9	12.7	49
Others	0	0	0.3	1
Caste				
SC	20.8	83	7	27
ST	10	40	7.3	28
OBC	49.2	197	75.8	292
Others	20	80	9.9	38
Education Level				
No schooling	14	56	32.7	126
Primary	24	96	48.3	186
Secondary	43.5	174	16.9	65
Higher	18.5	74	2.1	8
Marital Status				
Never married	19.5	78	16.9	65
Currently married	75	300	76.4	294
Divorced/ Separated	0.5	2	0.8	3
Widowed	5	20	6	23
Working Status				
Currently working	49	196	47	181
Currently not working	51	204	53	204

Table 2: Socio-economic and demographic characteristics of family members and caregivers of PwTB/PwhTB

Characteristics	Urban Vulnerable		Tea Garden Worker	
Total Sample (N)	400		385	
	Percentage	Numbers	Percentage	Numbers
Age (in years)				
18–29	27.5	110	33.5	129
30–39	25.0	100	27.3	105
40–49	25.8	103	21.8	84
50 and above	21.8	87	17.4	67
Gender				
Male	42.2	169	36.4	140
Female	57.8	231	63.6	245
Religion				
Hindu	86.5	346	86.2	332
Muslim	11.2	45	1.0	4
Christian	2.2	9	12.5	48
Others	0.0	0	0.3	1
Caste				
SC	20.0	80	7.8	30
ST	10.2	41	7.8	30
OBC	50.2	201	75.6	291
Others	19.5	78	8.8	34
Education Level				
No schooling	16.2	65	34.0	131
Primary	19.5	78	41.6	160
Secondary	44.5	178	22.1	85
Higher	19.5	78	2.3	9
Marital Status				
Never married	18.5	74	13.2	51
Currently married	76.2	305	81.8	315

Divorced/ Separated	0.0	0	0.3	1
Widowed	5.2	21	4.7	18
Working Status				
Currently working	63.2	253	71.4	275
Currently not working	36.8	147	28.6	110
Relation with PWTB/PWHTB				
Parent	20.2	81	16.6	64
Grandparent	0.8	3	0.5	2
Spouse	37.0	148	44.9	173
Children	20.0	80	15.3	59
Grandchildren	0.8	3	0.8	3
Sibling	16.0	64	8.1	31
Others	5.2	21	13.8	53

Table 3: Socio-economic and demographic characteristics of community members of PwTB/ PwhTB

Characteristics	Urban Vulnerable (N=400)		Tea Garden Worker (N=385)	
	Percentage	Numbers	Percentage	Numbers
Age (in years)				
18–29	25.0	100	28.1	108
30–39	30.0	120	30.6	118
40–49	21.8	87	27.0	104
50 and above	23.2	93	14.3	55
Gender				
Male	35.2	141	56.4	217
Female	64.8	259	43.6	168
Religion				
Hindu	87.8	351	85.5	329

Muslim	10.8	43	1.3	5
Christian	1.3	5	13.0	50
Others	0.3	1	0.3	1
Caste				
SC	20.0	80	7.5	29
ST	6.8	27	7.5	29
OBC	59.5	238	74.5	287
Others	13.8	55	10.4	40
Education Level				
No schooling	10.8	43	32.5	125
Primary	26.2	105	41.8	161
Secondary	45.5	182	20.8	80
Higher	17.5	70	5.0	19
Marital Status				
Never married	9.5	38	11.9	46
Currently married	86.0	344	81.6	314
Divorced/ Separated	0.0	0	0.3	1
Widowed	4.5	18	6.2	24
Working Status				
Currently working	62.3	249	67.0	258
Currently not working	37.8	151	33.0	127
Personally known number of people with PwTB/PwhTB				
None	49.0	196	7.8	30
One	23.2	93	28.8	111
Two or more	10.2	41	57.1	220
Don't know	17.5	70	6.2	24

Table 4: Socio-economic and demographic characteristics of healthcare providers

Characteristics	Urban Vulnerable (N=80)		Tea Garden Workers (N=86)	
	Percentage	Sample	Percentage	Sample
Age (in years)				
18–29	17.5	14	7	6
30–39	43.8	35	29.1	25
40–49	26.2	21	40.7	35
50 and above	12.5	10	23.3	20
Gender				
Male	63.7	51	64	55
Female	36.2	29	36	31
Religion				
Hindu	93.8	75	86	74
Muslim	3.8	3	4.7	4
Christian	2.5	2	9.3	8
Caste				
SC	28.7	23	2.3	2
ST	5	4	5.8	5
OBC	48.8	39	66.3	57
Others	17.5	14	25.6	22
Education Level				
Primary	1.2	1	3.5	3
Secondary	35	28	48.8	42
Higher	63.7	51	47.7	41
Marital Status				
Never married	17.5	14	10.5	9
Currently married	80	64	86	74
Divorced/ Separated	1.2	1	0	0
Widowed	1.2	1	3.5	3

Designation				
Medical officer	17.5	14	18.6	16
Senior treatment supervisor	6.2	5	8.1	7
STLS	3.8	3	8.1	7
Lab technicians	18.8	15	17.4	15
TB health volunteers	17.5	14	1.2	1
ASHA	36.2	29	34.9	30
Health Assistant	0	0	11.6	10
Worked with PWTB previously				
Yes	97.5	78	94.2	81
No	2.5	2	5.8	5

Figure 1.1: Major risk factor for TB as per PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Malnutrition/Unbalanced diet	45	28.3
Alcoholism	15	25.2
Smoking	13.5	1.6
Other	1.2	9.9
HIV	1	0

Figure 1.2: Signs and symptoms of TB as per PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Cough for more than 2 weeks	85.2	78.2
Fever	69.8	52.7
Fatigue	69.8	35.8
Weight loss	66.2	48.3
Loss of appetite	44.2	36.4
Chest pain	20.8	41.8
Night sweats	18.8	19.5
Blood in sputum	17.8	30.9
Other	0	11.2

Figure 1.3: Spread of TB as per PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Through air droplets when a person coughs or sneezes	98.9	73
Through eating from the same plate	9.4	82.2
Through touching items	3.4	42.7
Through handshakes	2.9	28.5
Other	0.3	5

Figure 1.4: Measures to get cured of TB as per PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Adherence to medicines	96.5	93.1
Regular check-up	82.4	65
Healthy food	69.8	47.5
Appropriate rest	26.4	28.6
Maintaining hygiene	26.2	30.3
Avoiding alcohol or tobacco	16.6	39.4
A positive mindset	12.8	24.4
Through prayer	0.8	2.8
Traditional medicine	0.5	2.8
Other	0	1.7

Figure 1.5: Comprehensive knowledge of TB among PwTB/PwhTB	Urban Vulnerable
Urban Vulnerable	77
Tea Garden Workers	44.42

Figure 1.6: Measures to prevent TB as per PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Cover mouth while sneezing or coughing	87.9	78.5
Through good nutrition	33.2	47.1
Avoid sharing plates with PwTB	25.9	81.1
Avoid shaking hands with PwTB	25.6	46.5
Wash hands after touching public items	6.3	30.3
Close windows	0	13.1
Other	0	7.4

Figure 1.7: Dimensions of stigma

Stigma	Urban Vulnerable	Tea Garden Workers
Perceived Stigma	41.5	14.3
Observed Stigma	16.5	5.2
Experienced Stigma	40.8	10.6

Figure 1.8: Stigma metrics among PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
I keep a distance from others to avoid spreading TB germs.	65	74.3
I feel hurt at how others react upon knowing I have TB.	54.8	30.1
I choose carefully who I tell about having TB.	33.5	26.8
I lose friends when I share with them that I have TB.	26.2	12.2
I am afraid to tell those outside my family that I have TB.	26.2	14
I feel guilty because my family has the burden of caring for me.	18.8	41.6
I feel alone.	15.5	30.1
I feel guilty for getting TB because of my smoking, drinking, or other careless behaviours.	12.8	28.6
I am afraid of going to TB clinics because other people might see me there.	8.8	7
I am afraid to tell others that I have TB because they may think that I also have HIV/AIDS.	8	2.6
I am afraid to tell my family that I have TB.	7.8	6.5
I am worried about having HIV/AIDS.	2.2	2.3

Figure 1.9: Perceived stigma as a barrier to seeking TB services

Urban Vulnerable	6.67
Tea Garden Workers	5.88

Figure 1.10.1: Stigma experienced by UV PwTB on their TB journey under different settings as a barrier to treatment journey (N=162)

Experienced stigma among PwTB	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	14.1	15.3	14.1	16	15.3	9.2	9.8
Stigma among community/ neighbours	42.9	59.5	42.9	49.1	58.9	30.7	28.2
Stigma in home/ family	29.4	41.1	27	31.3	36.8	19	20.2
Stigma at workplace	6.7	7.4	6.1	6.7	7.4	6.7	6.7

Figure 1.10.2: Stigma experienced by TGWs who are PwTB under different settings as a barrier to treatment journey (N=36)

Experienced stigma among PwTB	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	31.7	22	19.5	19.5	14.6	9.8	7.3
Stigma among community/ neighbours	41.5	39	34.1	31.7	29.3	19.5	4.9
Stigma in home/ family	9.8	12.2	9.8	9.8	7.3	4.9	0
Stigma at workplace	17.1	9.8	9.8	2.4	4.9	0	0

Figure 1.11.1: Stigma experienced by other UV PwTB on their TB journey under different settings as a barrier to treatment journey, as observed by PwTB/PwhTB (N=66)

Observed stigma among PwTB	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	12.1	16.7	12.1	13.6	15.2	12.1	12.1
Stigma among community/ neighbours	57.6	83.3	59.1	62.1	78.8	57.6	48.5
Stigma in home/ family	36.4	48.5	37.9	40.9	51.5	34.8	33.3
Stigma at workplace	7.6	10.6	6.1	9.1	9.1	9.1	9.1
Stigma in any other settings	1.5	1.5	1.5	1.5	1.5	1.5	1.5

Figure 1.11.2: Stigma experienced by other TGWs who are PwTB on their TB journey under different settings as a barrier to treatment journey, as observed by PwTB/PwhTB (N=18)

Observed stigma among PwTB	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	36.4	27.3	27.3	18.2	18.2	22.7	9.1
Stigma among community/ neighbours	40.9	22.7	18.2	22.7	22.7	18.2	9.1
Stigma in home/ family	4.5	4.5	4.5	4.5	4.5	9.1	4.5
Stigma at workplace	0	0	0	0	0	4.5	0
Stigma in any other settings	0	0	0	0	0	0	0

Figure 2.1: Knowledge of major risk factors for TB as per PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Malnutrition/Unbalanced diet	40.5	29.9
Don't know	24.2	32.5
Alcoholism	14.8	27
Smoking	18.5	1.6
Other	1.2	9.1
HIV	0.8	0

Figure 2.2: Signs and symptoms of TB as per PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Cough for more than 2 weeks	85.2	78.2
Fever	69.8	52.7
Weight loss	66.2	48.3
Chest pain	20.8	41.8
Blood in sputum	17.8	30.9
Loss of appetite	44.2	36.4
Fatigue	69.8	35.8
Night sweats	18.8	19.5
Other	0	11.2

Figure 2.3: Knowledge of transmission of TB among family members and caregivers of PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Through air droplets when a person coughs or sneezes	97.3	64.9
Through eating from the same plate	13.4	75
Through touching items	10.9	38.1
Through handshakes	4.6	25.9
Other	0.8	7.3

Figure 2.4: Knowledge of curative measures for TB among family members and caregivers of PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Adherence to medicines	96.4	92.6
Regular check-up	80.7	60.5
Healthy food	73.4	41.7
Avoid alcohol or tobacco	21.1	39.2
A positive mindset	17.3	24.3
Appropriate rest	24.4	29.3
Maintaining hygiene	23.6	27.5
Traditional medicine	0.5	3.1
Through prayer	0.8	3.3
Other	0.3	1.7

Figure 2.5: Comprehensive knowledge of TB among family members and caregivers of PwTB

Urban Vulnerable	82.75
Tea Garden Workers	48.83

Figure 2.6: Knowledge of preventive measures of TB among family members and caregivers of PwTB/PwhTB

	Urban Vulnerable	Tea Garden Workers
Cover mouth while sneezing or coughing	89.4	76.7
Good nutrition	31.7	42.1
Avoid sharing plates with PwTB	25.9	45.7
Avoid shaking hands with a person with TB	25.9	80.1
Wash hands after touching public items	6.1	26.8
Close windows	0.5	10.2
Other	0.3	14.2

Figure 2.7: Stigma among PwTB

	Urban Vulnerable	Tea Garden Workers
Perceived Stigma	85.5	83.12
Observed Stigma	16.5	5.2
Experienced Stigma	40.8	10.6

Figure 2.8: Perceived stigma metrics of family members and caregivers

	Urban Vulnerable	Tea Garden Workers
My family member asks me to keep my TB status a secret.	33.8	4.2
I hide the fact that my family member has TB from the	32.5	4.7
My family member hides his/her TB diagnosis from the	29.5	4.9
I avoid talking about TB in the presence of other family	27.3	5.5
I have noticed changes in my family member since the TB	24.2	23.1
I substitute another word for TB in conversations with my	16	3.4
I substitute another word for TB in conversations with my	15.5	3.6
I feel ashamed because my family member has TB.	5	4.2
I am afraid that someone will see me at the health care cl	3.5	3.1
I am worried about becoming infected.	3.5	13.2

Figure 2.9a: Stigma experienced by family members of UV PwTB under different settings as a barrier to treatment support (N=61)

Experienced stigma among PwTB	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	18	23	18	19.7	23	16.4	16.4
Stigma among community/ neighbours	52.5	73.8	55.7	57.4	73.8	37.7	16.4
Stigma in home/ family	29.5	37.7	23	29.5	32.8	16.4	18
Stigma at workplace	3.3	4.9	4.9	3.3	6.6	4.9	6.6
Stigma in other setting (college/ bus)	0	0	1.6	0	0	1.6	0

Figure 2.9b: Stigma experienced by family members of TGWs who are PwTB under different settings as a barrier to treatment support (N=11)

Experienced stigma among PwTB	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	14.3	14.3	4.8	4.8	4.8	4.8	4.8
Stigma among community/ neighbours	42.9	23.8	33.3	33.3	33.3	23.8	4.8
Stigma in home/ family	14.3	19	9.5	9.5	9.5	9.5	4.8
Stigma at workplace	9.5	9.5	14.3	14.3	14.3	14.3	4.8
Stigma in other setting (college/ bus)	4.8	0	0	0	0	0	0

Figure 2.10a: Stigma observed by family members of UV PwTB/PwhTB under different settings as a barrier to treatment support (N=70)

Observed stigma among family members	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	21.4	25.7	22.9	24.3	27.1	21.4	21.4
Stigma among community/ neighbours	55.7	78.6	65.7	68.6	78.6	58.6	21.4
Stigma in home/ family	44.3	68.6	51.4	55.7	67.1	47.1	45.7
Stigma at workplace	10	12.9	11.4	11.4	12.9	11.4	11.4
Stigma in other setting (college/ bus)	1.4	4.3	2.9	2.9	2.9	2.9	2.9

Figure 2.10b: Stigma observed by family members of TGWs who are PwTB under different settings as a barrier to treatment support (N=13)

Experienced stigma among PwTB	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	30.8	23.1	23.1	23.1	23.1	23.1	23.1
Stigma among community/ neighbours	46.2	46.2	46.2	46.2	53.8	46.2	23.1
Stigma in home/ family	7.7	15.4	7.7	7.7	7.7	7.7	0
Stigma at workplace	0	0	0	0	0	0	0
Stigma in other setting (college/ bus)	0	0	0	0	0	0	0

Figure 3.1: Community members' attitudes towards TB

		Urban Vulnerable	Tea Garden Workers
Level of seriousness	Very serious	20.2	51.4
	Serious	35.5	36.6
	Not very serious	41.8	10.9
	Don't know	2.5	1
Considering oneself susceptible	Yes	6.8	30.1
	No	78.5	57.4
	Don't know	14.8	12.5
Reaction to the revelation of having TB	Fear	49.2	49.6
	Surprise	15.8	14
	Shame	0.2	1.3
	Embarrassment	0.2	4.2
	Sadness/ Hopelessness	3.5	6.2
	Other	29.5	19
	Can't say	1.5	5.7

Figure 3.2: Knowledge of major risk factors for TB among community members

	Urban Vulnerable	Tea Garden Workers
Malnutrition/Unbalanced diet	33	28.8
Alcoholism	24.2	31.7
Don't know	24.2	26.5
Smoking	16.5	3.4
HIV	1.8	0
Other	0.2	9.6

Figure 3.3: Knowledge of signs and symptoms of TB among community members

Cough for more than 2 weeks	87.5	79
Fever	64	46.2
Weight loss	60.8	40.5
Chest pain	13.2	33.8
Blood in sputum	22.8	43.6
Loss of appetite	33.2	25.5
Fatigue	46.2	29.4
Night sweats	8.2	17.7
Other	0.2	6.2

Figure 3.4: Knowledge of transmission of TB among community members

Through air droplets when a person coughs or sneezes	96.6	69
Through touching items	9.1	39.4
Through eating from the same plate	15.3	67.2
Through handshakes	2.8	24.8
Other	0.3	9

Figure 3.5: Knowledge of curative measures of TB among community members of PwTB/PwhTB

Adherence to medicines	95.4	91.1
Regular check-up	77.7	57.5
Healthy food	55.1	38.9
Avoiding alcohol or tobacco	18.5	37.5
A positive mindset	8.9	19.7
Appropriate rest	13.7	24.4
Maintaining hygiene	18.5	26.1
Traditional medicine	0.8	4.4
Through prayer	0.5	3.1
Other	0	1.4

Figure 3.6: Comprehensive knowledge of TB among community members of PwTB

Urban Vulnerable	98.25
Tea Garden Workers	99.22

Figure 3.7: Knowledge of preventive measures of TB among community members of PwTB/PwhTB

Avoid shaking hands with people who have TB	23.5	45.3
Cover mouth or nose while coughing	86.4	70.4
Avoid sharing plates with people who have TB	32.8	70.9
Wash hands after touching public items	4.5	25.1
Close windows	0.3	12
Good nutrition	25.6	37.3
Other	0.3	7.4

Figure 3.8: Reporting of stigma by community members

	Urban Vulnerable	Tea Garden Workers
Perceived Stigma	86.25	86.49
Observed Stigma	34.75	6.23

Figure 3.9: Perceived stigma metrics towards PwTB/PwhTB

Some people might not want to eat or drink with friends who have TB.	63.5	42.9
Some people feel uncomfortable being near those who have TB.	52.5	36.6
If a person has TB, some community members will behave differently towards that person for the rest of their life.	28	20.5
Some people do not want those with TB playing with their children.	68.5	37.9
Some people keep their distance from people with TB.	66.8	52.7
Some people think people with TB are disgusting.	29.8	21.8
Some people do not want to talk to those who have TB.	35.2	24.9
Some people are afraid of people with TB.	40.5	35.1
Some people try not to touch people who have TB.	41.5	43.1
Some people may not want to eat or drink with relatives who have TB.	49.5	30.1
Some people prefer not to have people with TB living in their community.	28.7	15.6

Figure 3.10a: Stigma experienced by UV PwTB/PwhTB under different settings as a barrier to treatment journey, as observed by community members (N=139)

	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	15.1	20.9	13.7	16.5	20.1	12.9	12.2
Stigma among community/ neighbours	60.4	79.1	63.3	69.8	75.5	54.7	52.5
Stigma in home/ family	38.8	57.6	43.9	47.5	56.8	36.7	35.3
Stigma at workplace	7.9	10.8	10.1	10.8	12.2	8.6	8.6
Stigma in other setting (college/ bus)	5	5	3.6	5	5.8	4.3	3.6

Figure 3.10b: Stigma experienced by PwTB/PwhTB from the TGW group under different settings as a barrier to treatment journey, as observed by community members (N=18)

	Recognising symptoms	Seeking care	Getting an accurate diagnosis	Beginning treatment	Getting treatment adherence support	Completing treatment	Getting post-treatment follow-up services
Stigma in hospitals/ clinics	25	25	20.8	8.3	12.5	12.5	8.3
Stigma among community/ neighbours	58.3	50	50	45.8	45.8	37.5	16.7
Stigma in home/ family	16.7	16.7	16.7	16.7	16.7	16.7	16.7
Stigma at workplace	12.5	12.5	12.5	12.5	12.5	12.5	4.2
Stigma in other setting (college/ bus)	4.2	4.2	4.2	0	0	0	0

Figure 4.1: Health workers' attitudes towards TB

		Urban Vulnerable	Tea Garden Workers
Level of seriousness	Very serious	37.5	48.8
	Serious	26.2	37.2
	Not very serious	36.2	14
Considering oneself susceptible	Yes	55	79.1
	No	40	17.4
	Don't know	5	3.5
Reaction to the revelation of having TB	Fear	26.2	25.6
	Surprise	17.5	5.8
	Embarrassment	2.5	5.8
	Sadness/ Hopelessness	8.8	11.6
	Other	1.2	33.7
	Can't say	43.8	17.4
	Can't say	1.5	5.7

Figure 4.2: Knowledge of major risk factors for TB among HCWs

	Urban Vulnerable	Tea Garden Workers
Malnutrition/Unbalanced diet	41.2	33.7
Smoking	28.7	1.2
HIV	16.2	8.1
Alcoholism	12.5	33.7
Other	1.2	22.1
Don't know	0	1.2

Figure 4.3: Knowledge of signs and symptoms of TB among HCWs

Cough for more than 2 weeks	97.5	100
Fever	92.5	96.5
Weight loss	96.2	83.7
Chest pain	63.7	61.6
Blood in sputum	82.5	64
Loss of appetite	82.5	62.8
Fatigue	77.5	50
Night sweats	85	64
Other	0	12.8

Figure 4.4: Medium of transmission of TB as per HCWs

Through air droplets when a person coughs or sneezes	98.8	96.5
Through touching items	10	24.4
Through eating from the same plate	10	72.1
Through handshakes	10	16.3
Other	0	7

Figure 4.5: Stigmatisation among HCWs in different settings

		Urban Vulnerable	Tea Garden Workers
Experienced Stigma	Place of work (hospitals/clinics)	75	80
	Place of residence	50	40
	Family/relatives	25	20
Observed Stigma	Place of work (hospitals/clinics)	100	60
	Place of residence	60	60
	Family/relatives	40	20

Figure 4.6: Stigma towards PwTB/PwhTB by HCWs

	Urban Vulnerable	Tea Garden Workers
Some healthcare workers are nervous about treating TB patients.	17.5	17.4
Some healthcare workers feel pity for TB patients.	71.2	69.8
Some healthcare workers don’t like helping TB patients	12.5	15.12
Some healthcare workers stay away from TB patients	11.2	20.9
Some healthcare workers think developing TB is the person’s own fault.	18.8	33.7
Some healthcare workers feel angry towards TB patients	12.5	17.4
Some healthcare workers think it would be best for TB patients to be isolated during the intensive phase of treatment.	33.8	55.8
Some healthcare workers feel TB patients are dangerous.	15	31.4
Some healthcare workers think TB treatment should be forced if necessary.	48.8	3.3

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