Health-seeking Behaviour and the Barriers to Early Diagnosis and Initiation of Treatment among TB Survivors and Patients in Southern Districts of Tamil Nadu

Submitted to

Submitted by

Public Affairs Centre

December 2022

Preface

Public Affairs Centre (PAC) engages in action research focussing on Sustainable Development Goals (SDG) in the context of India. PAC is a not for profit Think Tank established in 1994 with a mandate to improve the quality of governance in India. The Centre is also a pioneer in deploying innovative Social Accountability Tools (SAT) to measure the quality and adequacy of public services. Over the years, its scope of work has expanded to include the whole gamut of research-advocacy-action to lead evidence-based research on governance across sectors, geographies and populations in India.

PAC was one of the first civil society-led institutional initiatives to mobilise demand for good governance in India. Dr. Samuel Paul (Founder Chairman) was instrumental in establishing PAC with a select group of friends. PAC is registered under Karnataka Societies Registration Act 1960 as a Society.

Designing and Editing by: PEC

Disclaimer

Public Affairs Centre
#15, KIADB Industrial Area,
Jigani-Bommasandra Link Road,
Jigani Post, Anekal Taluk,
Bangalore - 560105,
Karnataka, India
TeleFax: +918027839918/19/20

Email: pec@pacindia.org

Website: www.pacindia.org

Executive Summary

Public Affairs Centre (PAC) conducted a study titled "Health Seeking Behaviour and the Barriers in Early Diagnosis and Initiation of Treatment among TB Survivors and Patients in the Southern Districts of Tamil Nadu" funded by Blossom Trust and Stop TB Partnership. The study was conducted in the Madurai, Virudhunagar and Ramanathapuram Districts of Tamil Nadu.

The study aims to ensure a person-centred delivery of TB programmes promoting a gender-responsive TB approach, driven by meaningful community engagement. The study was conducted in the project areas of Blossom Trust - Madurai, Virudhunagar, and Ramanathapuram, 3 districts of Tamil Nadu over 10 months (February 22 to December 21, 2022).

PAC conducted a cross-sectional study which included both a Quantitative analysis (TB Survivor and patient – Demand side) and a Qualitative study (Senior Treatment Supervisors (STS) and Health Visitors (HV) – Supply side) to understand the health-seeking behaviour and the barriers in early diagnosis and initiation of treatment among TB survivors and patients.

Findings

1. The total number of TB survivors and TB patients who gave consent and were interviewed for the study was 236. Of these 76% (180) were TB survivors and 24% (56) were TB patients. Among them 61% (145) were male and 39% (91) were female. A majority of participants belonged to the age group of 36 – 50 years
2. Socio economic status is classified by using the Modified Kuppuswamy socio-economic scale 2021. A majority (69%) of the participants with TB (163) belonged to the upper lower class and only 13% were from the lower class before the illness. There was a change in the class level from upper lower class to the lower class after the TB diagnosis (66% of the participant belong to the upper lower class and 21% of the participant belong to the lower class)
3. Health-seeking behaviour – Out of 236 participants, 60 participants were self-medicated and 132 participants visited Private Health Care providers and spent an average of Rs. 500 to 50,000 before diagnosis
4. Delay in seeking health care can be divided into 2 components – patient delay and health system delay. The total delay in the current study is 45 days i.e., it took 45 days for the participant to initiate the treatment after the onset of symptoms
5. Out of 236 participants, 192 (81%) participants benefited from Nikshay Poshan Yojana (NPY) whereas 44 (19%) participants were not benefited from NPY.

Regression Analysis found that participants residing in rural areas and engaged in unskilled jobs or staying unemployed showed less knowledge on Tuberculosis. The present study shows that stigma has a more significant impact on women and also among poor or less educated community members. Low socio-economic status, stigma associated with Tuberculosis and consulting a private physician in the initial stages were found to be significantly associated with the diagnostic and treatment delay.

Recommendations

1. Improve community engagement through TB survivors and TB champions and train them to deliver effective awareness programmes (IEC Campaign) on the aetiology, symptoms and transmission of the disease to enhance the knowledge on TB in affected communities and regarding health-seeking behaviour
2. Plan active case findings in the affected geographic areas and Source Reduction (Contact Tracing) should also be done frequently to improve the notification of TB Cases.
3. Private sector notification can be improved by providing intensive training to the Doctors working in Private hospitals and Private clinics and emphasis about the importance of the End TB Strategy – Elimination of TB in India by 2025

4. Monitor the functioning of Direct Benefit Transfer (DBT) and providing Nutrition supplements through NGOs and the Public distribution system (PDS) will improve the Nutrition status of the TB-affected communities
5. Provide Gender-specific interventions that address individual-level stigma and health literacy barriers to improve access to TB services.

Contents

List of Tables

List of Figures

Introduction

Tuberculosis (TB) is a major public health challenge worldwide. It is the second leading cause of death from infectious diseases next only to the Human Immunodeficiency Virus (HIV). [1] More than 90% of global TB cases and deaths occur in the developing world where 75% of the cases are in the most economically productive age group (15–54 years).

Poor adherence to TB protocol that follows a strict regimen contributes to the worsening of the TB situation not only by increasing incidence, but also by creating drug resistance. Resistance to anti-TB drugs has become a serious obstacle in the control of the disease. Patients' poor adherence to anti-TB therapy, with an estimate of as low as 40% adherence in developing countries, remains the principal cause of treatment failure globally.[1] The WHO recommends at least an 85% cure rate for all diagnosed TB cases. To achieve this cure rate, adherence needs to be in the order of 85–90%.

Evidence from a variety of literature shows that there are many factors affecting the adherence to TB treatment. Lack of access to formal health services, traditional beliefs leading to self-treatment, loss of income, lack of social support, drug side effects, pill burden, lack of food, stigma with lack of disclosure, and lack of adequate communication with health professionals are some of the documented factors. [1]

Blossom Trust (BT), a leading NGO working in the area of TB eradication, is currently working on a project for creating a civil society network on TB to transform TB response at the national level by amplifying community voices to foster more inclusive gender-transformative and stigma-free access to health services at all levels. To ensure that the design of the TB response is backed by sound evidence collected on an experiential basis from stakeholders on the ground, BT reached out to the Public Affairs Centre (PAC), an independent not-for-profit think tank based in Bengaluru. PAC has been working on good governance since 1994 using a repertoire of Social Accountability Tools (SAT) that ensures evidence-based advocacy and action that is community-led and therefore context-specific and resource-sensitive as well.

An MoU was signed between BT and PAC to define PAC's role in supporting BT's endeavour to carry out informed advocacy among TB-affected patients and their households (Refer Annexure 1).

The following report is a detailed analysis and presentation of findings from the activities carried out by PAC in consensus with BT to meet the objectives outlined in the MoU.

Background

The Civil Coalition for TB Advocacy and Treatment Adherence is a project designed to bridge the gap between the TB community response and national-level policy. As outlined in the Deadly Divide, communities are calling for a TB response that acknowledges how stigma and discrimination exacerbate health inequality, minimal social support, economic insecurity, and low levels of TB literacy. Additionally, the ongoing impact of COVID-19 further minimizes the capacity of the healthcare system leading to a disruption of treatment adherence.[2]

Driven by this mission of the overarching project, the project led by BT aims to ensure a person-centred delivery of TB programmes promoting a gender-responsive TB approach, driven by meaningful community engagement. BT's programme has been designed to systematically address issues like the health-seeking behaviour of TB patients, human rights concerns and gender barriers within highly prevalent TB communities, and the factors affecting Treatment. The project will provide support to enhance community engagement among the TB communities which improve their health-seeking behaviour and reduce non-adherence to treatment among the TB communities.

The study presented in this report covered the project areas of Blossom Trust, 3 districts of Tamil Nadu - Madurai, Virudhunagar, and Ramanathapuram, over a period of 10 months (February 22 to December 21, 2022) to understand, assess and find ways to deter non-adherence and encourage health-seeking behaviour.

Problem Statement

Tuberculosis is a biological expression of social inequality despite being an infectious disease.

Key structural determinants of TB epidemiology include global socioeconomic inequalities, high levels of population mobility, rapid urbanization, and population growth. These conditions give rise to unequal distribution of key social determinants of TB, including food insecurity and malnutrition, poor housing and environmental conditions, and financial, geographic, and cultural barriers to health care access. The distribution of these social determinants influences the 4 stages of TB pathogenesis: exposure to infection, progression to disease, late or inappropriate diagnosis and treatment, and poor treatment adherence and success.

TB stigma and discrimination are perceived to increase TB diagnostic delay and treatment non-compliance. Therefore, it requires systematic effort to empower TB survivors and engage them in advocacy, communication and community engagement activities to improve awareness, normalise the disease and cast out myths.

Objectives

1. Assess the health-seeking behaviour patterns among TB Survivors and TB patients
2. Study the determinants of delay in diagnosis and initiation of treatment in TB
3. Compare the knowledge and perceived stigma towards tuberculosis among people with TB and those who have recovered from TB.

Research Methodology

The study involved a mixed-method approach that included the use of survey methods as well as Focus Group Discussion (FGD) among key stakeholders. While the survey covered the experiences and perceptions of TB survivors, TB patients and their caregivers in the households, FGD were carried out among service providers and policy makers to understand their issues.

This cross-sectional study was conducted in Tamil Nadu from Feb 2022 to Nov 2022. The districts were chosen based on Blossom Trust's project areas – Madurai, Virudhunagar, and Ramanathapuram. The project areas of the Blossom Trust are also on par with the Tamil Nadu state-prioritised list of districts of concern. According to TB Free Tamil Nadu – 2025, Madurai, Virudhunagar, and Ramanathapuram districts of Tamil Nadu were on the prioritised list to carry out intensified activities as they show a high burden of TB prevalence.

Sampling Strategy

Considering that the target population was very specific, though PAC initially planned to carry out a stratified random sampling approach (Refer to Annexure 2), the difficulty in access to data and the sensitivity of the disease led to adjustments. Purposive sampling was thus used to identify the participants in three Districts of Tamil Nadu (Madurai, Virudhunagar and Ramanathapuram). The district is the sample unit of the study.

Inclusion criteria

The criteria included that participants should be

1. Willing to participate in the study
2. Either a TB Survivor or a current TB patient
3. Have experience in approaching health care system for diagnosis and treatment.

Exclusion Criteria

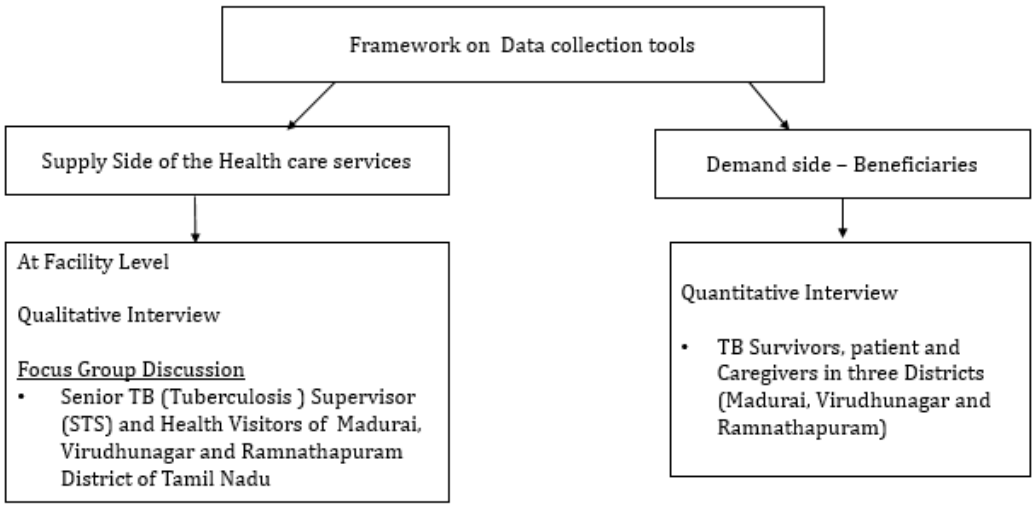
1. Not willing to participate in the study
2. Not a TB Survivor or current TB patient
3. Not having experience in approaching the health care system for diagnosis and treatment.

Data Collection Tool

Data collection was carried out in October 2022. Prior permission was obtained from the Tamil Nadu State TB Cell and the District TB Cell by Blossom Trust – Project Director to conduct the study. Data collection was done through a semi-structured closed-ended questionnaire for quantitative data. Qualitative data was collected through Focus Group Discussions (FGD).

Structure of the Data Collection Tool

Figure 1: Structure of Data Collection Tool



Source: Author created

Quantitative Tool

A structured questionnaire was developed by the PAC Study Team based on the conceptual model adopted from the Rao Kelleher Gender Framework Model. (Refer to Figure 2).

Gender-related factors play a role in the adherence to the strict protocol/guideline that a patient should adhere to complete the treatment regimen. However, it is also clear that these factors are influenced by the formal and informal systems around the patients and the knowledge and attitude of the patients themselves as influenced by formal and informal norms in their households and the community around them.

The Framework for Health Seeking Behaviour Among TB Patients (Adopted from Rao Keller Gender Framework Model) has been adopted as the reference framework for the study to identify factors coming under the quadrants covering systemic-formal, systemic-informal, individual-formal, and individual-informal aspects to be able to mobilise TB advocates through community-led monitoring and advocacy accordingly to overcome barriers related to Health seeking behaviour and stigma-related informal practices.

Questionnaire Themes

The themes were classified based on an extensive literature review on Health seeking behaviour and non–adherence to the treatment protocol (Refer to Annexure 3).

The questionnaire was translated into Tamil (the local language) and back-translated into English and pilot tested.

The questionnaire had the following sections:

1. Socio-demographic details
2. Personal habits like alcohol consumption and smoking
3. Monthly income
4. Health-seeking behaviour
5. Treatment adherence
6. Knowledge of symptoms
7. Modes of transmission and stigma (Refer to annexure 8).

Validated TB Stigma Scales developed by Van Rie et al., (2008) were used to measure stigma related to TB. Variables measuring stigma were coded on a 2-point Likert scale with the following levels: "0" as strongly Disagree and "1" as Strongly Agree.

KOBO Tool Kit Software

To build the pilot-tested questionnaire electronically, the PAC team used the KOBO Tool kit (Survey tool). The investigators were trained in the usage of an electronic tool (KOBO tool) before starting the survey. After the survey, the entered data was directly imported into A Microsoft Excel Sheet and the data analysis was carried out.

Qualitative Tools

Three Focus Group Discussions (FGD) were conducted among Senior Treatment Supervisors (STS), Health Visitors (HV) and Public Private Management (PPM) in three Districts (Madurai, Virudhunagar and Ramanathapuram) of Tamil Nadu (Refer to Annexure 9). An FGD Guide was prepared by the study team to conduct the qualitative study which primarily focuses on the functioning of the NTEP system, usage on the NIKSHAY Portal and the reason for the delay in diagnosis and initiation of treatment for TB patients and TB Survivors.

Informed Consent

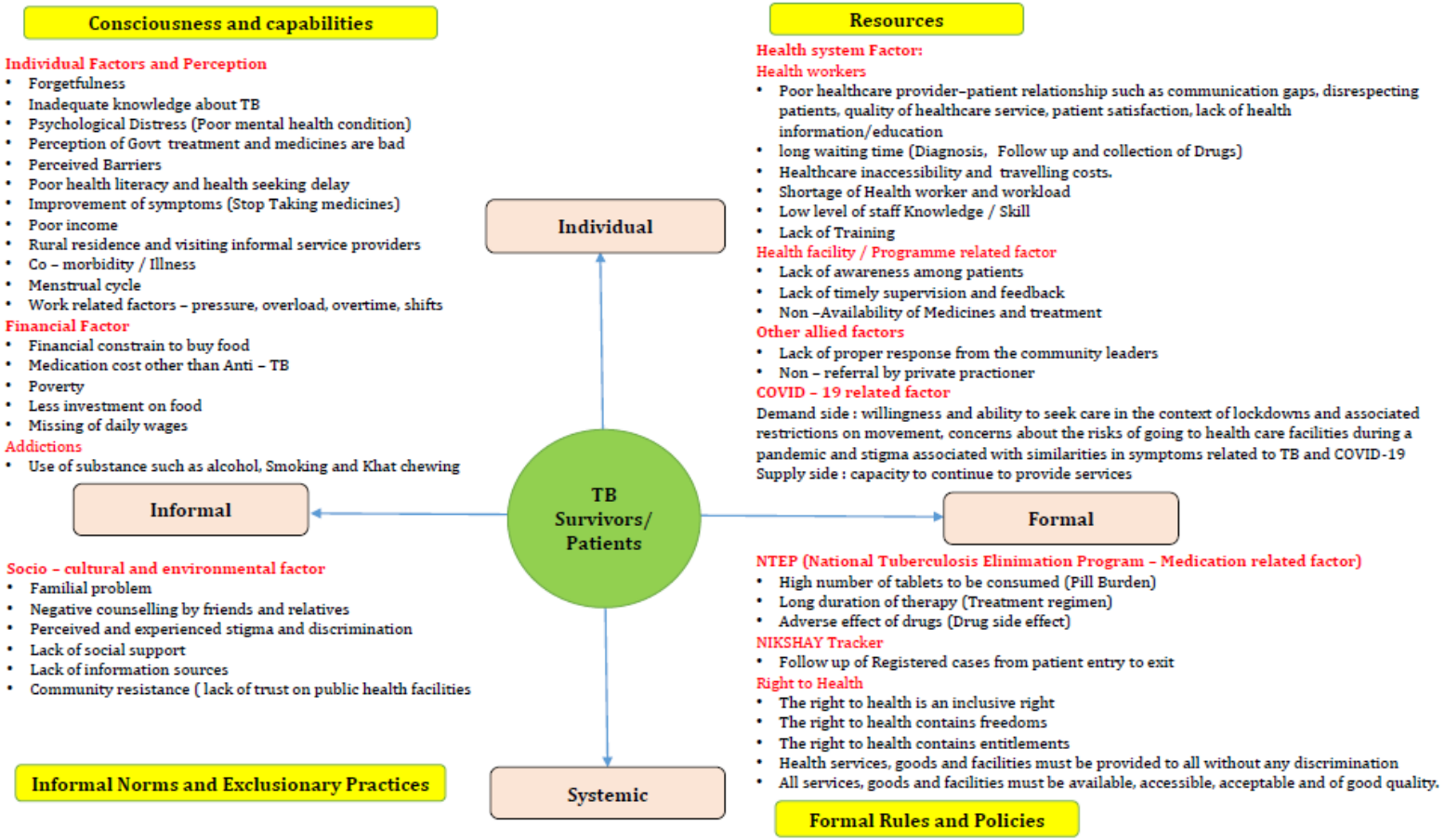
The investigators visited the participants and an information sheet (in Tamil) was explained to them regarding the purpose of the study, the voluntary nature of participation and confidentiality of the concerns and the disease. The participant was verbally explained in their language and further queries were clarified. Finally, their consent was taken orally and entered into the KOBO Tool Kit software.

Framework for Health-seeking Behaviour among TB Survivors and TB patients (Adopted from Rao Keller Gender Framework Model)

Reason for adopting the model: The Rao Keller Gender Framework Model was found to be suitable due to the interplay of both formal and informal institutions on the systemic provision and receipt of TB treatment, and on individual knowledge, behaviour and attitudes towards seeking treatment for TB and adherence to TB treatment protocols.

Availability, Accessibility and Affordability of the right treatment for the right individual at the right time. Socio–cultural factors which disables a person from availing or continuing the treatment and also depending on the strict protocol/guideline that that patient should adhere to complete the treatment regimen. All these factors vary from individual to individual and hence need to be placed in the right quadrant to be able to arrive at strategies that would address each of the issues placed therein. Hence Gender Framework by Rao and Kelleher was adopted to understand the specific factors contributing to Non – adherence to the TB treatment regimen. The Detailed explanation of the Rao Keller Gender Framework Model was attached in the Annexure 3.

Figure 2: Framework for Health Seeking Behaviour among TB Patients and Survivors (Adopted from Rao Keller Gender Framework Mode



Source: Author created

Data Management and Data Analysis

Data Analysis was planned based on the constructed variables. (Refer to Annexure 4). The main outcome variables were delay in diagnosis and treatment, knowledge of tuberculosis (symptoms, modes of transmission, treatment and follow-up) and perceived stigma related to TB.

Delay is the main outcome - delay can be divided into 2 components – patient delay and health system delay. It can also be divided into diagnostic delay and treatment delay.

Descriptive statistics of the socio-demographic variables were carried out. The mean delay in days (patient delay and health system delay) was calculated. Univariate and multivariate analysis was done to see the association between the determinants and the main outcome.

Knowledge and stigma were given scores and the total score was computed. Mean scores were calculated. Knowledge and stigma scores were dichotomised as people with adequate knowledge/inadequate knowledge and people who have perceived stigma/no stigma.

Findings

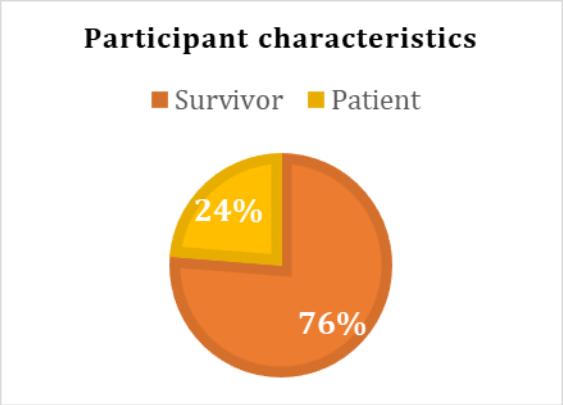
The participants consisted of both men and women in the age group of 18 years and above. The total number of patients who were interviewed for the study was 236.

Socio-Demographic Characteristics of the survey participants

Age and gender distribution of the TB Survivor and TB patient

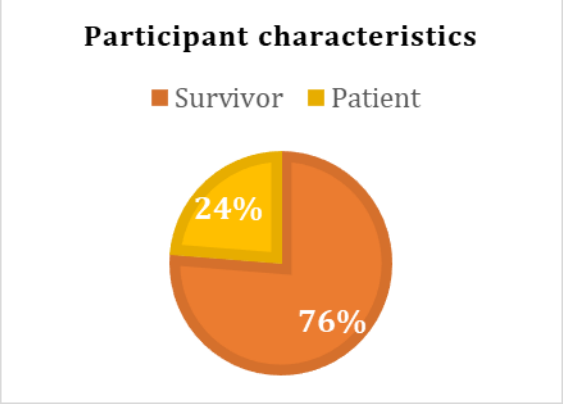
The total number of TB survivors and TB patients who gave consent and were interviewed for the study was 236. Of these 76% (180) were TB survivors and 24% (56) were TB patients (Figure 3). Among them 61% (145) were Male and 39% (91) were female (Figure 4). Most of the participants belong to the age group of 36 – 50 years. (Figure 5).

Figure 3: Participant Composition



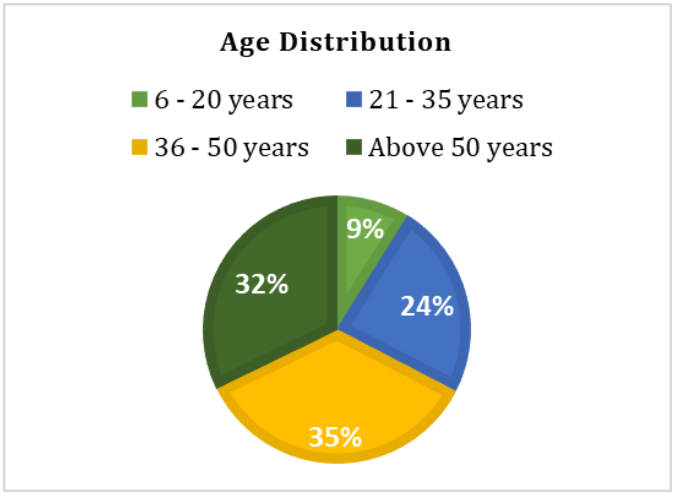
Source: Author created

Figure 4: Gender composition of the participants



Source: Author created

Figure 5: Age Distribution of the participants



Source: Author created

In terms of marital status, of the 236 participants, more than three-fourth were married (Table 1).

Table 1: Marital status of the participants

Marital Status	No of Participants	Percentage
Married	175	74%
Single	41	17%
Widow	14	6%
Divorce	6	3%

Disaggregation of age-wise data by gender shows that male participants were more from the cohort of 51-60 years as against females who were from a younger cohort - 36-50 years (Table 2).

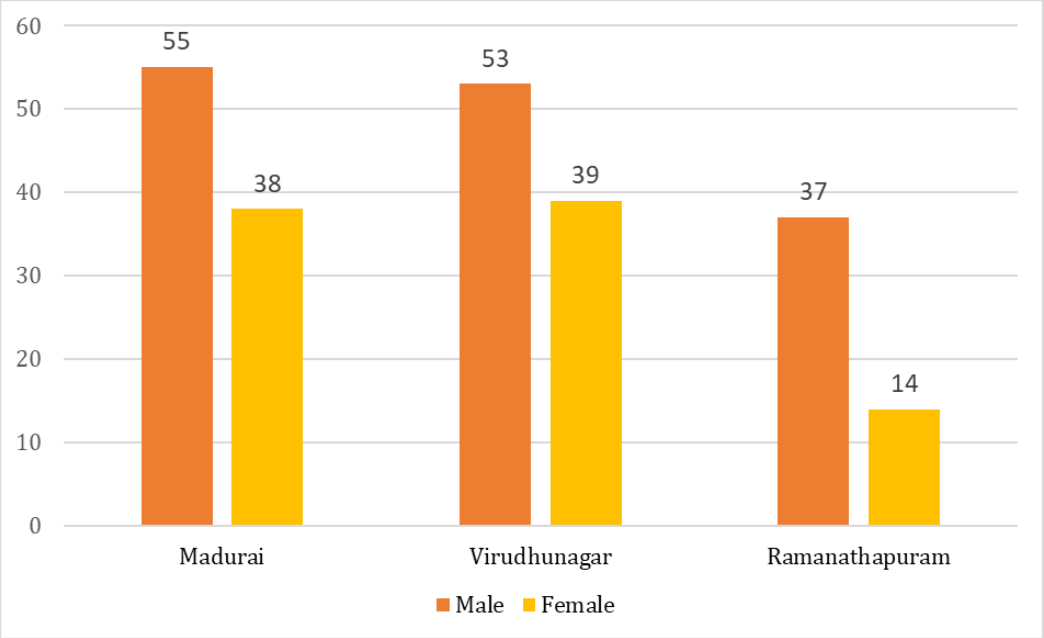
Table 2: Age-wise Gender Distribution of the Participants

Age groups of the participant	Female n (%)	Male n (%)	Total N (%)
6-20	8 (3.39 %)	13 (5.51%)	21 (8.9%)
21-35	29 (12.29 %)	27 (11.44%)	56 (23.73%)
36-50	42 (17.8 %)	41 (17.37%)	83 (35.17%)
51-65	10 (4.24 %)	57 (24.15%)	67 (28.39%)
66-80	2 (0.85 %)	7 (2.97%)	9 (3.81%)

Distribution of Participants in Three Districts by Gender

There were more female participants in the survey in Madurai and Virudhunagar districts than Ramanathapuram.

Figure 6: Gender Distribution by District

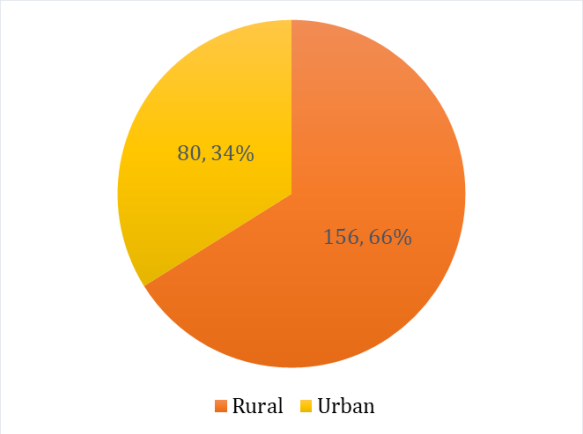


Source: Author created

Urban and Rural Distribution in Frequency and Percentage

One-third of the participants were from the urban areas of the three districts while the remaining were from rural areas.

Figure 7: Urban and Rural Distribution of the participant



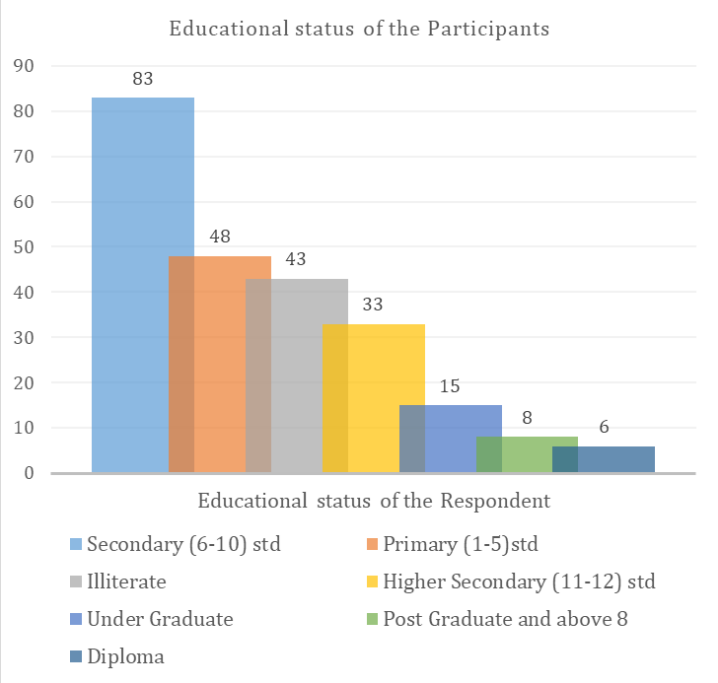
Source: Author created

Education, Occupation and Income of the Participants

Education of the participants

The education of the participants was classified based on Modified Kuppuswamy Scale[3]. Among 236 study participants, 83 participants had education up to Secondary standard (6 – 10 std), 48 participants had education up to Primary standard (1 – 5 std), 33 participants had education up to Higher Secondary standard (11 – 12 std), and only 29 of them had education up to college and above whereas almost 43 participants were illiterate (Figure 8).

Figure 8: Educational status of the participants



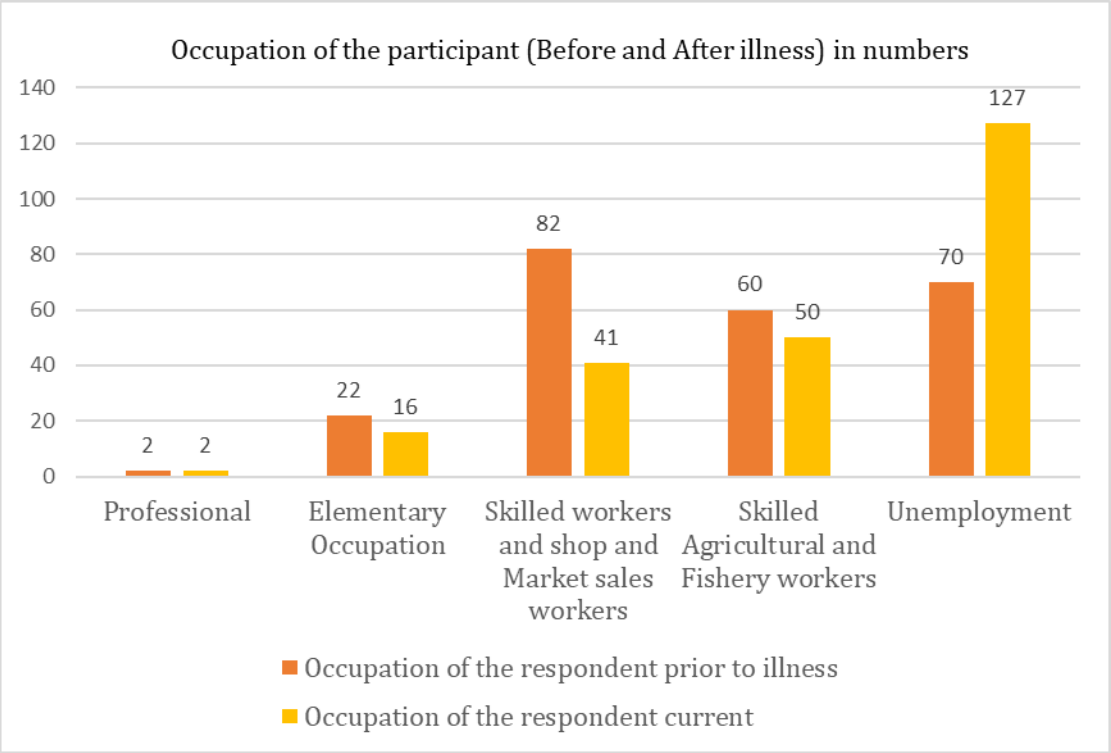
Source: Author created

Occupation of the Participants

Occupations of the participants were classified based on Modified Kuppuswamy Scale[3]. They are classified as Professional, Elementary Occupation, Skilled Workers and Shop and Market Sales Workers, Skilled Agricultural and Fishery workers and Unemployment.

The occupation of the study participants before illness and after illness were recorded in the survey. Most of the participants in this study worked as Skilled Workers Shop and Market Sales Workers (82) and Skilled Agricultural and Fishery Workers (60) but a drastic difference could be seen in Figure 9 which shows that the majority of the participants who worked as skilled workers, Agriculture and Fisheries left their job and became unemployed as they were affected by the disease. (Refer to Figure 9).

Figure 9: Occupation of the participants

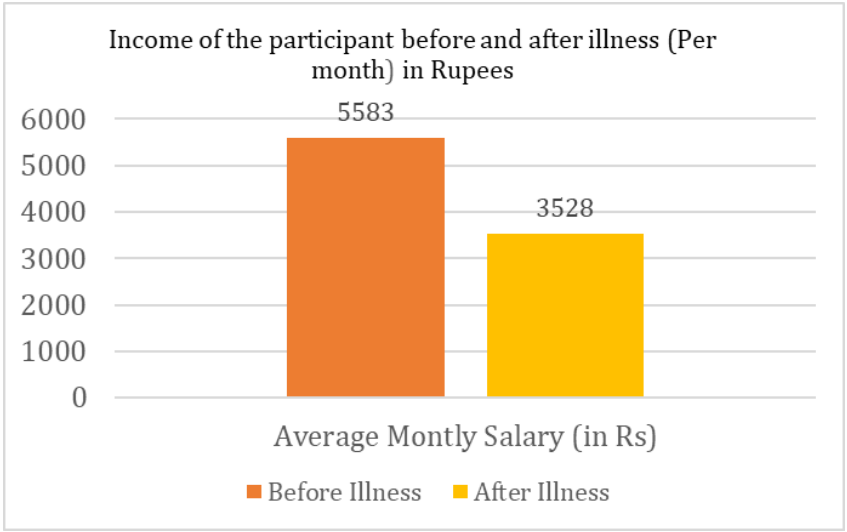


Source: Author created

Income of the participants

The income of the participant was classified based on the Modified Kuppuswamy scale 2021[3]. Figure 10 shows that there is a shift in the occupation before and after illness this is directly reflected in Income which is reduced to Rs. 3528 (per month) from Rs.5583 (per month).

Figure 10: Income of the participant in Rupees



Source: Author created

Socio-Economic Status of the Participants

Socio economic status is classified by using the Modified Kuppuswamy socio-economic scale 2021[3]. The majority (69%) of the participants with TB (163) belonged to the upper lower class and only 13% were from the lower class before the illness whereas there was a change in the class level from Upper Lower class to Lower class where only 66% of the participants belong to Upper Lower class and 21% of the participants belong to the Lower class. Observation from Table 3 shows that there is an 8% increase in the Lower class after they got affected by TB.

Table 3: Socio-Economic Status of the Participants

Modified Kuppuswamy Scale 2021				
Category	**No. of Participants before illness**	**Percentage (%)**	**No. of participants after illness**	**Percentage (%)**
Upper (I)	0	0	0	0
Upper Middle (II)	5	2	2	1
Lower Middle (III)	37	16	30	13
Upper Lower (IV)	163	69	155	66
Lower (V)	31	13	49	21

Personal Habits

The survey recorded the personal habits – smoking and alcohol consumption of the participants. This included the status, frequency and duration of smoking and alcohol consumption.

Smoking

A proportion of the participants with TB who were smoking in the past was 24% (57) as compared to 5% (12) current smokers (Refer Table 4). Among the smokers i.e. current smokers, as well as past smokers 48% (33) of them, consume 0 – 9 cigarettes/beedi per day. Duration of smoking as reported by the participants was 0 - 10 years among 36% (25) of the smokers and more than 10 years among 64% (44) of them. Out of 236 participants, 71% (167) participants stated that they did not have the habit of smoking.

Table 4: Smoking status of the participants

Smoking	**Categories**	**No. of Participants (n)**	**Percentage (%)**
Smoking Status	Past smoking	57	24
	Never	167	71
	Current smoking	12	5
	0-9	33	48
	10-19	28	41

Smoking	Categories	No. of Participants (n)	Percentage (%)
Daily consumption (no of cigarettes smoked per day)	20-29	6	9
	30-40	2	3
Duration of smoking (Years)	0-10	25	36
	10-20	19	28
	20-30	8	12
	30-40	11	16
	40-50	6	9

Alcohol Consumption

The proportion of participants with TB who never consumed alcohol was 69% (164), but 22% (51) of them were consuming alcohol in the past and 9% (21) were currently consuming alcohol (Table 5).

Among those who ever took alcohol (72) i.e., current alcohol abusers as well as those in the past

- 9% consumed weekly and 16% consumed Monthly
- 43% (31) have had the habit of consuming alcohol for less than 10 years whereas 57% (41) have the habit of consuming alcohol, for more than 10 years (Table 5).

Table 5: Alcohol consumption status of the participant

Alcohol Consumption		No. of Participants (n)	Percentage (%)
Drinking Status	Past user	51	22
	Never	164	69
	Current user	21	9
Frequency	Weekly	22	9
	Never	164	69
	Monthly	38	16
	Daily	12	5
Duration (Years)	0-9	31	43
	10-19	21	29
	20-29	9	13
	30-40	11	15

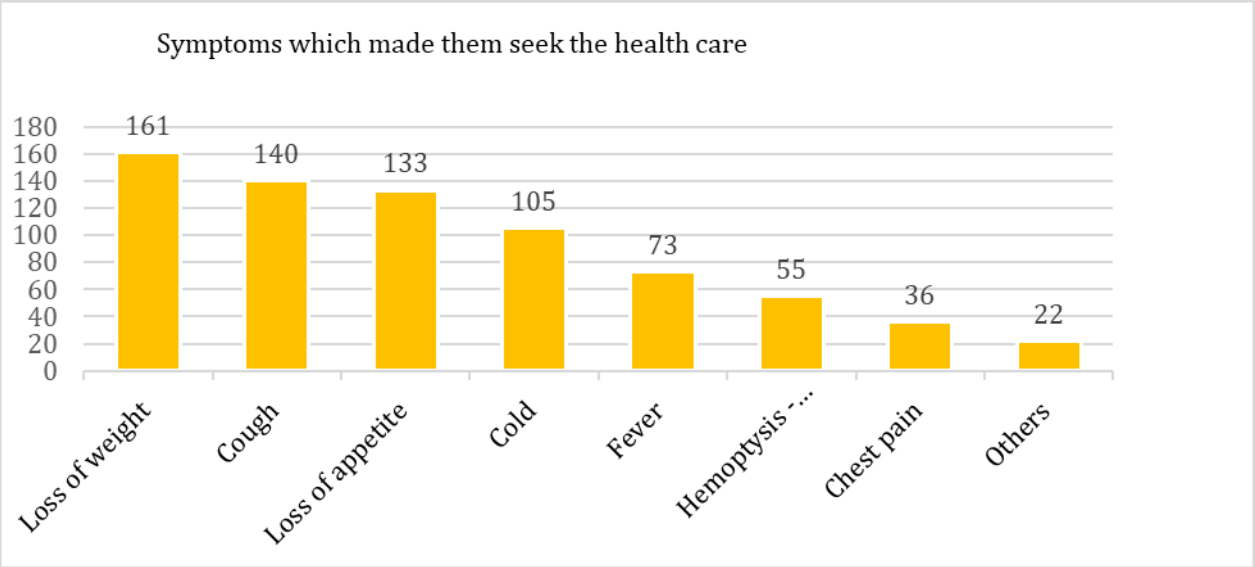
Health Care Seeking Behaviour

This section discusses about the health seeking behaviour of the participants after the onset of symptom to the initiation of the treatment.

Symptoms which made them seek health care

Symptoms which made the participants seek healthcare show that a mix of the symptoms pushed them into seeking health care (Refer to Figure 11).

Figure 11: Symptoms which made the participants seek health care

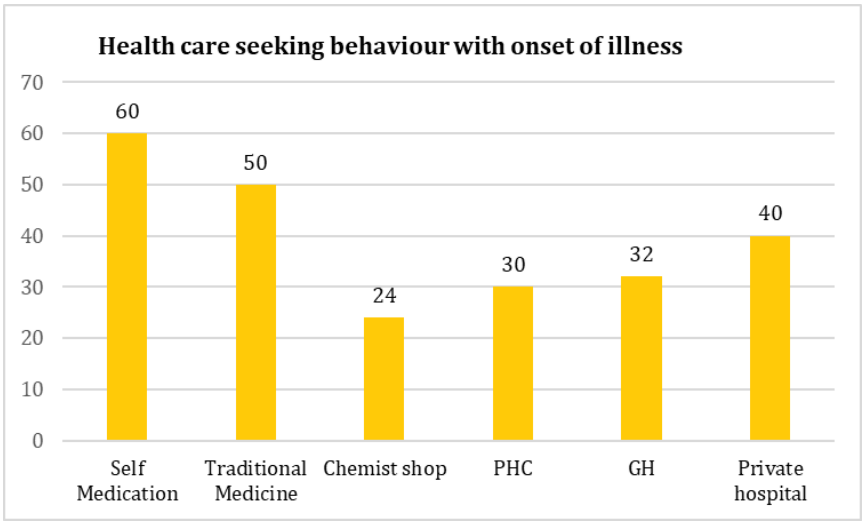


Source: Author created

Health care seeking behaviour with onset of illness

A majority of the participants chose to self-medicate themselves before realising the onset of an illness and sought treatment from both formal and informal institutions (Refer to Figure 12).

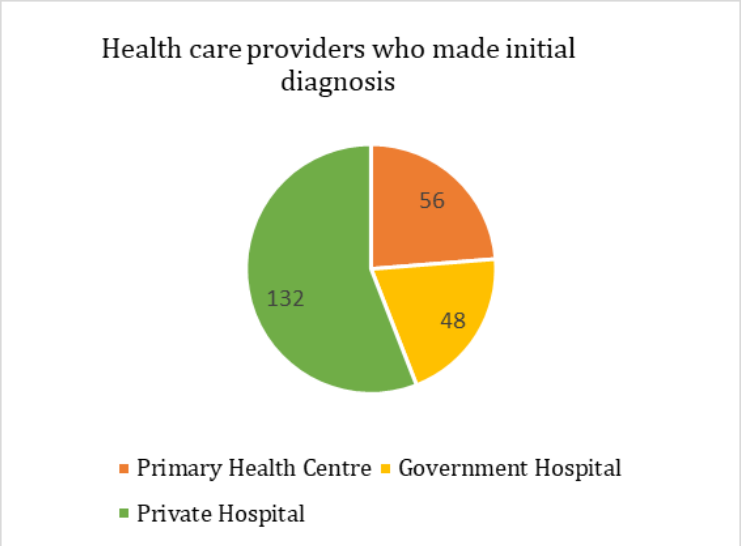
Figure 12: Health care seeking behaviour with onset of illness



Source: Author created

Participants approaching health care facilities before initial diagnosis

Figure 13: Participants approaching health care facilities before initial diagnosis

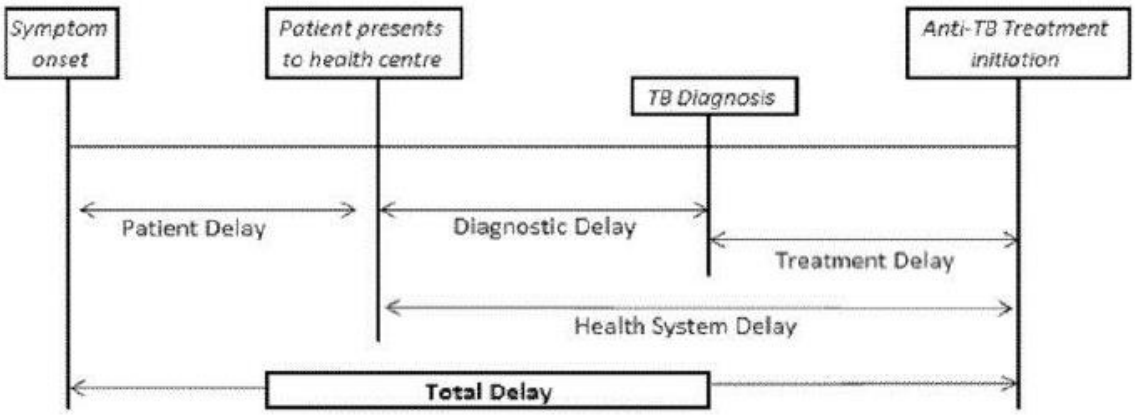


Source: Author created

Different categories of delay and their contribution to the total delay

Delay in the diagnosis and treatment of tuberculosis exacerbates the disease and clinical outcomes. It further enhances transmission of the infection in society as well as increases the severity of the illness and raised the rate of mortality. Figure 14 represents the pictorial representation of Patient delay and Health system delay.

Figure 14: Different categories of delay and their contribution to Total Delay



Source: Research study - Factors affecting delay in early diagnosis and initiation of treatment for tuberculosis in Vellore District-Tamil Nadu.

Mean patient delay

The time taken by the patient to approach the health facility for treatment with the onset of symptoms is taken as a patient delay. In this study, the mean patient delay was 22 days with a range of 1 day to 366 days.

Mean diagnostic delay

After the patient approached the health facility, the time taken by the health care system to confirm the TB Diagnosis is considered as diagnostic delay. In this study, the mean diagnostic delay was 10 days with a range of 1 to 193 days.

Mean treatment delay

The delay in starting the treatment once the diagnosis is made is considered as treatment delay. In this study, it was found that the mean treatment delay was 13 days in the present with a range of delay of 1 to 272 days.

Health system delay

After the patient approach the health Centre the time taken by the health care system to test, diagnose and initiate the treatment is considered as health system delay. The mean health system delay in the present study is 23 days.

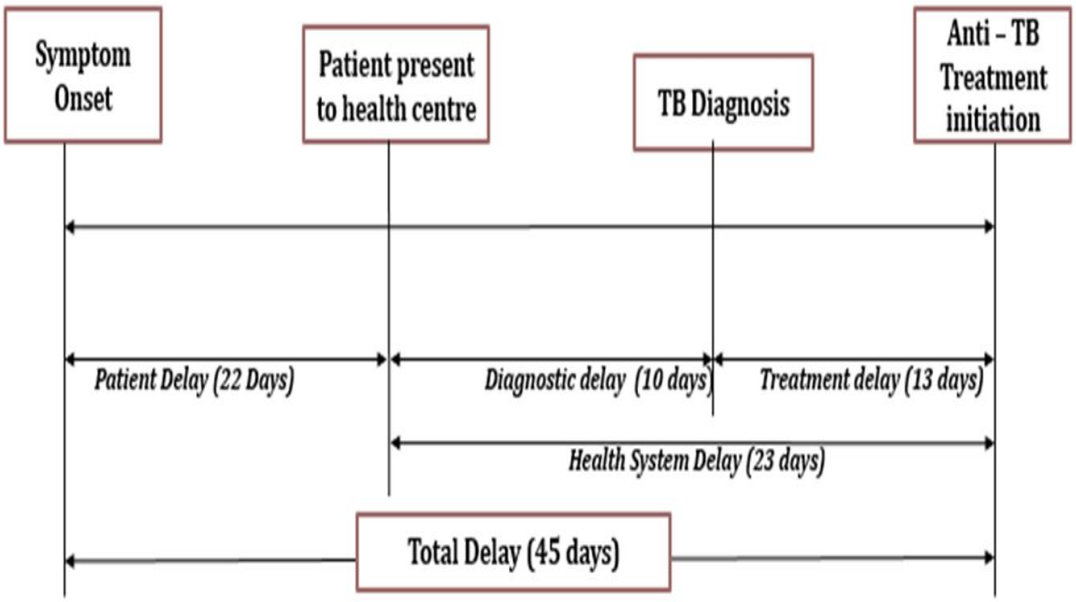
Total Delay

The time taken from the onset of symptoms to the initiation of treatment is a health system delay. In the present study, the mean total delay was 45 days (Refer to Figure 15).

Table 6: Different Types of Delay

S.No	Types of Delay	Mean	Median	Min	Max
1	Patient delay in reaching the health facility for diagnosis	22	7	1	366
2	Diagnostic delay (Testing of sputum to diagnosis)	10	3	1	193
3	Treatment delay (Diagnosis to treatment)	13	3	1	272

Figure 15 : Pictorial representation of different type of delay based on response from 236 participants



Source: Author created

Expenditure related to TB care

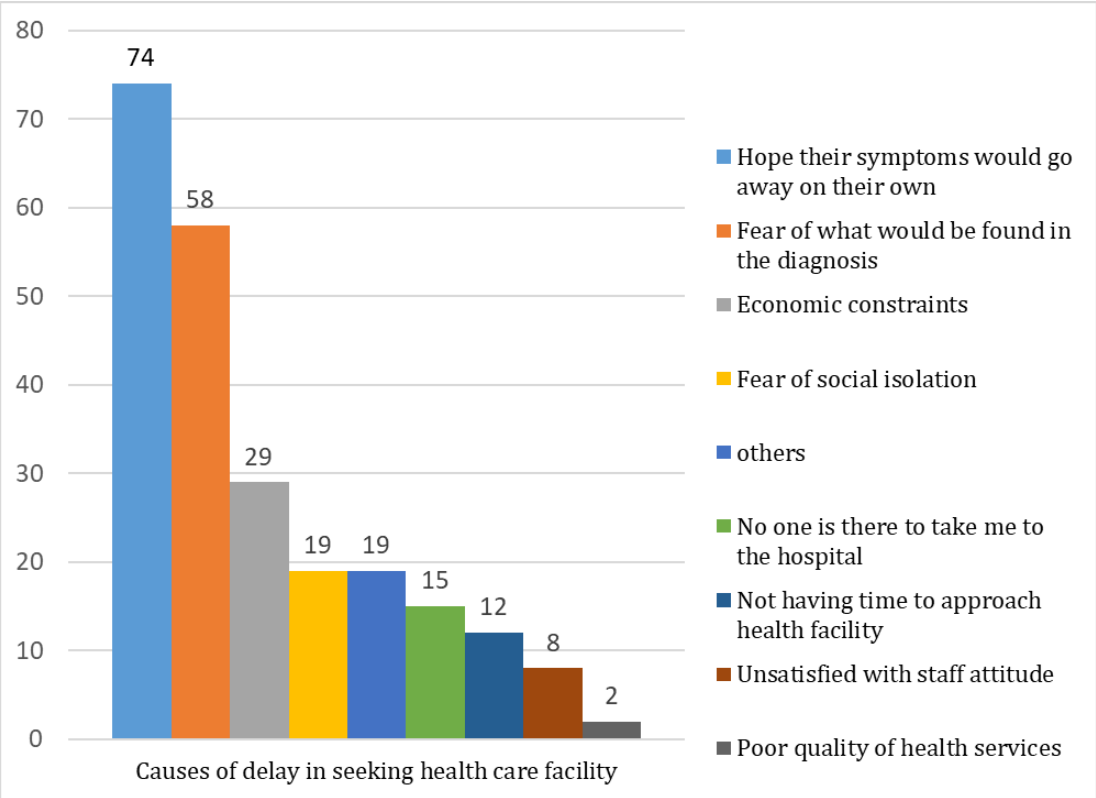
Money spent on approaching health providers for treatment (both direct and in direct costs) was calculated. The total cost before diagnosis spent by 52% of the participants was up to Rs.500 and only 4% of them spent money of more than Rs. 50,000 before diagnosis.

Participants' reason for the delay in seeking health care facility

Seven reasons were listed by the participants as their cause of delay in seeking health care facility (Figure 16). Out of 236 participants,

- 74 participants stated that they delayed visiting their health facility as they thought that the symptoms would go away on their own
- 58 participants feared what would be found in the diagnosis.

Figure 16: Causes of delay in seeking health care facility



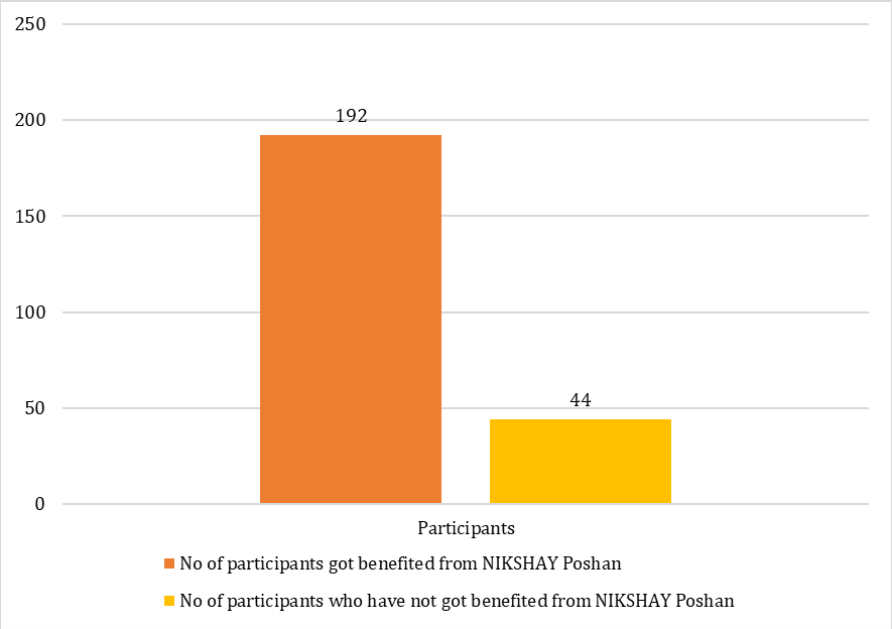
Source: Author created

NIKSHAY Poshan Yojana (NPY)

The NPY was launched in 2018 by the Ministry of Health and Family Welfare, Government of India. It aims to support every Tuberculosis (TB) Patient by providing a Direct Benefit Transfer (DBT) of Rs 500 per month for nutritional needs.

Out of 236 participants, 192 (81%) participants benefited from NPY whereas 44 (19%) participants were not benefited from NPY (Figure 17).

Figure 17: Availing of NIKSHAY Poshan Yojana

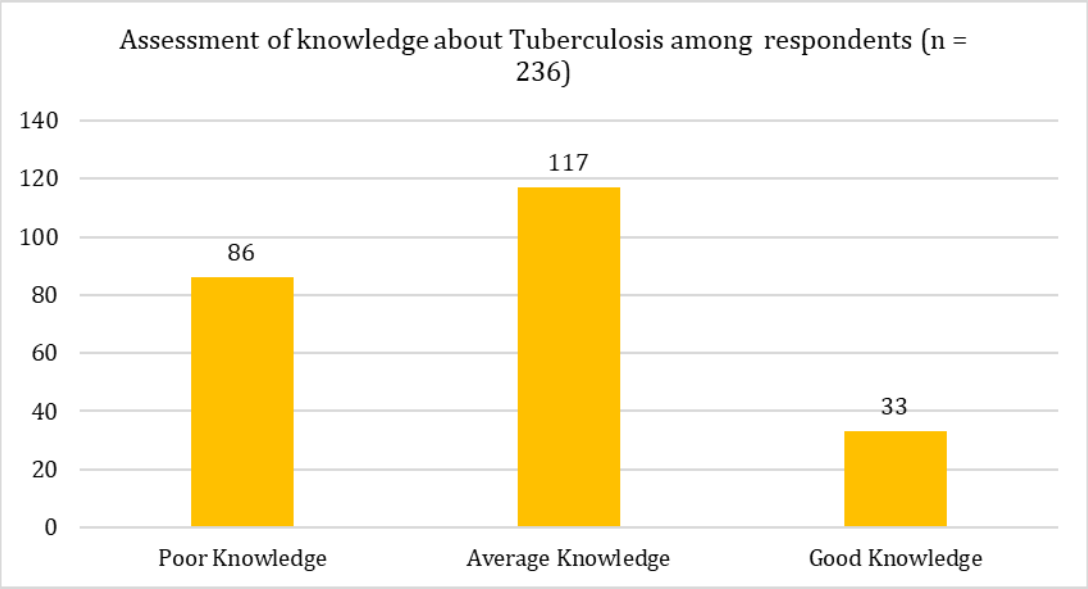


Source: Author created

Assessment of knowledge on Tuberculosis

Patients' knowledge was assessed by asking them eight questions – three questions on disease aetiology, one on the mode of transmission, and two each on treatment and prevention of TB. A scoring system was generated to assess the level of knowledge. Each correct answer was awarded one point and each wrong answer was awarded zero. Those who scored 28 and above were considered to have "good knowledge", those who scored between 21 – 27 were considered to have "average knowledge" while those who scored below 20 were considered to have "poor knowledge" about TB. As can be seen, nearly 50% had only average knowledge about the disease (Figure 18).

Figure 18: Assessment of Knowledge about tuberculosis among the participants



Source: Author created

In terms of gender, both female and male participants had only average knowledge about TB with regard to aetiology, transmission, treatment and prevention (Table 7).

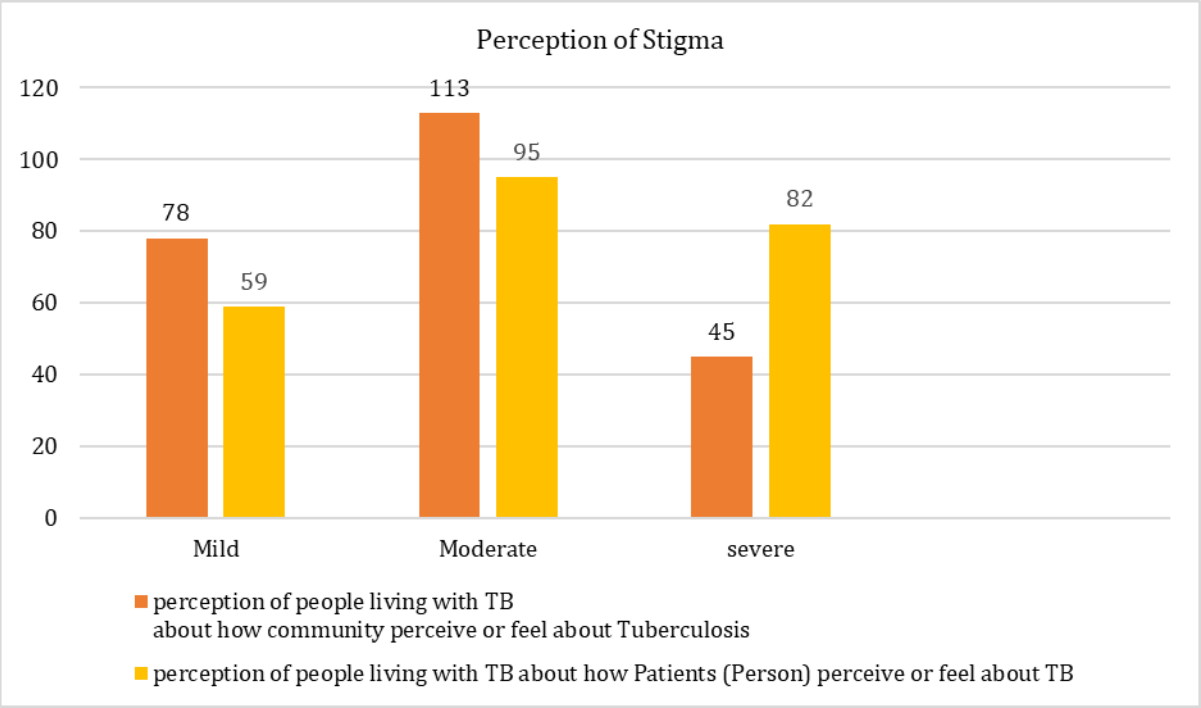
Table 7: Knowledge about TB - Gender Analysis

Category	Knowledge scoring	Female (n)	Male (n)	Grand Total (n)	Female (%)	Male (%)	Grand Total (%)
Poor	14-21	31	55	86	13.0	23.0	36.0
Average	21-28	43	74	117	18.0	31.0	50.0
Good	28-35	17	16	33	7.0	7.0	14.0

Perception of Stigma

A section in the questionnaire with 10 items on the perception of people living with TB about how the community perceives or feels about Tuberculosis (Community Tuberculosis Stigma Perception - 10 items) and 12 items on the perception of people living with TB about how Patients (Person) perceive or feel about TB (Patients' Stigma Perception - 12 items) was administered to the people with TB. Higher scores indicated higher stigma. Variables measuring stigma were coded on a 2 - point Likert scale with the following levels: '0' as disagree, and '1' as agreed. Figure 19 shows that stigma is severe among the participants who feel more stigmatised for getting affected with TB.

Figure 19: Perception of stigma among the participants



Source: Author created

Correlation Analysis

Determining the interconnection or a co-relationship between the variables.

In the present study, the association between knowledge, Stigma and Delay of Diagnosis and various factors (Socio-demographic Characteristics, socio-economic status, Family and previous history of TB, Knowledge on TB and Stigma associated with TB) was carried out on all 236 participants who were interviewed. Refer to Annexures (5, 6 and 7) for the detailed list of Correlations.

The analysis found that

There is a slight positive correlation (association) between the **knowledge of the participant** (low) and type of Residence (Rural), Previous history of treatment for TB, illiteracy, unemployment, family history of TB, Gender, Age and low Socio-Economic Status (SES)
There is a slight positive correlation (association) between the **perception of stigma** among participants (how they feel about themselves being affected by TB) and knowledge is low about TB, Marital status, family history of TB, gender, age, education, type of Residence (Rural), Low SES Status, unemployment and previous history of treatment for TB
There is a slight positive correlation between **delay in diagnosis and initiation of treatment** and gender, Visiting the health facility at the earliest, age, knowledge is low about TB, Illiteracy, unemployment and lower SES Status.

Regression Analysis

Regression explains how an independent variable is numerically associated with the dependent variable.

Regression analysis was done for all three major dependent variables ((knowledge about TB, Perception of Stigma among the participants (how they feel about themselves being affected by TB) and delay in diagnosis and initiation of treatment)) and the various factors associated with each of the independent variables.

Multivariate Analysis

Knowledge on tuberculosis – Logistic regression

A multivariate analysis is performed on the variables which showed a positive correlation concerning Knowledge about TB and type of Residence (Rural), Previous history of treatment for TB, illiteracy, unemployment, family history of TB, gender, age and low Socio-Economic Status (SES).

Age, gender, education, SES and personal habits did not show any statistically significant relationship with knowledge of the participants about TB. Those who reside in rural areas and do unskilled jobs or stay unemployed and showed low knowledge about Tuberculosis which was proved to be statistically significant.

Table 8: Logistic Regression - Knowledge of the participants and its determinant factors

Variables	Categories	Knowledge High		Knowledge Low		P-Value	Odds Ratio	95% CI
		n	%	n	%			
Age	age Above 35	85	36.02	74	31.36	0.568	0.85	(0.48,1.48)
	age below 35	39	16.53	38	16.10			
Alcohol	Drinking ever	35	14.83	37	15.68	0.454	1.39	(0.58,3.27)
	Drinking Never	89	37.71	75	31.78			
Family history of TB	Family history of TB: Absent	107	45.34	90	38.14	0.335	1.43	(0.68,2.97)
	Family history of TB: Present	17	7.20	22	9.32			
Gender	Male	74	31.36	71	30.08	0.786	0.92	(0.50,1.67)
	Female	50	21.19	41	17.37			
Education	Illiterate	28	11.86	15	6.36	0.134	0.55	(0.25,1.20)
	Literate	96	40.68	97	41.10			
TB	History of treatment for TB: Absent	106	44.92	107	45.34	0.093	1.25	(0.08,1.70)
	History of treatment for TB: Present	18	7.63	5	2.12			
Residence	Urban	52	22.03	28	11.86	0.007*	2.04	(1.21,3.41)
	Rural	72	30.51	84	35.59			
SES	SES Lower	43	18.22	36	15.25	0.932	0.97	(0.52,1.79)
	SES Upper	81	34.32	76	32.20			
Smoking	Smoking Ever	36	15.25	33	13.98	0.858	0.92	(0.37,2.25)
	Smoking Never	88	37.29	79	33.47			
Occupation	unemployment	73	30.93	54	22.88	0.038*	0.59	(0.35,0.97)
	employed	51	21.61	58	24.58			

*statistically significant

Perception of Stigma – Logistic Regression

A multivariate analysis was performed on the variables which showed a positive correlation between the perception of people living with TB about how the participants (TB Survivors / patients) perceive or feel about TB.

The variable which showed statistical significance to the perception of stigma are Gender (p-value 0.023, OR=1.77 & 95% CI = 0.49,0.88)); Education (p-value = 0.002, OR = 0.63 & 95% CI = (0.30, 0.82)); Knowledge p value = 0.04, OR = 0.59 & CI = (0.35,0.97)). The present study shows that stigma has a more significant impact on women and poor or less educated community members.

Table 9: Logistic Regression - Perception of stigma and its determinant factors

Variables	Categories	Stigma High		Stigma Low		P-Value	Odds Ratio	95% CI
		n	%	n	%			
Age	age Above 35	69	29.24	90	38.14	0.109	1.61	(0.89,2.90)
	age below 35	38	16.1	39	16.53			
Alcohol	Drinking ever	24	10.17	48	20.34	0.088	0.47	(0.19,1.11)
	Drinking Never	83	35.17	81	34.32			
Family history of TB	Family history of TB: Absent	93	39.41	104	44.07	0.169	0.6	(0.28,1.24)
	Family history of TB: Present	14	5.93	25	10.59			
Gender	Male	62	26.27	83	35.17	0.023*	1.77	(0.49,0.88)
	Female	45	19.07	46	19.49			
Education	Illiterate	17	7.2	26	11.02	0.002*	0.63	(0.30, 0.82
	Literate	90	38.14	103	43.64			
Smoking	Smoking Ever	26	11.02	43	18.22	0.973	1.02	(0.41,2.48)
	Smoking Never	81	34.32	86	36.44			
Knowledge	Knowledge High	65	27.54	59	25	0.04*	0.59	(0.35,0.97)
	Knowledge Low	42	17.8	70	29.66			
Marital status	Married	84	35.59	111	47.03	0.107	1.93	(0.862,4.28)
	Unmarried	23	9.75	18	7.63			

*statistically significant

Delay in Diagnosis and Initiation of treatment – Logistic Regression

A multivariate analysis was performed on the variables which showed a positive correlation between the delay in diagnosis and the initiation of the treatment (Refer to Annexure 4).

The variable which showed statistical significance to delay in diagnosis and initiation of treatment were SES (p-value = 0.008, OR = 1.09 & CI = (0.32, 0.97)), stigma (p-value = 0.021, OR = 2.57 & CI = (0.39, 0.85)) and Health facility (p-value = 0.001, OR = 1.61 & CI = (0.23, 0.83)). This present study shows that Lower socio-economic status, the stigma associated with Tuberculosis and first consulting a private physician were found to be significantly associated with the diagnostic and treatment delay.

Table 10: Logistic Regression - Delay in Diagnosis and initiation of the treatment and its determinant factor

Variables	Categories	Total Delay		P-Value	Odds Ratio	95% CI
		Count (n)	Percentage (%)			
Age	age Above 35	111	47.03	0.278	1.46	(0.73,2.90)
	age below 35	62	26.27			
Gender	Male	113	47.88	0.467	1.24	(0.69,2.23)
	Female	60	25.42			
Education	Illiterate	36	15.25	0.18	1.91	(0.74,4.90)
	Literate	137	58.05			
Residence	Urban	49	20.76	0.354	1.34	(0.72,2.49)
	Rural	124	52.54			
SES	SES Lower	63	26.69	0.008*	1.09	(0.32, 0.97)
	SES Upper	110	46.61			
Knowledge	Knowledge High	85	36.02	0.352	1.33	(0.72,2.45)
	Knowledge Low	88	37.29			
Stigma	Stigma High	86	36.44	0.021*	2.57	(0.39, 0.85)
	Stigma Low	87	36.86			
Health Facility	Government health facility	138	58.47	0.001*	1.61	(0.23, 0.83)
	Private health facility	35	14.83			

*statistically significant

Note: The percentage of response from the participant for the total delay is 73.3% and the remaining 26.7% did not respond. Hence the regression analysis was carried out among 173 participants only

Focus Group Discussion (FGD) – Qualitative Analysis

Discussions were held with Senior Tuberculosis Supervisors (STS), Public Private Management (PPM) and Health Visitors (HV) of NTEP Programme staff.

PAC and Blossom team visited TB Units and PHCs of Madurai, Virudhunagar and Ramanathapuram and conducted FGDs regarding the health-seeking behaviour of the TB patients and the issues faced by the providers to make them adhere to a strict protocol of TB Treatment regimen and also regarding the NIKSHAY portal usage.

Issues that emerged during the FGD are mentioned below[1] -

Lack of coordination between PHC staff and NTEP staff

The senior Treatment Supervisor (STS) mentioned that all the staff working in the PHCs have to refer and collect the symptomatic sputum from the patient as per an order issued by the State Government (GO). Despite passing GOs and providing them with training, the health staff were not working efficiently. The NTEP programme mainly depends on early diagnosis. If early diagnosis were to be conducted at the right time, then we can curb transmission to other persons effectively. Early diagnosis is possible only if the peripheral referrals do their duties properly.

Lack of human resources also appeared as a reason for the lack of coordination. National Health Mission (NHM) has placed most of the Human Resources on a contract basis. The pharmacist or lab technician is earning nearly 10k per month. If NTEP Staff is giving them work, that is an additional burden for them. So they cannot be blamed also. They have their targets for their programs. If we need an early diagnosis, then we should provide them with incentives. Any staff other than NTEP is expecting incentives to work for TB.

Health staff usually identify the NCD cases and refer them to the concerned department once the patient enters the PHCs with symptoms. But when it comes to TB elimination, there is a lack of involvement in working towards elimination stating that a separate department exists for TB elimination, Because of the lack of human resources and involvement from PHC staff NTEP staff are handling everything, so it gets very difficult which leads to missing cases thereby a delay in diagnosis.

Extra burden, low salary, lack of equipment (Tab), and lack of incentives were other major concerns raised by the PHC staff for their inefficiency and low contribution.

Reasons for delay in Diagnosis

The patient has to visit small clinics or PHCs when the symptoms arise. The delay here is that these small clinics may not identify the TB case or they will not be referred properly. When they are referred, the patients have to visit the nearby UPHC to get their sample collected on time if the doctors are available. If the doctors or NTEP staffs are not available, then there will be a delay in the diagnosis. After this, they have to visit the government hospital and follow a strict protocol for diagnosis. So, nearly it takes almost 40 days to get diagnosed. So after this, they will begin their treatment. During this period the patient would have transmitted the infection to many people. Initial diagnosis by the UPHC or additional PHC or PHC would help the patient to get diagnosed early for early treatment and also to stop the transmission of the disease.

[1] Some of the statements have been presented as relayed by the participants to retain the nuances of their response.

Stigma related to TB

Patients feel stigmatised after the TB diagnosis. They are not comfortable regarding home check-ups and prefer to come to the hospital and pick up the medicine. Their reason is that they think that their neighbours knew where the staff are working. Patients also provide wrong addresses to stop the staff from coming to the house and this makes it very difficult to trace them and they do it knowingly.

Economic Constraints

Money is one of the main barriers for patients. The patients expect the government health facility to be near them as the person approaching the government hospitals are below the poverty line. If the health facility is far away, they have to spend nearly their whole day visiting the hospital for diagnosis or treatment. So, they will lose their wages for the particular.

IEC Awareness

Patients are hiding their case records and are going to a private clinic after Intensive Phase (IP). They inform the doctors in the private clinic that they are having normal flu symptoms and get medicines for cold and fever and/or take injection. Even though we provide enough knowledge about the treatment protocol, continuous mass communication should be provided for the at least 6 months to change their perspective on TB and its effect on health. The way the people have been educated about corona the same has to be replicated for TB by following the same mass communication protocol. The knowledge about TB will stick to people's minds only when the programme broadcast about it repeatedly.

If mass communication is not possible, the government can do something similar to what they have done for NCDs. MTM (Makkalai thedum Maruthuvam*)* staff – Tamil Nadu state government has started this programme for NCDs – Diabetes, Hypertension, etc. They will check the people if they have Diabetes or hypertension then they will provide medicines at the patient's home itself. Now people are very familiar with these MTM staff and they have been provided with 4000/- salary per month. Each PHC has 10 to 15 MTM staff. They are selected through a Self-help Group (SHG). The MTM staff are chosen as the representative of the village they reside. So, their voice will be strong enough for awareness and communication. So, involving MTM staff in NTEP and provide incentives or salaries separately for NTEP then awareness and case identification will be easier. If they can move the community towards early diagnosis, sample collection, and drug supply or delivery then we can achieve the 2025 targets easily. If PHC staff are working 4 hours for NCD, contribute extra 2 hours for NTEP we will provide incentives based on the contribution

Either provide mass communication like COVID – 19 or mobilise the community through MTM staff. These two are the main solution for early diagnosis and treatment adherence.

Public-private management – Private Notification

Since we are providing incentives for private notification we are getting referrals or notifications from the private clinic and hospitals. It is very difficult to get the private count data before incentive initiatives. Now they are doing it in a better way. No need to wait till the month's end to get the notification. We will follow up in 10 to 15 days once with the private doctor and get the details of the patient. There is a drastic change in the notification after providing them incentives.

NIKSHAY Usage

Lab technician (LT) has to enter the details of the diagnosis first because they are meeting the patients initially. Then it will be transferred to the NTEP staff. LTs are not entering the cases in NIKSHAY. Sometimes one case is registered in three centres. This becomes very difficult to handle.

Recommendations

Recommendations are based on both Qualitative and Quantitative Analysis.

Delay – Diagnosis and Treatment

This study identified the delay from the first occurrence of symptoms to the initiation of Treatment as 45 Days (Total Delay). The following recommendations are suggested to reduce the total delay.

1. Improve community engagement through TB survivors and TB champions as the key strategy to reach the unreached as per the revised National Tuberculosis Control Programme
2. Train TB Survivors and TB Champions to deliver effective awareness programmes (IEC Campaign) on aetiology, symptoms and transmission of the disease to enhance the knowledge on TB in affected communities and regarding health-seeking behaviour
3. Plan active case findings in the affected geographic areas and Source Reduction (Contact Tracing) should also be done frequently to improve the notification of TB Cases
4. Provide Gender-specific interventions that address individual-level stigma and health literacy barriers to improve access to TB services.

Co-ordination between Primary Health Centre (PHC) Staff and NTEP Staff

1. The lack of Human Resources (Doctors, staff Nurse, Pharmacist and Lab technician) in PHCs is the main concern raised by the STS for their inefficiency in notifying the TB cases.
2. Optimising the human resources in PHC improves their efficiency in notifying the TB cases

Private Notification

1. Private sector involvement in public health actions related to TB control is not commensurate to its size and dominance in TB care
2. Even though incentives have been provided to the Private Management for TB Case Notification it is quite low comparatively as per our Qualitative analysis
    a. Private sector notification can be improved by providing Intensive Training to the Doctors working in Private hospitals and Private clinics and emphasis about the importance of the End TB Strategy – Elimination of TB in India by 2025.

Shift in the Occupation due to illness Resulting in a Change in the SES Class Level

Nikshay Poshan Yojana (NPY) was launched in 2018 by the Ministry of Health and Family Welfare, Government of India. It aims to support every Tuberculosis (TB) Patient by providing a Direct Benefit Transfer (DBT) of Rs 500 per month for nutritional needs. The present study observed the drastic shift in the employment and socio-economic status of the people affected with TB leading to economic constraints. In this current study it was documented that 44% of the participants had not utilised the NPY due to the non-availability of bank accounts and unlinked bank accounts.

Hence, the effective functioning of Direct Benefit Transfer (DBT) and Nutrition supplements through NGO and Public distribution system (PDS) will improve the Nutrition status of the TB-affected communities.

Occupational Hazards – Industry

In this study, a few of the participants were working in Industries (cotton mill, crackers, Rice mill and Cardboard) in the three Districts (Madurai, Virudhunagar and Ramanathapuram)

To identify the disease at the earliest

1. Baseline (preplacement) Screening and Testing by the Medical officer working in the Industries
2. Annual Health Screening for the employers
3. Awareness regarding the TB (Aetiology, Transmission and Prevention)
4. Active Case Finding by the health care provider (affected geographies).

Conclusion

Experience obtained from the TB Survivors and patients in the present study states that health seeking behaviour of the community depends on various socio demographic and economic factors such as Age, Gender and SES status. It also depends on the knowledge of the individual about the TB Disease. Poor knowledge on TB (consciousness and capabilities) and stigma related to TB (Informal norms) contribute to the delay in approaching the health care system (Formal). This matches with the framework that developed using Rao Keller Model.

Intensive awareness generation by the NTEP to the general public regarding the aetiology, Mode of transmission, symptoms, treatability, and curability of the disease is very important to prevent delay in diagnosis. TB Survivors and Champions are the torchbearers of the community led intervention. They play a major role in sensitizing the communities on TB, reduce stigma and provide real time feedback to the health system.

References

[1] C. Gugssa Boru, T. Shimels, and A. I. Bilal, "Factors contributing to non-adherence with treatment among TB patients in Sodo Woreda, Gurage Zone, Southern Ethiopia: A qualitative study," *J. Infect. Public Health*, vol. 10, no. 5, pp. 527–533, 2017, doi: 10.1016/j.jiph.2016.11.018.

[2] H. Application and G. Logout, "Challenge Facility for Civil Society Grant Management Home Application Guidelines Logout Section 2 - General Applicant Information," vol. 00, no. May, 2021.

[3] S. M. Saleem and S. S. Jan, "Modified Kuppuswamy socioeconomic scale updated for the year 2021," *Indian J. Forensic Community Med.*, vol. 8, no. 1, pp. 1–3, 2021, doi: 10.18231/j.ijfcm.2021.001.

[4] M. A. Asemahagn, G. D. Alene, and S. A. Yimer, "A qualitative insight into barriers to tuberculosis case detection in east gojjam zone, Ethiopia," *Am. J. Trop. Med. Hyg.*, vol. 103, no. 4, pp. 1455–1465, 2020, doi: 10.4269/ajtmh.20-0050.

[5] T. Bhattacharya, S. Ray, P. Biswas, and D. Das, "Barriers to treatment adherence of tuberculosis patients: A qualitative study in West Bengal, India," *Int. J. Med. Sci. Public Heal.*, vol. 7, no. 5, p. 1, 2018, doi: 10.5455/ijmsph.2018.0102220022018.

[6] Z. S. Nezenega, L. Perimal-lewis, and A. J. Maeder, "Factors influencing patient adherence to tuberculosis treatment in ethiopia: A literature review," *Int. J. Environ. Res. Public Health*, vol. 17, no. 15, pp. 1–12, 2020, doi: 10.3390/ijerph17155626.

[7] J. Zhang *et al.*, "Factors influencing medication nonadherence to pulmonary tuberculosis treatment in tibet, china: A qualitative study from the patient perspective," *Patient Prefer. Adherence*, vol. 14, pp. 1149–1158, 2020, doi: 10.2147/PPA.S252448.

[8] Government of India, "National Framework For a Gender-responsive approach to TB in India," *Cent. TB Div. Minist. Heal. Fam. Welf.*, 2019, [Online]. Available: https://tbcindia.gov.in/showfile.php?lid=3496.

[9] I. S. Pradipta *et al.*, "Barriers and strategies to successful tuberculosis treatment in a high-burden tuberculosis setting: a qualitative study from the patient's perspective," *BMC Public Health*, vol. 21, no. 1, pp. 1–12, 2021, doi: 10.1186/s12889-021-12005-y.

[10] WHO, "WHO Tuberculosis data," no. March, pp. 1–13, 2021, [Online]. Available: https://www.who.int/teams/global-tuberculosis-programme/data.

[11] C. F. McQuaid, A. Vassall, T. Cohen, K. Fiekert, and R. G. White, "The impact of COVID-19 on TB: A review of the data," *Int. J. Tuberc. Lung Dis.*, vol. 25, no. 6, pp. 436–446, 2021, doi: 10.5588/ijtld.21.0148.

[12] Gender at work, "Gender at work framework," pp. 29–32, 2019, [Online]. Available: https://genderatwork.org/analytical-framework/.

Annexures

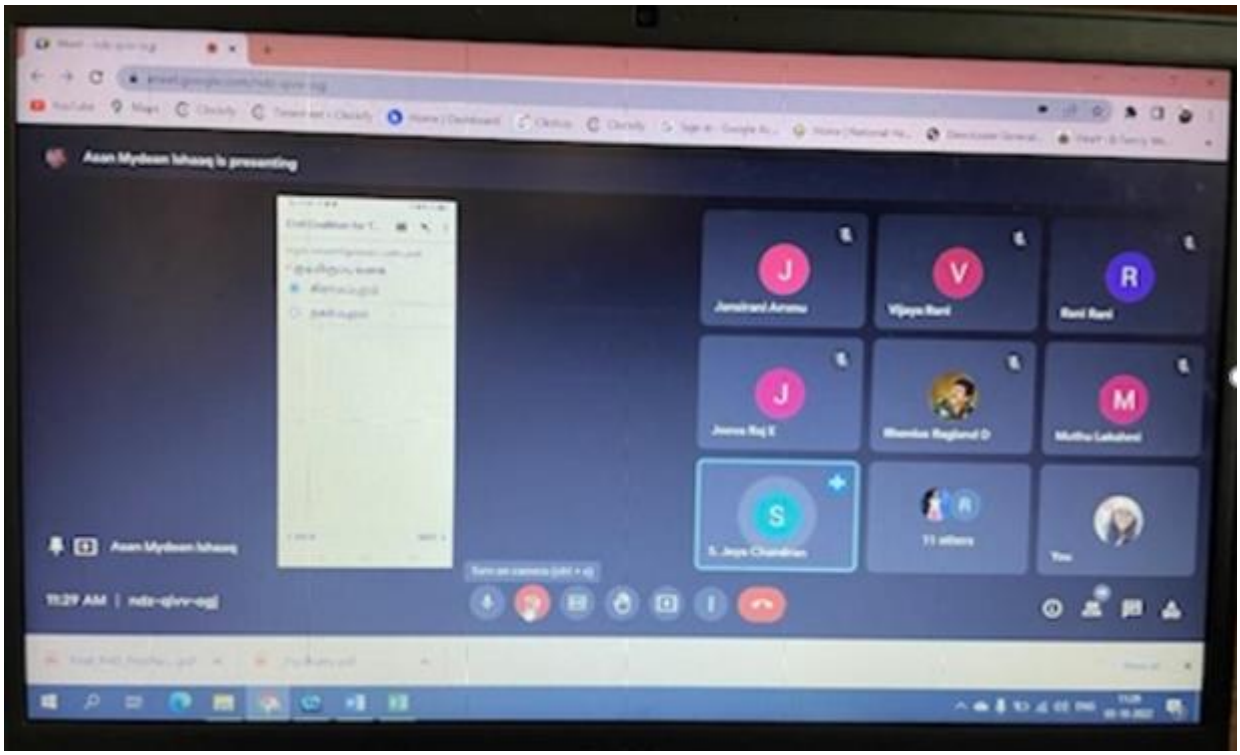
Annexure 1: List of Activities signed in MoU and action taken by PAC

Activity 2.1.1 - Develop survey tools, sampling and sample size framework on health-seeking behaviour for outreach workers to utilise when conducting outreach in the field.

The PAC team conducted an extensive literature review and developed a sample-size framework using the NIKSHAY portal. A detailed questionnaire was prepared to understand the health-seeking behaviour of the TB survivors and patients.

Pilot testing was done to test the questionnaire in the field. Once the questionnaire was finalised it was inbuilt into the KOBO Tool kit. Pilot testing of the tool kit has been done in the field and outreach workers were provided with the necessary training to conduct the study.

Figure 20: Screenshot of the training conducted regarding the KOBO tool kit for outreach workers



Source: Screenshot of the online training for TB Advocates of Blossom Trust conducted by PAC

Activity 2.1.1 - PAC will be responsible for compiling all data collected from field research to clean and analyse the data focused on health-seeking behaviours, including COVID-19, human rights concerns, and gender barriers within highly prevalent TB communities.

The PAC team extracted the data collected by the outreach workers in the field and data management was done. Findings were listed in the report based on the data analysis plan (Refer to Annexure 8)

Activity 2.2.1 - Development of a passive surveillance system to monitor community access to health care (including both private & public sectors).

Since the passive surveillance system (NIKSHAY - web-enabled patient management system for TB control under the National Tuberculosis Elimination Programme (NTEP)) has been already in place, the PAC team and Blossom trust went into a mutual agreement that instead of developing a passive surveillance system, PAC team can conduct focus group discussion among the users of NIKSHAY portal to understand the difficulties faced by the users and also to look into the variables included in the NIKSHAY

Out of these two sub-activities mentioned above (FGD and NIKSHAY portal access), FGD was conducted and findings and recommendations were shared in the report whereas accessing the NIKSHAY portal was not approved by the NTEP team due to sensitivity issues.

Activity 3.3.1 - Development of SOP identifying outcome indicators, associated risk factors and barriers, and data analysis plan for generating reports.

Data Analysis Plan (Annexure 8)

Identifying outcome indicators, associated risk factors and barriers (Refer to Annexure 6, Findings and Recommendations of the report)

Activity 3.3.1 - Draft a peer-reviewed publication evaluating the project's findings on human rights, gender and community challenges and interventions.

The report has been drafted to submit for publication. However further steps to publish the findings will be done based on the suggestions (type of Journal) and feedback provided by the blossom trust.

Annexure 2: Sample Size Estimation – Madurai, Virudhunagar and Ramnathapuram Districts

Introduction

The effectiveness of TB program is estimated by rate of individuals successfully completed TB treatment amongst registered cases for TB treatment.

PAC looked at the NIKSHAY – Surveillance program to identify the notifiable cases of Tuberculosis in the three Districts (Madurai, Virudhunagar and Ramnathapuram). The data was downloaded from https://reports.nikshay.in/Reports/TBNotification

TB Burden in India

India continues to be the highest TB burden country in the world. India accounts for a little more than a quarter of the global burden of TB and has the largest number of multi drug resistant TB (MDR-TB) patients worldwide.

Mortality due to TB is the sixth leading cause of years of life lost (YLLs), in the country. The estimated incidence (new TB patients per year) was nearly 2.8 million patients in 2016 (211 per 100,000 population). The estimated mortality due to TB is 423,000. In 2016, India detected and notified approximately 1.8 million new TB patients – 63% of the estimated burden. [2]

Tamil Nadu TB Burden

According to India state TN Statistics, Tamil Nadu ranks 6th position which loads the cases of 803 per one lakh population. [3]

Madurai District

The period prevalence of Tuberculosis for Madurai District was 161 per 1,00,000 populations as per NIKSHAY notification report 2021

Ramnathapuram District

The period prevalence of Tuberculosis for Ramnathapuram District was 113 per 1,00,000 populations as per NIKSHAY notification report 2021

Virudhunagar District

The period prevalence of Tuberculosis for Virudhunagar District was 125 per 1,00,000 populations as per NIKSHAY notification report 2021

Selection of period (May 2021 – May 2022) for this study

May 2021 – May 2022 period was selected for the study as PAC – Blossom is looking into both cured and on – going patient to understand their Health seeking behavior and treatment adherence to TB.

Table 1: NIKSHAY – Tamil Nadu District Wise Notification cases (May 2021 – May 2022)

District Wise Total Notified for state Tamil Nadu From: 01/05/2021 To: 31/05/2022		
District	Total Public Notified	Total Private Notified
Central Chennai	3145	1725
Coimbatore	2767	1469
Cuddalore	2444	235
Dharmapuri	1143	481
Dindigul	2676	513
East Chennai	4691	752
Erode	2459	624
Kancheepuram	5761	346
Kanniyakumari	1081	325
Karur	825	252
Krishnagiri	1065	422
Madurai	4128	1575
NAGAPATTINAM	1147	277
Namakkal	1376	276
North Chennai	801	384
Perambalur	1455	326
Pudukkottai	1374	192
Ramanathapuram	1241	504
Salem	3015	1116
Sivaganga	1317	466
South Chennai	635	375
Thanjavur	2612	510
The Nilgiris	188	15

District Wise Total Notified for state Tamil Nadu From: 01/05/2021 To: 31/05/2022		
District	Total Public Notified	Total Private Notified
Theni	1770	273
Thiruvallur	1857	177
Thiruvarur	1231	117
Thoothukudi	1816	425
Tiruchirappalli	2542	891
Tirunelveli	3054	823
Tiruppur	2044	316
Tiruvannamalai	1658	254
Vellore	2883	2451
Viluppuram	2643	164
Virudhunagar	2349	478
West Chennai	1519	1014
Total	**72712**	**20543**

Estimation of Sample Size

The top case registration districts of Madurai, Ramnathapuram, and Virudhunagar across three categories - 10147 cases of Tuberculosis (May 2021 – May 2022) as per NIKSHAY reports.

Table 2: NIKSHAY – Sample study District Wise Notification cases (May 2021 – May 2022)

District Wise Total Notified for state Tamil Nadu From : 01/05/2021 To : 31/05/2022			
Blossom Survey Area	Total Public Notified	Total Private Notified	Total cases
Madurai	4128	1575	5703
Ramnathapuram	1241	504	1745
Virudhunagar	2349	478	2827
Total Cases	7718	2557	10275

Considering the population size (TB patient registered cases), with a 95% confidence interval and 5% margin of error

The total sample size for this study (n) = 371

Formula to calculate PPS

PPS (Participant proportionate to Size) = Sample Size / Population size * Stratum Size

Table 3: Distribution of sample size proportionately across three Districts using PPS

Districts	Madurai	Ramnathapuram	Virudhunagar	Total
Stratum size	5703	1745	2827	10275
PPS	206	63	102	371
Total Sample size	371			

<u>Districts with Sample Size</u>

NIKSHAY (May 2021 – May 2022)	
Districts	Sample Size in each District
Virudhunagar	102
Ramnathapuram	63
Madurai	206
Total	371

Annexure 3: Literature review – Health Seeking behaviour and barriers to TB Treatment Adherence

Introduction to Review of Literature

Civil Coalition for TB Advocacy and Treatment Adherence is a project designed to bridge the gap between the TB community response and national level policy. This project has been designed to systematically address issues like health-seeking behaviour of the TB patients, human rights concerns, and gender barriers within highly prevalent TB communities, and the factor affecting Treatment.

A review of literature is one of the most important steps in the research process. The literature review was carried out in this study to identify the indicators related to health-seeking behaviour and the factors affecting the treatment adherence of the TB patient. This process of review of literature helps the researcher to draw the framework using the indicators and frame an evidence-based questionnaire tool to carry out the survey effectively. It also helps to look into the methodology, relationship with the indicator, regional disparities, etc.,

In this study, literature was reviewed from the secondary data source using search engines like Google Scholar, PubMed, Medline, and the official website of WHO (World Health Organisation) and TB – NTEP. The articles selected mainly focused on looking into the Barriers or factors affecting the TB treatment and the health-seeking behaviour of the TB patient. Through Literature search we identified the framework which enlists the themes and indicators relating to Non – adherence to TB treatment and the health-seeking behaviour of the TB patient.

Articles selected for the study

Study 1: A Qualitative Insight into Barriers to Tuberculosis Case Detection in East Gojjam Zone, Ethiopia[4]

Study 2: Barriers to treatment adherence of tuberculosis patients: A qualitative study in West Bengal, India[5]

Study 3: Factors Influencing Patient Adherence to Tuberculosis Treatment in Ethiopia: A Literature Review[6]

Study 4: Factors Influencing Medication Non - adherence to Pulmonary Tuberculosis Treatment in Tibet, China: A Qualitative Study from the Patient Perspective[7]

Study 5: National Framework for A Gender-Responsive Approach to TB in India[8]

Study 6: Barriers and strategies to successful tuberculosis treatment in a high-burden tuberculosis setting: a qualitative study from the patient's perspective[9]

Study 7 : WHO – COVID 19 and TB[10]

Study 8: The impact of COVID-19 on TB: a review of the data[11]

Study 9: Gender at Work Framework (The Rao and Kelleher model)[12]

Study 1: A Qualitative Insight into Barriers to Tuberculosis Case Detection in East Gojjam Zone, Ethiopia

The objective of this study was to identify possible barriers to TCD in East Gojjam Zone, northwest Ethiopia. The study used a descriptive phenomenological research method. The study participants included 21 TB patients, six TB control officers, and 40 health workers (HWs) selected by a

heterogeneous purposive sampling technique. In-depth interviews and focus group discussions were used to collect data.

The study participants identified numerous barriers to TCD which were grouped into three major themes and 14 subthemes: 1) patient-related barriers including rural residence, low income, poor health literacy, and health-seeking delay; 2) healthcare system barriers grouped into two subthemes: HWs barriers (shortage of HWs, lack of training access, and low level of knowledge and skills) and health facility barriers (health service delay, using only passive TCD strategy, poor health education provision, and lack of regular supervision and timely feedback); 3) sociocultural and environmental barriers which included stigma and discrimination, lack of health information sources, poor transportation infrastructure, and community resistance.

Main and subthemes about the barriers to TB case detection (TCD) in East Gojjam zone of Ethiopia, 2018.

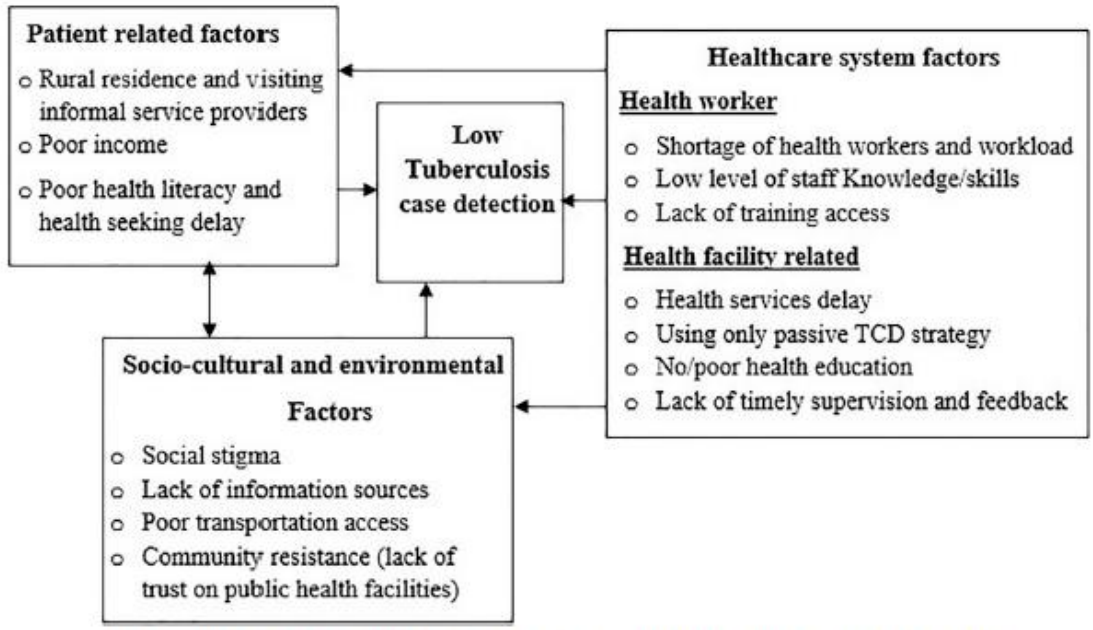


Figure 2. Main and subthemes about the barriers to TB case detection (TCD) in East Gojjam zone of Ethiopia, 2018.

Study 2: Barriers to treatment adherence of tuberculosis patients: A qualitative study in West Bengal, India

The objectives of this study were to explore factors contributing to non-adherence among defaulter TB patients and to delve into the perceived barriers to adherence according to directly observed treatment, short-course (DOTS) providers, and staff of the TB unit (TU) at Burdwan Municipality.

Materials and Methods: A total of 14 in-depth interviews of defaulter TB patients, 4 focus group discussions with 30 DOTS providers, and 4 key informant interviews with staff of TU were conducted from May to November 2017 at Burdwan Municipality, West Bengal.

Key reasons contributing to default appeared to be addiction, improvement, and non-improvement of symptoms, side effects and pill burden with the long regime of the drugs, loss of daily wages, lack of awareness, stigma, poverty, non-referral by a private practitioner, familial problem, negative counselling by friends, and perceptions of government medicines are bad.

Table 1: Pile sorting of causes of non-adherence into themes with reasons and suggested solution by key informants (STS, TBHV)

Pile number	Theme	Causes of non-adherence	Reasons for grouping	Suggested solutions
1	Financial problem	1. Less investment on food 2. Poverty 3. Missing of daily wages	Directly attributed to financial status of the patient	1. Provision of food items with or without help from NGOs 2. Universal basic income
2	Medication-related factors	1. High number of tablets to be consumed 2. Long duration of therapy 3. Improvement of symptoms 4. Non-improvement of symptoms 5. Adverse effects	Directly related with drugs and duration of the regimen	1. Introduction of regimen with shorter duration 2. Dosages if possible, adjusted or reduced per tablets 3. Provision of drugs to take care of S/E along with ATD
3	Program-related factors	1. Unable to collect medicines 2. Lack of awareness among patients	Directly related with RNTCP implementation	1. Reinforcing house tracking and counseling of patients by DOTS provider 2. Widespread IEC activities
4	Social factors	1. Familial problem 2. Negative counseling by friends and relatives 3. Stigma and discrimination	Directly related to individual	1. Increasing emphasis on counseling to counter prevalent social dogma by the health-care workers
5	Addiction	1. Alcohol	Directly related to behavior and social problem	1. BCC, IEC, deaddiction center 2. Psychological counseling should be made available under RNTCP 3. Ensure stringent law against alcohol smuggling
6	Individual perception	1. Perceptions of government medicines are bad	Quality of free items is perceived as improper	1. Increasing awareness among local leaders, requesting them to spread the same among the population 2. More emphasis on advertising the RNTCP treatment as high quality, zero cost option
7	Other allied factors	1. Lack of proper response from community leaders 2. Non-referral by private practitioner	Not direct lacunae of the program but influencing the adherence	1. Enforce strict legislation compelling private practitioner to refer 2. Strong and empathetic political commitment needed

NGO: Non-government organization, S/E: Side effect, BCC: Behavior change communication, IEC: Information education communication. RNTCP: Revised National Tuberculosis Control Program, DOTS: Directly observed treatment, short-course, ATD: Antituberculosis drugs

Study 3: Factors Influencing Patient Adherence to Tuberculosis Treatment in Ethiopia: A Literature Review

Articles were searched from PubMed and Science Direct databases, as well as manual searches through Google and Google Scholar search engines. Both quantitative and qualitative studies that showed factors associated with or reasons for non-adherence, default, or loss to follow-up from TB treatment were included. A total of 276 articles were screened, and 29 articles were ultimately included in the review.

Findings: The extracted factors were synthesized thematically into seven dimensions of patient-centred, social, economic, health system, therapy, lifestyle, and geographic access factors.

Our literature review has found some similar influencing factors of non-adherence to TB treatment as those described in the previous two systematic reviews conducted in Ethiopia. These factors were

Forgetfulness
Inadequate knowledge about TB and its treatment regimen,

Psychological distress (poor mental health condition),
Perceived barriers,
Long waiting time,
Drug side-effects,
TB-HIV-infection,
Being on the continuation phase of treatment,
Healthcare inaccessibility, and traveling costs.

Adherence interventions included

1. Providing health information about TB and its treatment regimen
2. Dealing with side-effects
3. Providing reminders and other health system interventions could be used to resolve these factors.

However, in this review, we have found several additional factors of non-adherence to TB treatment that were not identified by the previous two systematic reviews.

These factors included

1. Lack of social support
2. Being busy with work
3. Being away from home
4. Perceived and experienced stigma
5. Discrimination
6. Beliefs such as perceived wellness/cured
7. Perceived risk
8. Financial constraints to buy food and medication costs other than anti-TB
9. Poor healthcare provider-patient relationships such as communication gaps, disrespecting patients, quality of healthcare service, patient satisfaction, lack of health information/education, pill burden, the persistence of symptoms after initiation of treatment, and use of substances such as alcohol, smoking, and khat chewing.

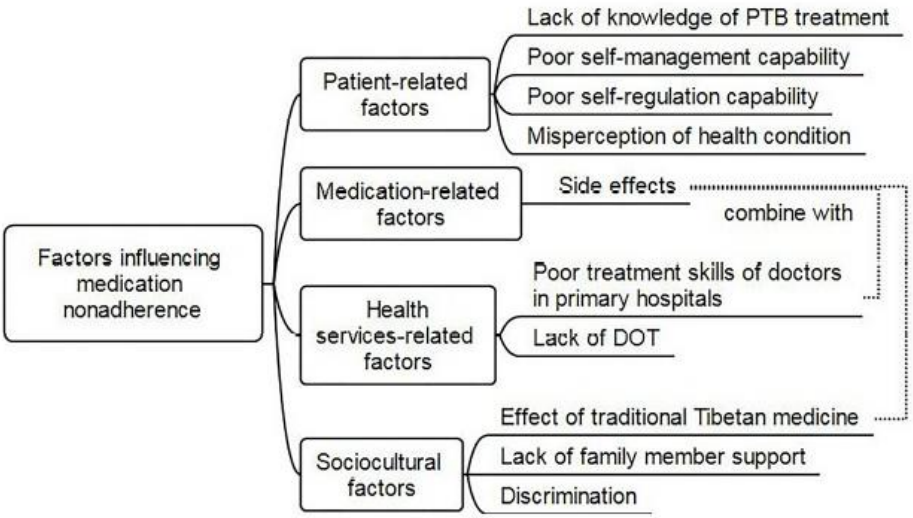
Study 4: Factors Influencing Medication Non - adherence to Pulmonary Tuberculosis Treatment in Tibet, China: A Qualitative Study from the Patient Perspective

This study aimed to explore factors influencing medication non-adherence to pulmonary TB (PTB) treatment in Tibet, China, from the patient perspective.

In this qualitative study, seventeen PTB patients in Tibet were recruited by purposive and maximum variation sampling methods. In-depth semi-structured interviews were conducted to collect data on factors influencing medication non-adherence, and Colaizzi's seven-step method was used to analyse the data.

The medication non - adherence of PTB patients in Tibet was influenced by one or a combination of the following four factors.

1. First, patient-related factors included a lack of knowledge of PTB treatment, poor self-management capability, poor self-regulation capability, and misperception of health conditions.
2. Second, a medication-related factor was medication side effects. Third, health service-related factors included the poor treatment skills of doctors in primary hospitals and a lack of directly observed treatment (DOT).
3. Last, sociocultural factors included the effect of traditional Tibetan medicine, lack of family member support, and discrimination.



ure 1 Factors influencing medication nonadherence to PTB treatment in Tibet.

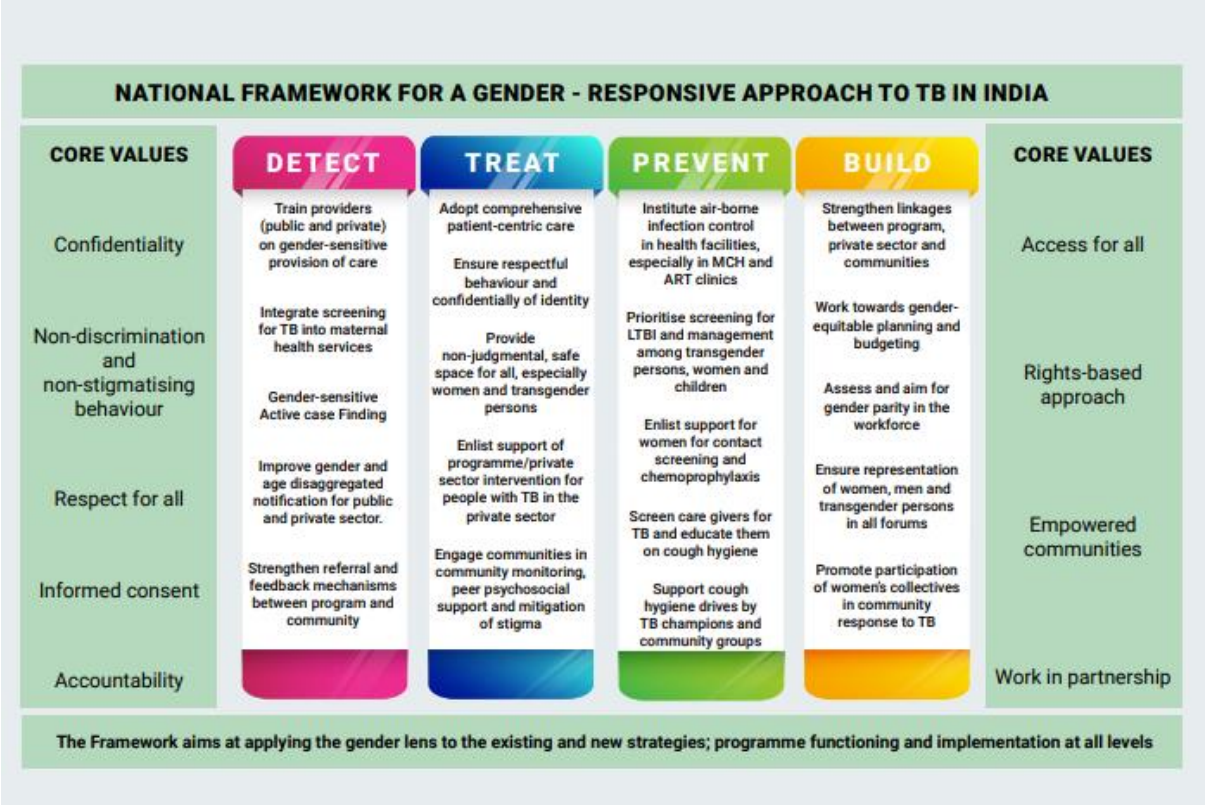
Study 5: National Framework for a Gender-Responsive Approach to TB in India

An attempt was made in this paper to develop a national framework. Objectives of the study included -

- To aim for equitable, rights-based TB services for women, men, and transgender persons by adopting a gender-specific programmatic approach at all levels
- To mobilize, empower and engage women, men, and transgender persons in the TB response at the health system and community levels

Basic steps for gender-responsive programming:

- Assess provider knowledge of gender-responsive programming and existing gender-sensitive practices.
- Build capacity of providers on the gender perspective and provide comprehensive person-centric care.
- Conduct baseline assessment of facilities, infrastructure, and linkages in the context of gender-responsive programming.
- Promote active involvement of people affected by TB of all genders in all aspects of the design, planning, and delivery of programs. The participation of people affected by TB and survivors must be supported through capacity building and mentoring. Accordingly, all the activities outlined under the NSP heads - Detect, Treat, Prevent and Build - incorporate components of community engagement.



Study 6: Barriers and strategies to successful tuberculosis treatment in a high-burden tuberculosis setting: a qualitative study from the patient's perspective

This study aimed to identify potential patient-centred care strategies to improve TB treatment outcomes in Indonesia.

A qualitative study was conducted in a province of Indonesia with a high TB prevalence. Participants from various backgrounds (i.e., TB patients, physicians, nurses, pharmacists, TB activists, and TB programmers at the district and primary care levels) were subject to in-depth interviews and focus group discussions (FGDs)

We interviewed 63 of the 66 pre-defined participants and identified 15 barriers. The barriers were classified into three themes, i.e., socio-demography and economy; knowledge and perception, and TB treatment. Since the barriers can be interrelated, we determined five main barriers across all barrier themes, i.e., lack of TB knowledge, stigmatization, long distance to the health facility, adverse drug reaction, and loss of household income.

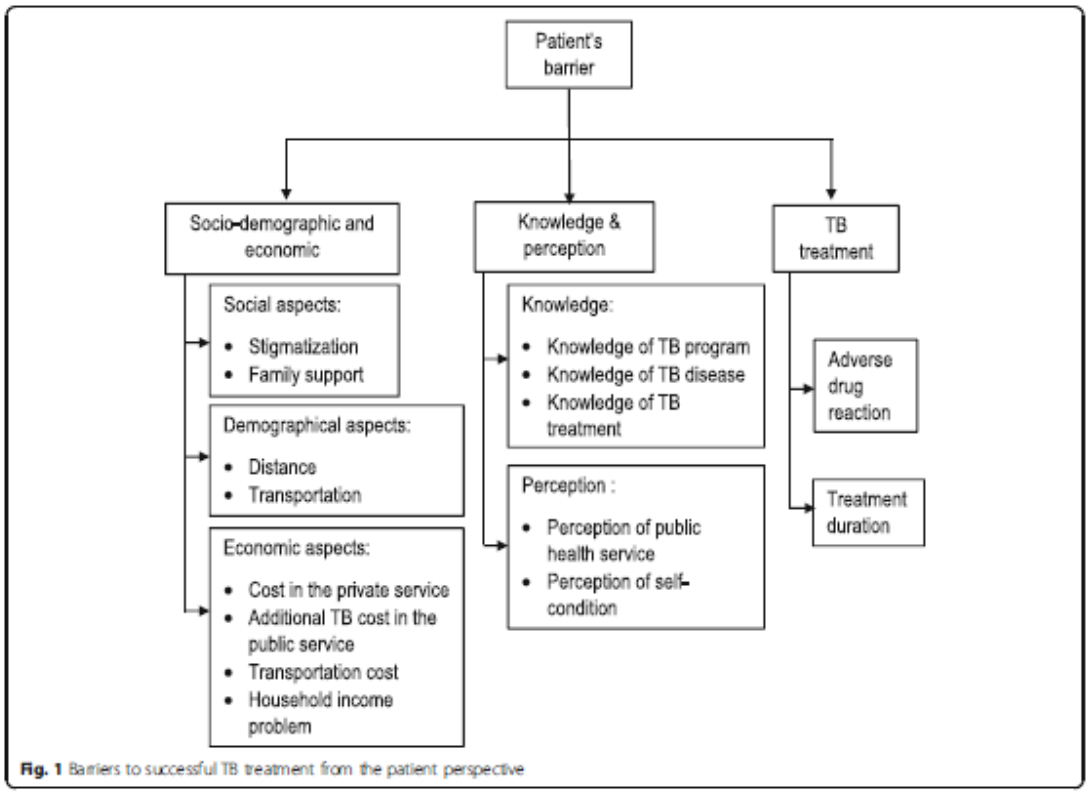


Fig. 1 Barriers to successful TB treatment from the patient perspective

Study 7: WHO – COVID 19 and TB

The coronavirus (COVID-19) pandemic has caused enormous health, social and economic impacts in 2020 and 2021. This includes impacts on the provision of and access to essential tuberculosis (TB) services, the number of people diagnosed with TB and notified as TB cases through national disease surveillance systems, and TB disease burden (incidence and mortality). The following points were observed in this study -

- The World Health Organization's (WHO's) *Global tuberculosis report 2020 (1)* included provisional estimates of the impact of disruptions to health services caused by the COVID-19 pandemic on the number of global TB deaths in 2020 and beyond, provisional data on TB notifications in the first 6 months of 2020 and data about response strategies implemented by national TB programs (NTPs).
- A widely available indicator that can be used to assess the impact of disruptions caused by the COVID-19 pandemic on essential TB services at the country level is the national number of monthly or quarterly notifications of people diagnosed with TB.
- This indicator reflects impacts on access to diagnosis and treatment on both the supply side (e.g. capacity to continue to provide services) and the demand side (e.g. willingness and ability to seek care in the context of lockdowns and associated restrictions on movement, concerns about the risks of going to health care facilities during a pandemic, and stigma associated with similarities in symptoms related to TB and COVID-19).

WHO has issued guidance on TB in the context of the COVID-19 pandemic *(12, 13)*. Advice includes:

1. Leverage the expertise and experience of ntps, especially in rapid testing and contact tracing, for the COVID-19 response;

2. Maximize remote care and support for people with TB by expanding the use of digital technologies;
3. Minimize the number of visits to health services that are required during treatment, including through the use of WHO-recommended, all-oral TB treatment regimens and community-based care;
4. Limit the transmission of TB and COVID-19 in congregate settings and health care facilities by ensuring basic infection prevention and control for health staff and patients, cough etiquette, and patient triage;
5. Support the provision of TB preventive treatment by building synergies with contact-tracing efforts related to COVID-19;
6. Provide simultaneous testing for TB and COVID-19 for individuals when indicated, including by leveraging TB laboratory networks and platforms; and
7. Ensure proactive planning and budgeting for both conditions (including for the catch-up phase), procurement of supplies, and risk management.

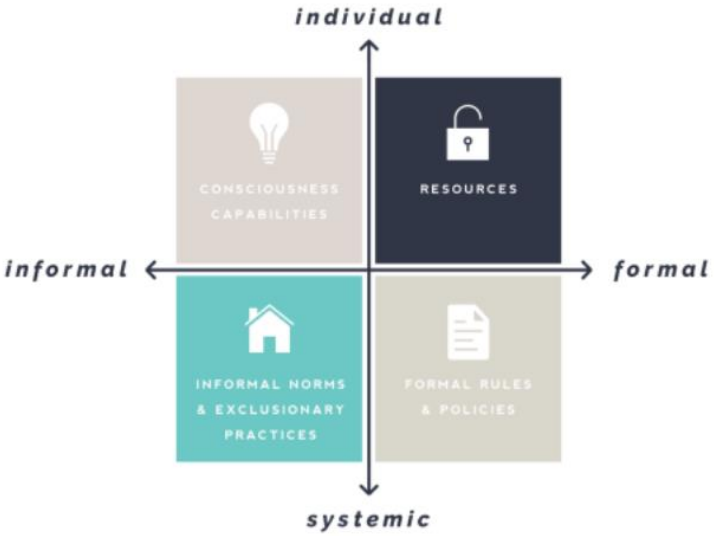
Study 8: The impact of COVID-19 on TB: a review of the data

The study comprising a review of data on impact of COVID-19 on TB showed that

- Early in the COVID-19 pandemic, models predicted hundreds of thousands of additional TB deaths as a result of health service disruption.
- To date, empirical evidence on the effects of COVID-19 on TB outcomes has been limited. Here we summarise the evidence available at a country level, identifying broad mechanisms by which COVID-19 may modify TB burden and mitigation efforts.
- From the data, it is clear that there have been substantial disruptions to TB health services and an increase in vulnerability to TB. Evidence for changes in Mycobacterium tuberculosis transmission is limited, and it remains unclear how the resources required and available for the TB response have changed.

Study 9: Gender at Work Framework (The Rao and Kelleher model)

The Gender at Work Framework highlights the interrelationship between gender equality, organizational change, and institutions or 'rules of the game' held in place by power dynamics within communities.



The top two quadrants are related to the individual.

- On the right change in noticeable individual conditions, e.g., increased resources, voice, freedom from violence, access to health and education.
- On the left individual consciousness and capability – knowledge, skills, political consciousness, and commitment to change toward equality.

The bottom two clusters are related to the systemic.

- The cluster on the right refers to formal rules as laid down in constitutions, laws, and policies.
- The cluster on the left is the set of informal discriminatory norms and deep structures, including those that maintain inequality in everyday practices.

The Framework can be used by change agents in both organizations and communities to uncover opportunities and barriers to gender equality, map a strategy for change, and guide evaluative efforts to mark progress. It makes visible dimensions of gender equality and the extent to which there is a shift in gendered power relations – in line with national priorities and principles agreed upon in CEDAW, the Beijing PFA, and other guiding documents.

It has been cited in academic work and used by a wide range of organizations, from large NGOs like Oxfam International to women's organizations and funds, such as the Global Fund for Women, and by women and community groups all over the world.

Gender-related factors contributing to Non – Adherence to treatment protocol in the Gender Framework

Reason for adopting the model:

- Gender plays a major role in the TB treatment regimen. Gender-related factors contributing to Non – adherence to treatment protocol depends on availability, accessibility, and affordability of the right treatment to the right individual at the right time, the health-seeking behavior of the individual, and the socio-cultural factors which disable him/her to avail or continue the treatment. It also depends on the strict protocol/guideline that that patient should adhere to complete the treatment regimen.

- All these factors vary from individual to individual. Hence Gender Framework by Rao and Kelleher was adopted to understand the gender-specific factors contributing for Non – adherence to the TB treatment regimen

The top two quadrants are related to the individual

On the right change in noticeable individual conditions i.e., the Individual decision of Non - adherence to treatment protocol depends on the factors that are listed below

- *Health workers and Health facility-related factors:* Poor healthcare provider-patient relationship, long waiting time (Diagnosis, Follow up, and collection of Drugs), Healthcare inaccessibility and traveling costs, Shortage of Health workers and workload, and Low level of staff Knowledge / Skill / Training,
- *Health facility / Programme related factors:* Lack of awareness among patients, Lack of timely supervision and feedback, and Non –Availability of Medicines and treatment
- *Other allied factors:* Lack of proper response from the community leaders and Non – referral by private practitioners

On the left individual consciousness and capability

ie.., Adherence to treatment protocol also depends on the individual belief, His / her health-seeking behavior, and the capability of the individual to invest in his / her treatment (i.e.., Money, Time, dedication etc.,). Factors affecting the Individual consciousness and capability which leads to Non – adherence to treatment depends on the following factors

- *Individual Factors and perception:* Forgetfulness, Inadequate knowledge about TB, Psychological Distress (Poor mental health condition), Perception of Govt treatment and medicines are bad, Perceived Barriers, Poor health literacy, and health-seeking delay
- *Financial Factor:* Financial constrain to buy food, Medication cost other than Anti – TB, Poverty, Less investment in food, and Missing daily wages
- *Addictions:* Use of substances such as alcohol, Smoking, and Khat chewing

The bottom two clusters are related to the systemic.

The cluster on the right refers to formal rules as laid down in constitutions, laws, and policies.

I.e.., The systemic policy and guideline released by NTEP (National Tuberculosis Elimination Programme) pertaining to adherence to treatment protocol have some drawbacks which make the patient discontinue the treatment regimen. The following factors are listed below

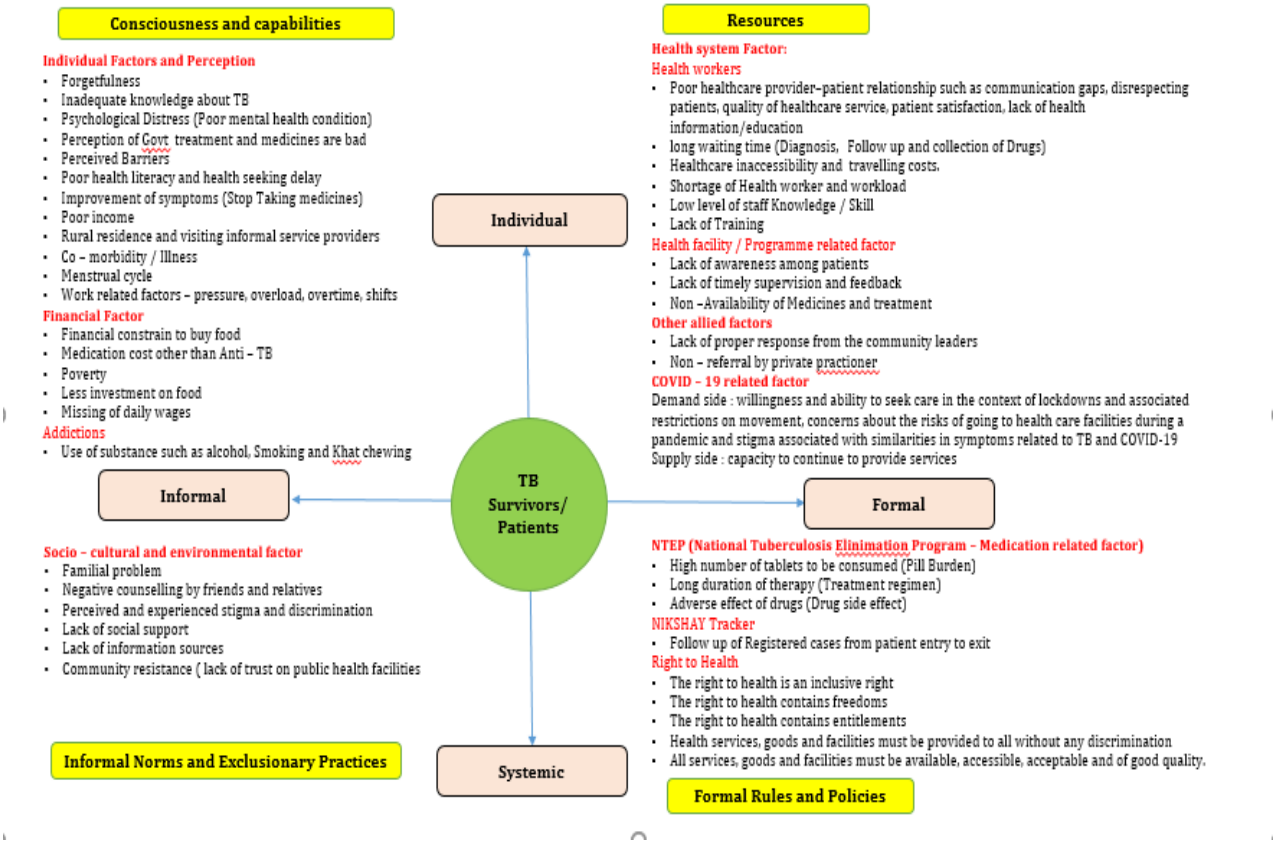
- *NTEP (National Tuberculosis Elimination Program – Medication-related factor)* - High number of tablets to be consumed (Pill Burden), Long duration of therapy (Treatment regimen), and Adverse effects of drugs (Drug side effects)
- Addition to, the *Right to Health* plays a vital role and its one of the important factors which enhance adherence to the treatment protocol. If the patient is unaware of what he is going through, what medication has been provided to him/her, or what are all the side effects he/she will face during treatment there is a higher chance that the patient will discontinue the treatment due to lack of knowledge on Diagnosis, Medication and Treatment protocol.

The cluster on the left is the set of informal discriminatory norms and deep structures, including those that maintain inequality in everyday practices.

i.e.., The systemic informal factors which contribute to Non – treatment adherence is mainly due to the stigma and discrimination associated with the disease (Tuberculosis). Lack of Family support and information sources plays a critical role which disables the patient to discontinue the treatment

Socio-cultural and environmental factors: Familial problems, Negative counseling by friends and relatives, Perceived and experienced stigma and discrimination, lack of social support, lack of information sources, and Community resistance (lack of trust in public health facilities

Conceptualized Framework – Factors affecting Non – adherence to TB Treatment



Source: Author created

Conclusion:

By reviewing the various literature across India and other countries, the PAC team has conceptualized the Gender Framework by Rao and Kelleher to understand the gender-specific factors contributing for Non – adherence to the TB treatment regimen. Gender-related factors contributing to Non – adherence to treatment protocol depends on the availability, accessibility, and affordability of the right treatment to the right individual at the right time, health-seeking behavior of the individual,and socio-cultural factors which disable him/her to avail or continue the treatment. It also depend on the strict protocol/guideline that that patient should adhere to complete the treatment regimen.

The questionnaire tool was developed based on the conceptualized framework developed by the PAC team.

Annexure 4: Steps in Data Management

- The first step is to translate the data from Tamil to English, wherever the translation is required (i.e. Occupation of the respondent, occupation of the spouse). The identified indicators were taken and gender-based analysis was carried out to check how gender plays an important role.
- Based on the sample data collected, the PAC team analyzed the proportion of gender age groups, marital status, and what is the educational status of the respondents and spouses, Occupation of the respondents before and after illness, the income of the respondents before and after the illness.
- Identified the socio-economic status of the respondents using Modified Kuppuswamy Scale 2021 and categorised the status of the respondents.
- This Kuppuswamy Scale comprised of three main indicators - education, occupation and income. Each sample was categorised and the scored**.** Higher the score higher the Socioeconomic Class.
- For smoking and drinking, PAC team have considered the respondents and the proportion of them coming under each category like drinking status, frequency, and duration in years.
- For adherence, the research team considered no of options they said yes if the sum is zero then there is no adherence if the score is one and above then there is adherence.
- Delay is categorized into three types- patient delay, treatment delay, and diagnostic delay:
    1. Patient delay is calculated as no of days he took to approach the hospital from the onset of symptoms. We consider the average no of days the respondents took to seek healthcare.
    2. Diagnostic delay is calculated as no of days from the testing of sputum to the diagnosis for this we considered the date when respondents gave sputum and when they started their diagnosis.
    3. Treatment delay is calculated as no of days from diagnosis to treatment for this we considered the date when the respondent was diagnosed and when they started the treatment.
    4. The Total delay (Health system delay) is calculated as no of days from the onset of the symptom to the treatment.
- Amount spent by the participants was calculated as the average amount spent from the no of visits and created ranges to check under which category the respondents are falling.
- For the knowledge, stigma and delay, PAC used logistic regression to check which indicators are affected most.
- For the knowledge, delay and stigma the related indicators are identified and correlation was done to check which indicator is highly correlated.
- Those highly correlated indicators was taken into the regression analysis for knowledge, delay and stigma.

Annexure 5: Correlation - Knowledge about TB and its determinant factors

Correlation - Knowledge about TB and its determinant factors	
age Above 35	0.026381207
age below 35	-0.02638121
Male	-0.03811757
Female	0.038117565
Illiterate	0.118855132
Literate	-0.11885513
unemployment	0.10673989
employed	-0.10673989
Smoking Never	0.004742951
Smoking Ever	-0.00474295
Drinking ever	-0.05216371
Drinking Never	0.052163706
Urban	0.178652941
Rural	-0.17865294
Previous history of treatment for TB: Present	0.16924344
Previous history of treatment for TB: Absent	-0.16924344
Family history of TB: Absent	0.079770431
Family history of TB: Present	-0.07977043
SES Upper	-0.02682004
SES Lower	0.026820041

Annexure 6: Correlation - Perception of stigma and its determinant factor

Correlation - Perception of stigma and its determinant factor	
age Above 35	-0.0561
age below 35	0.05608
Male	-0.0654
Female	0.06543
Illiterate	-0.055
Literate	0.05503
unemployment	0.02423
employed	-0.0242
Smoking Never	0.09888
Smoking Ever	-0.0989
Drinking ever	-0.1598
Drinking Never	0.15979
Urban	0.04907
Rural	-0.0491
Previous history of treatment for TB: Present	0.01642
Previous history of treatment for TB: Absent	-0.0164
Family history of TB: Absent	0.08439
Family history of TB: Present	-0.0844
SES Upper	-0.0394
SES Lower	0.03936
Knowledge low	-0.1497
Knowledge high	0.14965
Maternal status Unmarried	0.0991
Maternal Status Ever Married	-0.0991

Annexure 7: Correlation - Delay in Diagnosis and Initiation of Treatment and its determinant factor

Correlation - Delay in Diagnosis and Initiation of Treatment and its determinant factor	
age Above 35	-0.11
age below 35	0.11
Male	0.13
Female	-0.13
Illiterate	0.11
Literate	-0.11
unemployment	0.02
employed	-0.02
Smoking Never	0.08
Smoking Ever	-0.08
Drinking ever	-0.10
Drinking Never	0.10
Urban	-0.20
Rural	0.20
Previous history of treatment for TB: Present	-0.06
Previous history of treatment for TB: Absent	0.06
Family history of TB: Absent	0.09
Family history of TB: Present	-0.09
SES Upper	-0.10
SES Lower	0.10
Knowledge low	0.11
Knowledge high	-0.11
Stigma Patient High	0.15
Stigma Patient Low	-0.15
Private Health facility	-0.24
Government Health facility	0.24

Annexure 8: Questionnaire

Study Title: To study the health seeking behaviour and the barriers in early diagnosis and initiation of the treatment among TB patient and Survivors in Southern Districts of Tamil Nadu.

I have read information sheet / I have been informed by the investigator that this study is carried out to find out the barriers in delay of early diagnosis and thereafter initiation of treatment in people affected with the rural tuberculosis. I have understood that the result of the study is to increase the awareness among the community. Also to identify the reasons in delay of treatment, this is very essential to reduce the transmission of disease to achieve a healthy community. I understand that my participation in this study is purely voluntary. My unwillingness to participate or decision to withdraw will not affect my (family) current or future care with any of the programme the investigators institution. I understand that my privacy will be maintained and all information given by me will be kept confidential and be used for the purpose of the study only. However summary results for this study may be shared with for publication purposes. 91 I understand that the investigator and the other researchers will not need my permission to look at my study information both in the current study and any further research that may be conducted in relation to it. I agree to this access. However, I understand that my identity will not be revealed in any investigation released to third party investigator or if this study is published. I confirm that I have read (or have read to me in my own language) and understood the information sheet for the above study and have had the opportunity to ask questions. I agree the investigators contacting me over the phone and meeting me personally to know the details related to my illness

Questionnaire

Socio Demographic characteristics

1	Date of Interview	
2	District	1. Madurai 2. Ramanathapuram 3. Virudhunagar
3	Block	1. Thiruparakundram 2. Thirumangalam 3. Kallupatti 4. Kallikudi 5. Vadipatti 6. Alanganallur 7. Madurai East 8. Madurai West

		9. Melur 10. Karungalkudi 11. Kottampatti 12. Chellampatti 13. Usilampatti 14. Virudhunagar 15. Sattur 16. Sivakasi 17. Vembakkotai 18. Srivaliputhur 19. Rajapalayam 20. Watrap 21. Kariyapatti 22. Aruppukotai 23. Thiruchuli 24. Narikudi 25. Ramanathapuram 26. Mandapam 27. Thiruppulani 28. Bogalur 29. Nainarkovil 30. R.S Managalam 31. Thiruvadanai 32. Paramakudi 33. Kamudhi 34. Mudhugalathur 35. Kadaladi
4	Type of Residence	1. Rural 2. Urban
5	Village Name	
6	Type of house	1. Hut 2. Thatched 3. Tiled 4. Terraced

7	Number of rooms in the house	
8	Location	
9	Are you a TB survivor or TB patient?	1. Survivor 2. Patient
10	Name of the respondent	
11	Age	
12	Gender	1. Male 2. Female 3. Transgender
13	Marital status	1. Single 2. Married 3. Divorced/separated 4. Widowed
14	Number of household members	
15	Education of the respondent	1. Illiterate 2. Primary (1-5)std 3. Secondary (6-10) std 4. Higher Secondary (11-12) std 5. Under Graduate 6. Post Graduate and above 7. Diploma
16	Education of the Spouse	1. Illiterate 2. Primary (1-5)std 3. Secondary (6-10) std 4. Higher Secondary (11-12) std 5. Under Graduate 6. Post Graduate and above 7. Diploma
17	Total no of earning persons in the family	

18	Are you breadwinner of the family	1. Yes 2. No
19	Occupation of the respondent prior to illness	
20	Daily wage / Salary prior to illness (per-month)	
21	Family income-per month (Prior to illness)	
22	Occupation of the respondent currently	
23	Daily wage / Salary currently	
24	Family income (Currently)-per month	
25	Occupation of the Spouse	
26	History of smoking	1. Never 2. Past smoking 3. Current smoking
27	Type of Tobacco	1. Any form of Tobacco 2. Smokeless only 3. Smoking only
28	If 2 or 3 to Q No 22,	number of cigarettes smoked/day:
29	Duration of smoking	years-------, months----------
30	History of alcohol use	1. Never 2. Past user 3. Current user
31	How frequently	1. Daily 2. Weekly 3. Monthly

32	For how many years have you been drinking alcohol?	
33	Previous history of treatment for TB of the patient	1. Yes 2. No
33a	If Yes, How many years back?	
34	a. Family history of TB:	1. Yes 2.No
34a	If Yes who got affected?	
35	Any family members passed away due to TB in last 12 months?	1. Yes 2. No
36	Treatment Phase	1. Currently under TB Treatment 2. Have completed TB Treatment
37	Patients other chronic illness	1. none 2. HIV 3. Diabetes 4. COPD 5. Bronchial asthma 6. Blood Pressure (BP) 7. Other If Others please specify

Treatment seeking behaviour

38	Which of the above symptom/s made you seek health care?	1. Cough 2. Fever 3. Loss of weight 4. Loss of appetite 5. Hemoptysis - Coughing or spitting blood 6. Chest pain 7. Cold

		8. Others If Others please specify
39	Whom do you discuss the above mentioned symptoms in the family	1. Father 2. Mother 3. Spouse 4. Daughter 5. Son 6. Son-in-Law 7. Daughter-in-Law 8. Grand son 9. Grand Daughter 10. Friends 11. workplace Colleagues 12. Nobody 13. Others If Others please specify
40	Which health care facility you visited first?	1. Government Health facility 2. Private Health facility

41 Health seeking after onset of symptoms but before initial diagnosis and cost of consultation

No of Visits	**Place of Treatment**	**Outcome of treatment**	**Reason for choosing**	**Total Medical expenditure**	**Duration in days**
1st Visit					
2nd Visit					
3rd Visit					
4th Visit					

Code

	Place of treatment		**Outcome**		**Reasons**
Code No	Health Care Provider	Code No	Outcome	Code No	Reasons

0	None	0	NA	0	NA
1	Self - medication	1	No improvement	1	Accessible
2	Traditional Medicine	2	Slight improvement	2	Confidence in getting cured
3	Pharmacist	3	Worsened	3	Service available any time
4	PHC	4	Cured, but recurred	4	Referred by private health services
5	Government Hospital			5	Free Services
6	Private Doctor			6	Recommended by someone
7	others			7	I didn't think it as serious
				8	Thought it will go by its own
				9	others

42	Reasons for non-consultation of Government Health Facility (PHC/GH/CHC/GVMC/CHAD/CMC) with the onset of symptoms	1. Thought 'as not necessary' 2. Too far 3. Health facility too busy/long waiting time 4. Bad experience 5. No money 6. Lockdown 7. Inaccessible 8. Others If others please specify
43	what are the causes of delay in your health seeking behaviour?	1. Fear of what would be found in the diagnosis 2. Hope their symptoms would go away on their own 3. Fear of social isolation 4. Economic constraints 5. Unsatisfied with staff attitude 6. Poor quality of health services 7. Others If others please specify

44	In the Centre where you were diagnosed, what did they do?	1. Medical History 2. Physical examination 3. Test for TB Infection – Skin test and Blood test 4. Chest X Ray 5. Sputum examination 6. Medicine and follow up 7. HIV Test
45	Are you satisfied with the service related to TB provided by Government health facility	1. Yes 2. No
46	Please explain to us the challenges faced by you during COVID – 19?	1. Accessing the health facility 2. Getting a diagnosis 3. Availing treatment 4. Not affected 5. None

Diagnosis and Initiation of treatment

47	TB registration number	
48	TB Unit	
49	Date of testing sputum:	
50	Date of diagnosis:	
51	Date of initiation of treatment:	
52	Are you getting treatment from the same center where you diagnosed with TB	1. Yes 2. No
53	If No then after how many days were you started on regular treatment?	
54	Did you have the medicines to manage till then?	1. Yes 2. No
55	What is the distance from your house to the nearest health facility for your current/latest treatment? (in KM)	
56	How many days you could not go to work due to your illness?	

Knowledge about signs and symptoms, Transmission and Prevention of Tuberculosis

57	When you suffered from cough or fever / decreased weight / loss of appetite for more than 2 weeks, did you ever think that you might be suffering from TB?	1. Yes 2. No
58	Before you were diagnosed with TB, had you ever heard about TB?	1. Yes 2. No
59	In your opinion, how serious is tuberculosis? [Read the options and mark one answer only]	1) Very serious 2) Somewhat serious 3) Not that serious 4) Not sure
60	How serious do you consider the issue of TB to be in your community? [Read the options and mark one answer only]	1) Very serious 2) Somewhat serious 3) Not that serious 4) Not sure
61	What are the signs and symptoms of tuberculosis? (Unprompted; Multiple response)	1. Cough 2. Cough lasting more than 2 weeks 3. Chest pain 4. Cough with blood 5. Fever 6. night fever 7. Evening fever 8. Short of breath 9. Cough with phlegm 10. Constant fatigue 11. Loss of weight 12. Loss of appetite 13. Cold 14. Sputum with blood 15. Breathing difficulty 16. Not sure

62	In which ways can someone get tuberculosis? (Unprompted; Multiple response)	1. By a hand shake 2. Through air, when somebody with T.B coughs /sneezes 3. Sharing meals, using same plate/cups 4. Touching something a person with TB has touched 5. Sitting next to someone with TB 6. Hereditary 7. Contagious disease 8. Age 9. Low Immunity 10. Others If others please specify
63	How can a person prevent from getting this disease? (Unprompted; Multiple response)	1. Avoiding hand shakes 2. Covering your mouth or nose while coughing 3. Avoid sharing meals 4. Washing your hands after touching something in public places 5. Opening the windows, having good ventilation 6. Having good nutrition 7. Praying 8. Others 9. Do not know If others please specify
64	In your opinion who can get tuberculosis? (Unprompted; Multiple response)	1. Anyone 2. Poor people 3. Homeless people 4. Alcoholics 5. People with HIV/AIDS 6. People with diabetes 7. Others 8. Don't know

		If Others Please specify
65	Can TB be cured?	1. Yes 2. No 3. Don't know
66	Is it a hereditary disease or not?	1. Yes 2. No
67	How can a person suffering from TB be cured? (Unprompted; Multiple response)	1. Herbal medicines 2. Praying 3. Resting at home without taking any medicine 4. Taking Medication regularly as prescribed by a doctor or a health centres 5. Tuberculosis medication administered/ supervised by DOTS provider 6. Taking proper diet 7. Others 8. Don't know If Others Please specify
68	What is the approximate duration of treatment?	
69	Are you expected to check your sputum sometime after starting treatment?	1. Yes 2. No 3. Don't know
70	If yes to Q No 58, how many times?	
71	If yes to Q No 58, how many months after starting treatment?	

Right to information - Health care provider's services to TB patients

72	Before diagnosis were you informed regarding disease pathology and the required tests to be taken?	1. Yes 2. No
73	Once the diagnosis is confirmed have they informed you regarding	1. Yes

	the treatment protocol, importance of treatment adherence and side effects of the treatment?	2. No
74	Have you been informed about the diet plan?	1. Yes 2. No
75	Are you following the diet plan?	1. Yes 2. No
76	If no select the reason of not following the diet plan	1. Financial constraints 2. Nobody is there to take care of me 3. Non-availability of food 4. Others If Others please specify
77	Who supporting / supported you to follow the diet plan?	1. Government organization 2. NGO 3. Nobody 4. Others If Others please specify

Direct Benefit Transfer NIKSHAY- POSHAN

78	Are you getting benefited from NIKSHAY Poshan?	1. Yes 2. No
79	Have you raised the concerns to the higher officials?	1. Yes 2. No
80	Have they addressed your concerns?	1. Yes 2. No

TB treatment adherence

Medication related factors – During your treatment, have you ever…

81	Are you aware of the name of the person providing tablets for you?	1. Yes 2. No
82	Who is providing tablets for you?	1. Senior Treatment Supervisor (STS) 2. Health Visitor (H V)

83	Who is helping you to get the tablets?	1. Myself 2. Care Giver 3. Health Visitor
84	How frequently are you visiting the health facility to get the tablets?	1. Weekly 2. Fort-night 3. Monthly

Medication related factors

85	Forgotten to you take medication? Been careless about taking medication? Stopped taking medicine when feeling better? Stopped taking medicine when feeling worse?	1. Yes 2. No
86	Were/ are you experiencing any side effects while taking medication?	a) Yes b) No
87	If yes, what were / are the side effects that you are experiencing / you experienced? (Unprompted; Multiple response)	a) Skin rash b) Blurred or changed vision c) Stomach pain d) Brown urine or light-colored stool e) Tiredness f) Fever for 3 or more days g) Flu-like symptoms h) Lack of appetite i) Nausea j) Vomiting k) Yellowish skin or eyes l) Dizziness m) Tingling or numbness around the mouth n) Tingling sensation in the hands and feet o) Stomach upset p) Joint aches q) Easy bruising or bleeding If Others, please specify
88	What happens if you don't complete the full course of treatment?	a) The disease may come back or need to take treatment again b) Get worse/not cured c) Pass disease on to others d) Don't know
89	During your course of treatment have you informed to the health care provider regarding any complications that you have faced?	1. Yes 2. No
90	If yes whom did you inform	1. STS 2. HV 3. Medical officer 4. Social worker

91	What happens if you don't complete the full course of treatment?	1. The disease may come back or need to take treatment again 2. Get worse/not cured 3. Pass disease on to others 4. Don't know
92	How many months did it take you to complete the treatment?	1. I finished the course as recommended by the physician 2. I skipped it and I continued it again and completed the course
93	If you finished Please specify the months	
94	If skipped Please specify the months	
95	What motivated you to stick to the treatment protocol ?	1. To protect my family 2. fear of losing the job 3. Fear of death 4. Frequent visits from the health care provider 5. Motivation from the social worker (Blossom Staff) 6. Support from the family and friends 7. Self motivation 8. Others If others please specify
96	Can you please share the challenges that you faced to complete the treatment protocol?	1. Physical challenges 2. emotional Challenges 3. Societal Challenges 4. Health care facility challenge 5. Health care provider challenge 6. Relatives and friends 7. Nothing like that

Questionnaire related to Stigma

Community perception with regard to tuberculosis (from person with TB)

		Agree	**Disagree**	**Not Sure**
1	Some people may not want to eat or drink with friends who have TB			
2	Some people feel uncomfortable about being near those with TB			
3	If a person has TB, some community members will behave differently towards that person for the rest of their life			

4	Some people do not want those with TB playing with their children			
6	Some people think that those with TB are disgusting			
7	Some people do not talk with others about TB			
8	Some people are afraid of those with TB			
9	Some people try not to touch those with TB			
10	Some people may not want to eat or drink with relatives who have TB			
11	Some people do not want to have those with TB live in their community			

Patient perspectives towards tuberculosis (from person with TB)

		Agree	**Disagree**	**Not Sure**
1	Some people who have TB feel hurt because of how others react to knowing they have TB			
2	Some people who have TB lose friends when they share with them they have TB			
3	Some people who have TB feel alone			
4	Some people who have TB keep their distance from others to avoid spreading TB germs			
5	Some people who have TB are afraid to tell those outside their family that they have TB			
6	Some people who have TB are afraid of going to TB clinics			

	because other people may see them there			
7	Some people who have TB are afraid to tell others that they have TB because others may think that they also have AIDS			
8	Some people who have TB feel guilty because their family has the burden of caring for them			
9	Some people who have TB will choose carefully with whom they share that they have TB			
10	Some people who have TB feel guilty for getting TB because of their smoking, drinking, or other careless behaviour			
11	Some people who have TB are worried about having AIDS			
12	Some people who have TB are afraid to tell their family that they have TB			

	In general, what kind of support you expect to complete the treatment	1. Psychological support – Counseling 2. Nutritional Support - Weekly / Monthly once 3. Extra financial support 4. Others If Others please specify
	During the treatment phase is someone is there to take care of you?	1. Yes 2. No
	If Yes, Is caregiver present during the time of interview?	1. Yes 2. No

References

1. http://repository-tnmgrmu.ac.in/id/eprint/2149
2. https://www.cdc.gov/tb/publications/factsheets/testing/diagnosis.htm
3. https://pubmed.ncbi.nlm.nih.gov/34483522/
4. http://repository-tnmgrmu.ac.in/10987/1/201500119ilavarasan.pdf
5. https://bmchealthservres.biomedcentral.com/track/pdf/10.1186/1472-6963-13-110.pdf

Annexure 9: Field visit to study area of the Blossom Trust

PAC – CODR team acts as an operational research partner for Blossom Trust in CC - TATA Project.

Tuberculosis (TB) is a major public health challenge worldwide. It is the second leading cause of death from infectious diseases next only to the human immune deficiency virus (HIV). Above 90% of the global TB cases and deaths occur in the developing world where also 75% of the cases are in the most economically productive age group (15–54 years).

Evidence from a variety of literature shows that there are many factors affecting adherence to TB treatment. Lack of access to formal health services, traditional beliefs leading to self-treatment, loss of income, lack of social support, drug side effects, pill burden, lack of food, stigma with lack of disclosure, and lack of adequate communication with health professionals are some of the documented factors.

To assess practices of accessing health care and following treatment protocols among TB survivors and patients, PAC team developed Questionnaire tool and piloted it. Following two earlier visits, PAC team visited Virudhunagar, Ramnathapuram and Madurai District of Tamil Nadu between 12th to 14th October 2022 to conduct Key Informant Interview (KII) with the Key Stakeholder of CC – TATA project.

On 13th October 2022, PAC and Blossom Trust Programme Manager met National TB Elimination Program (NTEP) officials - Senior Treatment Supervisors (STS) and Health Visitor (HV) of CC – TATA project at Ramnathapuram District of Tamil Nadu and conducted KII to understand the pattern of health – seeking behaviour and delay in diagnosis and treatment among TB patient.

Figure 21 : PAC and Blossom team met NTEP team and discussed the pattern of health seeking behaviour of TB patients in Ramnathapuram District of Tamil Nadu

Public Affairs Centre
#15, KIADB Industrial Area,
Jigani-Bommasandra Link Road
Jigani Post, Anekal Taluk
Bengaluru - 560105
Karnataka, India