



# PATIENT SUPPORT GROUP



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# Strategy note







# introduction

Tuberculosis (TB) the world's top infectious killer, and India accounts for almost a quarter of the global disease burden of 10 million cases annually. TB takes not only a physical toll on patients' bodies, but affects them emotionally and financially. The disease, while curable, requires strict adherence to a months-long course of treatment before the patient can be cured. These months can be intensely difficult for patients, not just because the TB drugs can have severe side-effects, but also because patients may lose their incomes and face stigma from their families and the community. The treatment period can also be a trying time for caregivers, who may not fully understand TB and how best to support the infected people while also keeping the rest of the family safe; this often results in caregivers isolating patients from the rest of the family. These factors – social, physical, economic and emotional – often affect patients' treatment adherence, raising the risk of relapse and the rise of drug-resistant TB. In such an environment,

the person who can best support the TB patient is often a fellow patient who has undergone the same experience and can understand the concerns, apprehensions and fears faced during the lengthy journey to recovery. A peer-to-peer connect and experiential learning can help allay the patients' concerns and help them deal with the socio-economic fallout of TB, allowing them to focus on their recovery.

While TB patients receive their treatment at local health facilities, they are often unable to get the information they need or clarify their doubts about their condition beyond the initial consultation. Public health facilities offer free testing and treatment, but anecdotal evidence suggests that patients do not want to visit them, perceiving that the service is inferior to private health facilities. It is also a common perception that public health facility staff do not treat them well. A baseline study conducted in Bengaluru in 2016-2017, on patient and health system delays in the urban slums, found

that on an average, patients were reaching a private facility (20 days) earlier than a government facility (29 days). 42% of the patients reported that the good reputation of a healthcare facility prompted them to seek treatment and 38% of the patients reported that they sought the healthcare providers because he/she treated patients nicely.

KHPT developed the concept of Patient Support Groups in patient-friendly facilities, in alignment with India's National Strategic Plan (NSP) for Tuberculosis Elimination (2017-2025), which emphasizes the importance of patient support mechanisms for holistic approaches to care. The approach is designed to



Make public health facilities patient friendly



Provide patients a safe space to interact with healthcare providers outside the consultation room



Allow patient to learn from the experiences of other TB patients

The approach, built on KHPT's successes in implementing peer learning interventions in HIV and maternal health programs, incorporated the importance of peer support with the need for patient-friendly and approachable facilities. Patient Support Groups (PSGs) served as a monthly platform for patient-provider engagement and experiential learning conducted at health facilities. They were intended to provide the correct information to TB patients in a less clinical setting and to create a positive atmosphere for the discussion of sensitive issues such as stigma, disclosure and family troubles, with other patients. For diseases, such as TB, which are feared and stigmatized, it is important to discuss not only matters related to disease management, but also the socio-economic barriers and the stress that the patient undergoes that hinder recovery, in order to enable treatment adherence and completion.

KHPT and its partner TB Alert India implemented this approach under the Tuberculosis Health Action Learning Initiative (THALI) funded by the United States Agency for International Development (USAID) to ensure that patients receive quality health care services from a provider of their choice. It was implemented in the three south Indian states of Karnataka, Telangana and Andhra Pradesh, reaching out to a population of over 25 lakh.





# stories from the field

## Senior Treatment Supervisors observes healthy habits among patients attending PSGs

Vinaya Reddy has been working in the National Tuberculosis Elimination Program (NTEP) for five years. As Senior Treatment Supervisor at the Barkas Designated Microscopy Centre (DMC) in Hyderabad, Telangana, she knows well the challenges of treatment adherence and giving the patients enough time to address their issues. When PSG meetings started at the Barkas facility in 2019, Vinaya began attending and found them a useful platform to explain the importance of treatment adherence and nutrition to a larger number of patient without having to repeat herself to every patient. She was very pleased to see the interaction between patients and healthcare providers, and believes that the meetings have helped reduce treatment interruptions among the patients. “I haven’t seen this type of patient and provider meeting before, even though I have been with NTEP since last five years,” she says. “I believe the meetings will lead to good treatment outcomes and reduce the rates of deaths and patients lost to follow-up.”

She believes the involvement of caregivers is vital for the families to understand what the patient is going through and encourages the caregiver to attend even if, for some reason, the patient cannot. The challenge is getting all the patients to attend. Some patients, even after contacting them, do not come for meetings regularly. The THALI team suggested setting a fixed day for meetings, and stamping attendance on patients’ cards. This has helped improved patient attendance.

Vinaya thinks that the meetings are already showing results. “Some patients were not taking food properly, but after attending these meetings they changed their food habits and gained weight. These meetings are very important for patients for improved outcomes and better health.”

**what  
is a patient  
support  
group?**

A patient support group (PSG) is an inclusive gathering of patients and caregivers visiting a particular health facility once a month. This serves as a platform to discuss concerns about treatment with healthcare facility staff and to support and receive support through experience-sharing with other patients. This platform becomes an easy point of access to all patients and caregivers in a given area at a given point in time during the treatment phase to avail additional care and support services such as psycho-social counselling, nutrition support, provision of incentives and linkages to social entitlements for improving treatment adherence.

PSGs are founded on the belief that peer support can potentially help patients and caregivers deal with challenges that they face. Through conversations with patients and caregivers who have been similarly affected by treatment-associated difficulties such as side effects, as well as social stigma and isolation from extended family members and community members, PSGs provide an outlet for discussions and support. A safe, non-judgemental space for patients to air their grievances, and also serve as a learning experience for health facility staff on the importance of counselling and providing information in an informal environment that enables discussion on an ongoing basis. PSGs have also enabled the identification of TB Champions, patients who have recovered from TB and wish to help the patient communities in a variety of ways, ranging from in-person counselling and support to representing patients' interests to state health authorities.



# patient support groups: the approach

The Government of India's National Strategic Plan (NSP) for Tuberculosis Elimination 2017-25 lays out the importance of community ownership and mobilization for case finding and treatment adherence support for TB patients. It emphasizes the need for patient networks in planning, implementation and monitoring of the program, and the importance of community monitoring groups, peer group support and patient mentorship programs through TB advocates. According to the Patients' Charter for TB Care, patients are not passive recipients of services but active partners. The goal of PSGs is to enable better TB treatment experiences for TB patients. The PSGs not only aim to help patients and caregivers to support each other emotionally on their journey to recovery, but also enlist the support of people cured of TB, who can best empathize with them, and with whom participants can relate.

These meetings become especially important for vulnerable patients belonging to a certain

occupation or living in an institutional setting with no family support or caregiver. The PSG platform also makes it possible to introduce gender-specific support, particularly for women and adolescent girl TB patients who are often stigmatized very differently from their male counterparts and whose needs may vary from the rest.

THALI aimed to create a standardized model for PSGs, which could be adopted across health facilities, whether they are Designated Microscopy Centres (DMCs) at Primary Health Centres, Community Health Centres or larger facilities such as district hospitals or medical college hospitals, while also allowing flexibility to tailor activities to the requirements of the patients and capacities of the facilities.

The overall value addition of such an approach includes creating positive influences on health seeking behaviour and the overall well-being of the patients.

## objectives

The objectives of establishing Patient Support Groups are:

- To help patients overcome unpleasant treatment experiences and stigma during the treatment period using a peer support approach
- To improve communication between healthcare providers, patients and care givers to improve knowledge on TB and available services, as well as address issues related to treatment
- To work towards standardization and sustainability of PSGs in health facilities

## evolution of the process

When THALI began implementing the approach, it aimed to establish PSGs within the community, at patients' houses or the residences of key opinion leaders identified by community health workers. However, patients did not wish to have meetings within their communities for the fear of being recognized and stigmatized. The meetings were moved to health facilities subsequently, in order to protect patient confidentiality and also to facilitate exchanges with healthcare providers in a group setting. The meetings were held on days during which medication was distributed to the patients, to be more convenient for patients travelling long distances.

PSG meetings were carried out every month on a fixed day and fixed time at the DMCs. THALI Community Health Workers (CHWs), in co-ordination with TB Health Visitors (TBHVs), inform TB patients and their family members about the meetings.



## activities

PSGs were organized by the CHWs with the aim of not only creating an enabling environment for TB patients, but also to bring issues faced by the patients to the attention of the healthcare providers. It is through the voices of TB patients that healthcare providers can understand the role that mental stress, challenges in family or community support and access to nutritious food can play in affecting treatment completion, allowing them to formulate a strategy to address these issues amongst all the patients with whom they work. The PSGs are also a platform for healthcare providers to provide important and relevant common information to TB patients which they may not be able or available to explain to every patient on a case-by-case basis. This includes important information on accessing the monthly Direct Benefit Transfer (DBT) payments under the government's Nikshay Poshan Yojana scheme, for which all TB patients are eligible. CHWs have also mobilized support including nutrition support from local donors during meetings, and organized sessions on the preparation of nutritious food with the help of community organizations.

PSGs are designed to be engaging sessions of 60-90 minutes which feature components of information dissemination, experience sharing and allow the flexibility to involve communities, caregivers and key opinion leaders in the conducting of activities. To prevent PSGs from becoming a repetitive exercise for patients, THALI created a set of modules addressing different topics over different sessions. However, the flow of PSG Meetings are aligned with the objectives:

### objective 1

#### **To help patients overcome unpleasant treatment experiences and stigma during the treatment period using a peer support approach**

**TB patients act as positive influencers:** PSGs are designed to not only engage patients on treatment, but also to continue associations with people who have completed treatment and been cured. These patients are influencers and important resources because they can understand and empathize with TB patients. All this can be done while providing constructive suggestions and encouragement to patients on dealing with stigma, managing side effects, adhering to treatment and taking support from friends and family. Cured TB patients can also speak to caregivers accompanying the patients to alleviate their fears and concerns. THALI CHWs identified cured patients with a strong interest in representing the group's interests to health officials, and enabled them as TB Champions to speak up at district-level forums and other meetings of health authorities at different levels.

**Nutrition support:** PSGs are an ideal platform for the distribution of nutrition support. THALI CHWs would mobilize nutrition support in the form of nutrition powder, milk, eggs and pulses from local donors such as the Rotary Club, political leaders and community welfare organizations and distribute it amongst patients attending the meeting, while talking about the importance of eating a healthy diet to ease the recovery process.

### objective 2

#### **To improve communication between healthcare providers, patients and caregivers to improve knowledge on TB and available services, as well as address issues related to treatment.**

**Dissemination of correct information on TB services and benefits available to patients:** Despite having been diagnosed with TB, patients and caregivers may not have had a chance to fully understand and communicate their concerns to doctors at the time of treatment initiation. Having healthcare providers attend the meeting and address the group of patient together is a time-saver for the providers and also helps them give relevant information to the patients on an ongoing basis. This information includes details on TB care, patients' eligibility for welfare schemes and how to access these benefits.



**Provision of psychosocial counselling:** Healthcare providers or frontline workers attending meetings can provide counselling to patients on their issues including disclosure, stigma, alcoholism and correct nutrition. Interactions with other patients also creates a sense of community that may reduce patients' feelings of isolation and help them and their caregivers deal with their issues.

### objective 3

#### To work towards standardization and sustainability of PSGs in health facilities

**Advocacy with the NTEP to sustain PSGs:** THALI created a set of capsules to guide activities at patient support group meetings, and developed a set of Behaviour Change Communication materials which can be used to engage patients.

**Capacity building of facility staff to conduct PSG Meetings:** THALI built capacity of facility staff by conducting PSGs alongside them. The CHWs brought together frontline workers to mobilize patients to attend meetings and community structures to mobilize resources for patients and conduct sessions for them.



# stories from the field

## **A TB patient with comorbidities gains confidence about her recovery**

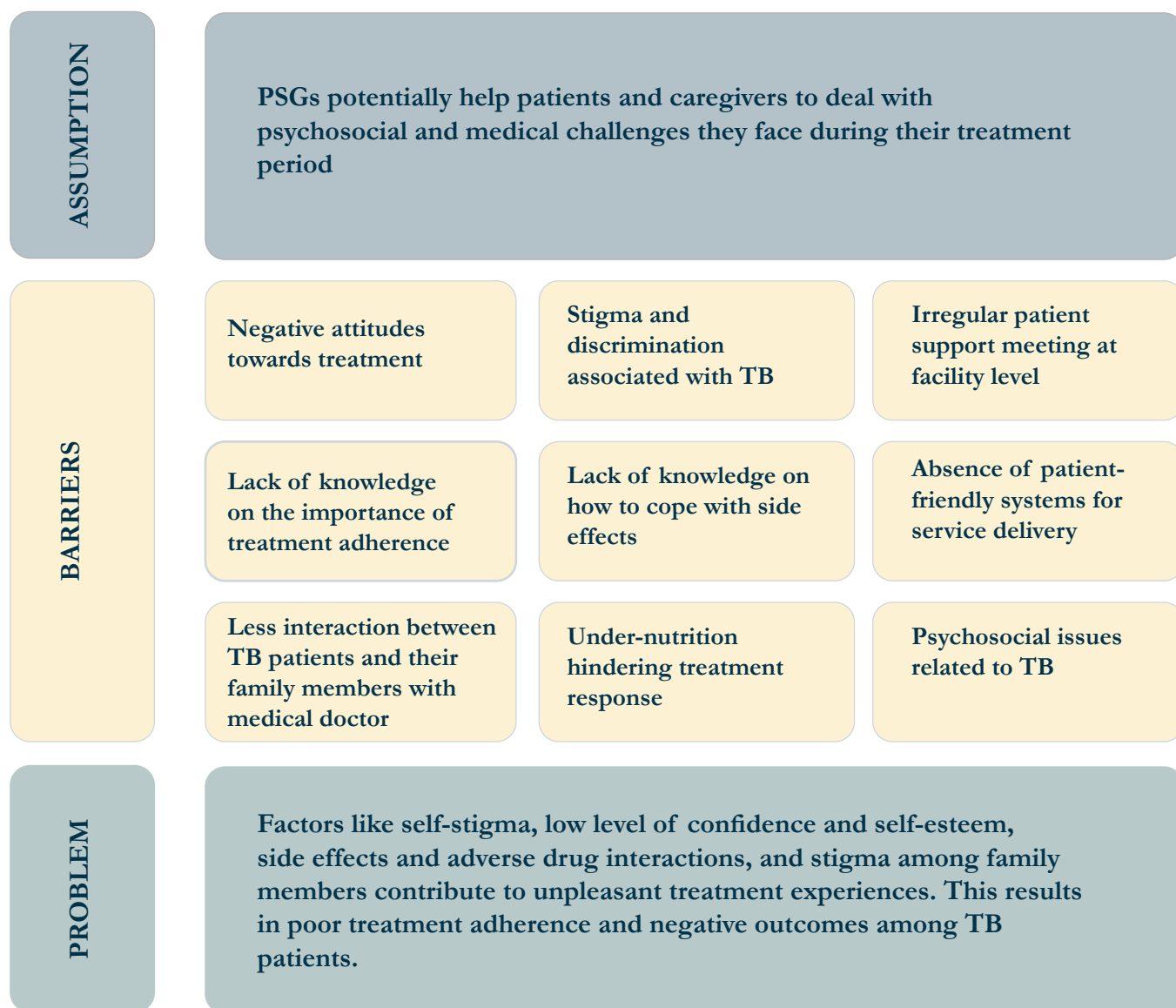
**D.** Jojamma, 48, lives in Hyderabad, Telangana. She is diabetic, and when she was diagnosed with TB, she was afraid that she would not be able to handle the treatment for both conditions, and worried that she would not recover. She was counselled by THALI staff, as well as the NTEP team at the Lalapet DMC where she collected her medication, and advised to attend patient support group (PSG) meetings held at the facility on a monthly basis. At the meetings, other patients she'd never met shared how they had been cured of TB by taking treatment regularly, giving her confidence that she could also be cured. Health facility staff talked about the side effects of medication and simple home remedies to help alleviate them. Jojamma found their advice on nutrition to be very useful. Although her family could not attend these meetings, Jojamma would return home and share what she had learnt about eating healthy, the importance of screening family members and maintaining cough hygiene.

"I felt happy to attend these meetings as I felt that somebody is thinking about my health, caring for me, supporting me and giving me details about nutrition for diabetic patients," she says. "Also I was grateful to hear the experiences shared by other patients on how they overcame issues like side effects."

Jojamma plans to continue attending meetings and sharing her experiences with other TB patients. "Yes (I will continue to attend), because it's very important to improve one's knowledge on TB, treatment and I can share my experiences with the gathering and transfer my knowledge to others in future for their good health."

# theory of change





## patient support groups: the process



- Engaging with staff at health facilities to assess feasibility:** THALI CHWs visited community health facilities, particularly Designated Microscopy Centres, to assess
  - if the facility had the space to offer for PSG meetings,
  - whether they were willing to offer that space once a month for patient meetings for around an hour, and
  - whether the staff at the DMC were willing to help facilitate the meetings

Each health facility had designated days for vaccination and other health-related programmes, so the CHW had to check the facility's schedule to determine the day of the meeting.

After CHWs organized an initial series of meetings, they realized that it was difficult for patients to travel to the health facility multiple times, especially if they came from far away locations or had to be accompanied by caregivers.

They also realized that some patients did not want to be seen coming to the health facility numerous times for the fear that their communities would find out that they had TB and would stigmatize them. In consultation with the facility staff, the team decided to hold the meetings on the days that patients came to collect their medication.

2. **Mobilizing patients with the help of frontline health workers:** Once the meeting dates and times had been finalized, THALI CHWs worked to sensitize patients and mobilize them to attend PSG meetings. Many patients were hesitant, fearing for their confidentiality. The CHWs explained, often through one-on-one meetings that the meetings were a safe space where patients could share their concerns with health officials, learn from the experiences of other patients and people who had been cured, and share their experiences for the benefit of other patients. The meetings would also give them the opportunity to understand the benefits for which they were eligible. THALI CHWs then elicited the support of frontline health workers such as the ASHAs to follow up with the patients, calling upon them to attend the meetings.
3. **Working with community structure and local leaders for nutrition and other forms of support:** Community structures are local organizations such as Self-help Groups, slum associations, youth organizations and faith-based organizations, which have community welfare built into their mandate. The THALI CHWs had built capacity in community structures to take ownership of TB control activities in their area. Community structure members mobilized nutrition support for TB patients or volunteered their time to conduct sessions at PSG meetings. They were also requested to mobilize patients for PSGs and help address patients' issues one-to-one if requested by the patients.



## structure of the meetings

1. The patients are welcomed by facility staff such as the Medical Officer, TB Health Visitor or Senior Treatment Laboratory Supervisor. They ask the patients if they are taking tablets regularly, reiterating the importance of treatment adherence and then ask the patients if they are having any other problems. This provides the patients the opportunity to get their concerns, including those relating to symptoms and side-effects, addressed. Facility staff also use this opportunity to take their weight, talk about nutrition and accessing direct benefit transfer payments for nutrition support.
2. Community health workers/frontline health workers lead the patients into a series of activities and discussions, which allow them to discuss topics of stigma, nutrition, treatment adherence, healthy habits and protecting one's family from getting TB. These activities use behaviour change communication (BCC) materials and simple, easily available equipment to better communicate messages and elicit responses. These activities (see patient support group capsules) prevent the meetings from becoming repetitive and lecture-based. Community organizations, whose capacity building initiatives are complete, are also encouraged to attend the meetings and contribute to sessions in areas such as the preparation of healthy food.
3. Patients are also given time to share their experiences, giving rise to discussions that develop organically, with little prompting from the facilitating staff and community health workers. Patient advocates (TB Champions) are trained to share their experiences during the discussions and motivate patients not to give up their treatment if they are experiencing side effects, having family problems, or even if they are feeling better.
4. THALI CHWs were often able to mobilize nutrition support from local donors or organizations and would distribute nutrition support in the form of powders, vegetables, bread, eggs and milk to the patients.





## key learnings

1. PSGs can be best sustained in health facilities: THALI CHWs initially attempted to set up PSG meetings in the houses of patients or key opinion leaders to enable easy access for patients. However, due to patients' fears of being stigmatized, the inability to fix a date and time each month, and the constraints that prevented health facility staff from attending meetings in the community, the meetings were shifted to health facilities. Having the meetings in a healthcare facility ensures that the facility staff are available to facilitate and answer concerns of the patients, and remove the uncertainty about time, place and frequency, while building the image of a patient-friendly facility and sustaining PSGs.
2. PSGs can help frontline workers identify patient advocates: Patient advocates, or TB Champions, are vocal and involved community members who represent the needs of patients at different levels of governance. THALI CHWs have frequently identified such patient representatives at PSG meetings, and helped them to get involved in various TB control efforts, locally or at higher levels, even after they have been cured.
3. Problems of access can be overcome through the involvement of community structure, patient advocates and frontline health workers: The experience of implementing PSGs led CHWs to understand that despite creating a safe space for patients, some, especially alcoholics or wealthy patients, would not attend the meeting. Incapacitated / Bedridden patients were also unable to access health facilities to get their medication or attend the meetings. The PSG meetings served as a platform which could link such patients with resources they need. Community structures and frontline workers, could, upon consent of patients, speak to their families if they were being stigmatized, or help families ensure treatment adherence among alcoholic patients. Patient advocates could also learn about the problems patients were facing and advocate with local leaders to solve the problems.
4. Caregivers also benefit from attending PSGs: PSGs, while tailored to be a safe and engaging space for TB patients, are also useful for caregivers, who often do not fully understand the patients' conditions or how to support them. Caregivers are often isolated themselves as they try to prevent their loved one from being stigmatized by their extended families. Bringing together caregivers to understand patients' needs while reassuring them that they will be cured and resume normal life if they adhere to treatment, is essential to ensure that patients receive the support they need from caregivers during the treatment period.



# monitoring and evaluating the initiative

THALI rigorously evaluated the patient support group initiative, which was implemented in 3 districts in Karnataka, 3 in Telangana and 2 in Andhra Pradesh. In the period between July 2019-March 2020, 98.6 percent of DMCs or health

facilities in the intervention districts had conducted PSG meetings. About 40 percent of the meetings were attending by a medical officer, which indicates an increasing buy-in from facility staff, which is essential for the sustainability of the initiative.

Patient Support Group (PSG) indicators (Jul 2019 to Mar 2020)	Achievements
Number of PSGs formed in Intervention districts - cumulative	143
% of DMCs/facilities conducted PSG meetings during the reporting period	98.6
% of PSG meetings attended by a Medical officer during the month	40.4
% of TB patients participated in the PSG meeting during the reporting period	36.6
% of TB patients attending PSG, having $\geq 90\%$ of treatment adherence	18.9
Number of TB advocates trained during the reporting period	130

*Note: The achievements were measured against targets set in discussion the project donor. Targets may be set by implementers according to the scale of program, geography and number of TB patients in the geography.*

# sustainability of the initiative

THALI's goal is to transition PSGs to health facilities and make them a part of the regular schedule of health facilities, which already have designated days for vaccination and antenatal care visits. A set of materials that can help health facility staff facilitate these meetings, including BCC materials and short capsules on pertinent topics with accompanying activities, have been developed during the project.

THALI is advocating with the state to include PSGs into health facilities across the state, promoting patient-friendly facilities which serve not just the medical needs, but also the psychosocial needs of the patient.



# stories from the field

## Learnings through interaction at PSG meetings

Pharahat Sultana is 37, and before she was diagnosed with TB, was working along with her husband in a tailoring in Millerpete, Ballari, Karnataka. Pharahat already had diabetes and thyroid problems, and the THALI Community Coordinator Sunitha informed her that she would have to take extra care of herself. Sunitha noticed her husband's involvement in his wife's care and motivated them to attend patient support group meetings together. Pharahat enjoyed the interactive nature of the meetings, especially an activity in which Sunitha distributes slips of paper to the patients. Each slip has a topic such as 'TB Symptoms', 'TB tests', 'Starting treatment', 'Adherence', 'Nutrition' and 'Side-effects'. Each person who picks a slip talks about what they know on the topic. The other patients and caregivers gathered, as well as health officials, add more points. This discussion has helped Pharahat remember the important basic information on TB. Pharahat also found a session on the preparation of nutritious food using locally available grains to be useful, and was grateful to receive a nutrition powder mobilized by donors to help supplement her diet as she recovers.



# **Patient Support Group capsules**







## background to patient support groups

Tuberculosis is a curable disease, but its effects range widely beyond the physical toll it takes on the people affected by it. TB affects the employment prospects, financial security, emotional stability and mental health of people due to a combination of factors including the high out-of-pocket expenditure on health seeking, weak nutritional status of the patient and stigma from loved ones. The toll of taking medication every day for months on end, with side effects ranging from nausea to abdominal pain to numbness of the hands and feet, is compounded by the socio-economic fallout of the disease. The path to recovery can be a long and lonely one, and the barriers to treatment adherence can lead to incomplete courses of medication, raising the risk of relapse and developing drug-resistant TB.

Although patients receive free testing and treatment from the public sector, as well as nutrition support, they do not always receive counselling support from healthcare providers. Healthcare facilities and staff are often perceived as unfriendly and accessing healthcare can be a stigmatizing

experience. The people best positioned to offer them such support are those who have undergone similar experiences, but at the risk of stigma, patients may hesitate to reach out to other patients for support. What they need is more than just a prescription for medications; they need access to patient-friendly and approachable facilities, as well as correct information and an enabling environment to share their experiences and learn from each other, if they are to complete their treatment successfully.

Under the Tuberculosis Health Action Learning Initiative (THALI), an initiative funded by the United States Agency for International Development (USAID), KHPT developed a set of patient-centred innovations designed to support TB patients and address the barriers in the way of treatment completion and recovery. The concept of patient support groups (PSGs) is one such innovation which aims to serve as a platform for TB patients and their caregivers to support one another by sharing experiences regarding treatment and concerns about sensitive issues such

as disclosure and confidentiality in an enabling environment. This platform becomes an easy point of access for all patients during the treatment phase to avail additional care and support services such as psycho-social counselling, nutrition support, provision of incentives and linkages to social entitlements for improving treatment adherence. The PSG platform also makes it possible to introduce gender-specific support, particularly for women and adolescent TB patients whose needs may vary from the rest.

PSGs served two important purposes. One, to enable engagement between healthcare providers and patients in a non-clinical setting, while also

helping healthcare providers address patient issues and disseminate important information to a large group. Secondly, PSGs are intended to harness the power of peer support to enable every TB patient and their caregiver adhere to an extended course of TB treatment, especially for those from socio-economically vulnerable groups. The concept was based on the belief that the cured patients have the responsibility of contributing to community health and showing solidarity by passing expertise gained during treatment to other TB patients in the community. The goal of the PSG initiative was to enable better TB treatment experiences within government TB facilities for the patients.

## the structure of patient support groups

PSGs, as envisaged by THALI, are gatherings of patients, caregivers, community health workers and staff of healthcare providers at health facilities, usually a Primary Health Centre, on a fixed day each month for 60-90 minutes, preferably the day on which TB patients come to the local health facility to collect their medication. PSGs were designed to bring together patients, their families, health officials, frontline workers and project staff to discuss, share experiences, learn about TB and help each other through the treatment phase. Often, community leaders would attend to lead sessions on healthy habits and healthy food

preparation, which apart from teaching patients and caregivers, also communicated acceptance and solidarity. The idea of bringing all patients together in an informal yet institutionalized manner was conceptualized in order to make it a fixed part of the patients' and health workers' schedules, without creating a sense of hierarchy.

The meetings would be facilitated by either the THALI Community Coordinator, the Senior Treatment Supervisor or the TB Health Visitor from the National Tuberculosis Elimination Programme (NTEP) stationed at the health facility. Each meeting can be attended by anywhere from 10 to 20 patients and caregivers. Concepts such as the importance of disclosure, nutrition, side-effects of treatment and the need for adherence to treatment schedule were explained through the use of Behaviour Change Communication material developed by THALI. To avoid the repetition of similar activities at each PSG meetings, THALI developed a set of capsules detailing activities that could be done at successive PSG meetings. Each capsule consists of a discussion and a short activity. The activity is designed to illustrate a particular concept through a game or a role-playing exercise which can elicit discussion and lead to a larger information sharing activity, resulting in the creation of a positive and hopeful environment for people with TB and their caregivers.





Capsule (Segment) Name	Additional Activity Count and Types	Materials required
Stigma and Disclosure	<b>3:</b> Importance of Positive Thinking, Good practices for TB patients, Importance of positivity for TB patients	Flipchart on stigma and disclosure, stand, markers, empty transparent bottle, cup, water, sugar, 2 sheets of paper, 2 transparent glasses, mud, chairs
Treatment Adherence	<b>2:</b> Importance of long term adherence, challenges of stopping midway	BCC materials on Bullet, TB Vruksha, Whiteboard, Markers, Stand, chairs
Importance of Nutrition	None	Flipchart materials on nutrition, Kitchen equipment, simple food supplies for display and usage, disposable cups, dustbin, Forms for DBT, chairs
Healthy Habits	None	‘Weigh the consequences’ flipchart, Idly-Vada poster, stand, chairs
Keeping your family safe	None	Posters and Handouts on cough hygiene and handwashing, soap and towel if facility permits, chairs

During each PSG, only one or part of one of the above capsules (segments) is addressed with the gathering. Apart from this, some time is set aside for sharing of information from the healthcare provider, a general discussion on challenges that can be raised by the participants and distribution of nutrition material that is raised through support of donors/community structures.





# stigma and disclosure



## objectives

To provide patients an opportunity to discuss the stigma they have faced from friends, family and colleagues, and to encourage patients to disclose their TB status to their families and take their support in completing treatment and enabling their recovery.



## rationale

TB patients, especially women, are often discriminated against when friends, family members and colleagues get to know of their condition. Patients are often kept separate from the rest of the family, given separate bedding and vessels, and in the case of married women patients, are sometimes sent back to their parents' home and separated from their children. This session allows patients at the support group to discuss their experiences with stigma and discrimination, and how they overcame it.

The facilitator then uses behaviour change communication materials on disclosure to share key messages on talking to family about one's TB status and taking their support to complete treatment.



## duration

1 hour



## methodology

Group discussion and explanations using flipcharts by facilitator



## equipment

A copy of the flipchart on stigma and disclosure (see annexure)



## process

1. Ask the group if they know what stigma means. Why are people stigmatized? Explain that stigma happens when something or someone is perceived as different, as external to what people know. Stigma can stem from fear, or from a closed mentality, shaped by religious background or habits or experiences shaped while growing up. It is a manifestation of biases people have, against qualities such as a person's colour, profession, case, language or gender. Give examples of such biases relevant to the local context.
2. Talk about stigma and disease. In case of diseases, stigma may be rooted in the fear of contracting the disease, in a lack of information about the disease. People may also stigmatize patients, attributing their disease to the ways patients are different from them and how being different has resulted in them contracting the disease.
3. Ask patients or caregivers present if they would like to share any experience with stigma they might have had because of TB, or might have seen in their own communities.
4. After they have shared their experience (if it is their own), ask them how the stigma affected them, and how they overcame it. Ask the group if anyone would like to respond to this experience.
5. Invite other patients from the group to share their experiences. If there are caregivers, invite them to speak as well.

6. Use the flipchart on stigma and disclosure (in annexure) to highlight the following points:
- Anybody can get TB. Having TB is not a reflection on your character or your choices. Highlight the different ways that one could contract TB
  - TB is curable if you take the entire course of medication
  - Disclose your TB status to your close immediate family. Allow them to accompany you to health facilities to better understand the disease from facility staff. Let them support you through recovery by providing nutritious food and reminding you to take your medication on time
  - People with TB need not be separated from their families. Staying together creates an atmosphere of positivity that helps facilitate recovery
- Display the image on the flipchart to the group, and use the text on the opposite side to tell the story of the patient Chitra, who is afraid to tell her family that she has TB. Use the guiding questions in the material to seek responses from the group.

## activity 1: the importance of positive thinking



### objectives

The objective of this capsule is to promote positive thinking among TB patients, and deal with stigma from family and close friends or colleagues.



### rationale

Many TB patients face stigma from their families, friends, neighbours, and at the work place, ranging from actions such as isolation and confinement to separate rooms of the house, to separate dishes and bedding being kept for patients, and even being fired from work upon disclosure of the TB status. These have the potential to compound the stress a patient with TB is already facing and can create a sense of hopelessness and depression. While patients cannot always fight against stigma, they can control the way they respond to negativity.



### equipment

A bottle and a cup of water



### process

1. Tell the group that you are about to conduct a small activity. Hold up an empty bottle and pour water into it until full. Add some sugar to the water. Say that this bottle is like a person with TB. The level of water represents his/her thoughts and the thoughts of other people around him/her. He/she has heard everyone's thoughts and is unable to hold any more. Even if more water is added, the water in the bottle remains sweet. The sweet water represents a person's positive thoughts. If the person with TB hold positive thoughts, they will have a positive attitude and no matter how many negative thoughts/reactions they experience, the positivity and sweetness will stay.
2. Mention that they, as TB patients, may have faced negative reactions from close family and friends or colleagues. The patients may have thought (if they have not spoken about it earlier):
  - "I will never go to meet anyone again."
  - "People are taking advantage of me when I am ill."
  - "Everyone think I have become weak, and I may not recover."



3. Say that the best way to prevent this situation is for the person with TB to change the way he/she reacts to a situation. The key is to react positively and not negatively, to influence the impact that the situation has on them.
4. Ask the participants to give examples of a positive response they have made or a potential positive response to a negative situation.
5. If there is no response, the give examples such as:
  - “If a person with TB gets told not to attend a wedding, he/she should say, “It’s okay, I’ll attend the next wedding!”
  - “If a person with TB is given separate utensils than the rest of the family, he should think that is just a short-term precaution.”

**NOTE:** The examples that you give must be real to TB patients. Collect the comments and remarks made by people towards TB patients frequently. Use every response of the participants to show them how that can be converted into positive thinking.

6. Wrap up the session, asking if there are any other comments, and re-emphasizing the need to be positive thinkers.

## activity 2: good practices for TB patients



### objectives

The objective of the activity is to directly touch upon aspects of stigma and good practices that are needed to be followed for the patient’s benefit.



### rationale

Stigma from family, close friends or colleagues of the TB patient may affect the patient’s treatment adherence, and they may give up on healthy habits they have been told about, such as taking medications on time and eating nutritious food. This activity encourages them to continue with these good practices to be happy in the long run.



### equipment

Sheet of paper and a marker/pen



### process

1. Take a piece of paper and draw a happy face and a sad face. Ask the participants if they know why one face is happy and the other face is sad.
2. If there are no responses from the participant or they say ‘no’, say that both people, the sad and the happy, are people with TB. Ask the group if they know why one face is sad. The participants may say that the he/she is sad because he/she has found out he/she has TB. He/she may be experiencing side-effects from the medication, the family may not be offering support, or he/she may have lost his/her job.
3. Ask them why one of the people with TB is smiling. Mention that the smiling face belongs to a person who takes medicines regularly, is not facing stigma from the family, is managing the side effects of medication and is going for regular follow-ups to the doctor. He/she is managing TB well, and is on the road to recovery
4. Repeat the good practices happy TB patients should follow:
  - They should take their medications on time and every day for the entire course of treatment, even if they feel better after a few weeks.

- They should enlist the support of their family to take their medications
  - Consumption of nutritious food
  - Taking support of close family/friends or healthcare providers to share their fears, details on side effects and concerns in order to lower mental stress
5. The sad person with TB is not taking treatment regularly, does not have family support and is not visiting the doctor for follow-ups., Ask the participants which person with TB it is important to be.
  6. Ask the participants if they have any questions or responses before closing the discussions.

## activity 3: the importance of positivity for TB patients



### objectives

The activity is intended to show the importance of filling the lives of TB patients with happiness and positivity to enable recovery



### rationale

People with TB are often stigmatized and isolated by relatives and close friends. This can hinder treatment adherence, with stigmatizing behaviour sometimes driving patients into anxiety and depression. Family support is vital for patients to complete their treatment period.



### equipment

Two transparent glasses, water, sugar and mud



### process

1. Hold up two clear glasses half-filled with water. Add sugar to one, and mud to the other. Ask the participants what they see. Which one can they drink? The participants respond, saying the water with sugar is drinkable.
2. Tell the participants that the water dissolved both sugar and mud. However, the water with sugar in it is clear and clean, the water with mud in it is undrinkable. Do the participants agree?
3. Tell the participants that it is the caregivers, friends and relatives who decide whether they want to add sweetness or muddy up the lives of people with TB. What the caregivers, friends and relatives add to patients' lives will shape their future. Patients will absorb both care and negative emotions, and their response/reactions will differ. Life becomes sweet when they are given good care and affection. Muddy water, however, makes it difficult to see the future, to a time when they are recovered.
4. Close the session by asking the group if they have any questions or clarifications.

# stories from the field

## **A mother is inspired to raise awareness in the community after PSG meetings**

Mangalagouri, 27, lives in Hospet, Ballari, Karnataka. Her son was just six years old when he was diagnosed with TB. When THALI Community Coordinator Annapurna conducted a routine home visit, she advised Mangalagouri to attend the PSG meetings at the Urban Primary Health Centre in Gandhi Chowk. The trip was not cheap; with no buses in the area, she had to take an auto which cost her Rs 100 for a round trip. However, when she attended the meeting, she found that many of her questions about her son's conditions were answered. She was able to get recommendations from her doctor to treat his side-effects. Most useful was the nutrition powder that was distributed at the meeting. Her son had not been eating well, and the powder, she felt, helped strengthen him.

"I got confidence and encouragement from the staff, who told me that TB could be cured," she says. "I got information about DBT (direct benefit transfer payment). I have even received the money in my bank account." She believes that the PSG is an opportunity for all TB patients to share their problems, and has been inspired to talk about TB with her family and her neighbours. "Three months back, I referred two people who were showing symptoms. They went for testing, but they tested negative for TB."



# treatment adherence



## objectives

To help patients in the support group, especially new patients understand the importance of adhering to treatment, using BCC materials and the voices of patients who were cured of TB.



## rationale

The course of medication for TB patients is at least six months long, and patients often discontinue treatment if they experience severe side effects or if they get relief from symptoms after taking medication for a few days / weeks. This raises the risk of the patient relapsing or developing a drug-resistant form of TB. The facilitator mobilizes patients who have completed their course of treatment and are free of TB to talk to patients on treatment about how they can adhere to the course of treatment. The facilitator also uses BCC materials ('Bullet' and 'TB Vruksha') as simple aids to explain the importance of treatment adherence.



## duration

60 minutes - 70 minutes



## methodology

Group discussion and demonstration using BCC tools for promoting adherence



## equipment

A copy of 'Bullet' and 'TB Vruksha' materials (see annexure)



## process

1. Ask the participants about the importance of completing any activity or task. Why do we leave tasks and activities unfinished? What are the repercussion of leaving activities unfinished? Allow the participants to give a few examples.
2. Tell them that from the examples, it was clear that the work should have been finished. Completing work is important even if we have to compel ourselves to do it, such as getting up to go to work each day, so that we do not miss our salary. Our health is also important, one of the most important things we have. However, why do we then not take our treatment? Why do we neglect our health?
3. Ask the patients gathered if they have had trouble taking TB medication. Ask them for reasons why. They may talk about the difficulty in taking multiple tablets, in accessing facilities to get medications regularly and side effects from the medication. Ask them if that has resulted in them missing doses.
4. Ask a person in the group who has completed treatment (he/she may be identified prior to the meeting) if they would like to address their concerns through a sharing of his/her experiences.
5. Give the patients on treatment an opportunity to ask questions of those who have completed treatment. If there are no questions, ask the cured people attending the meeting to talk about how they overcame issues such as side effects, forgetting to take treatment etc.
6. Use the TB Vruksha material to explain to the patients gathered that if they take treatment, they can be healthy and prosper, like the tree that is pictured. If they do not take care of the

health, their condition will worsen, like that of the dried up tree pictured. Ask the patients if they have understood and give them an opportunity to ask questions.

7. Use the 'Bullet' material to show the TB bacteria as a monster which will win if the patient does not take treatment. If the patient takes treatment regularly, there will be peace in the family, which is safe from TB. Ask the patients if they have understood and give them an opportunity to ask questions.
8. If there is a medical officer attending the meeting, ask them to talk about simple home remedies to side effects or how to prevent discomfort from taking the medication by taking tablets after small meals etc. The medical officer can also mention at which points patients should come for a consult if their side effects are severe.
9. Conclude the session by repeating the message that treatment adherence is essential for TB to be cured and that patients should not stop treatment due to side effects (unless recommended by the doctor) or because symptoms have reduced.

## activity 1: the importance of long-term treatment adherence



### objectives

The activity aims to draw the attention to the importance of the 'bigger picture' of treatment completion and the importance of not leaving the course of treatment incomplete.



### rationale

People with TB have a months-long course of treatment, which is often beset with side effects such as chills, nausea, weakness, which can lead to patients giving up medication. Patients also tend to give up medication after a few weeks, when they feel better, leading to an incomplete recovery and a rising risk of drug-resistant TB. The activity shows that colouring only a few 'boxes' does not complete the picture.



### equipment

Whiteboards, markers of different colours OR chart paper and markers of different colours



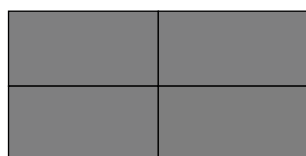
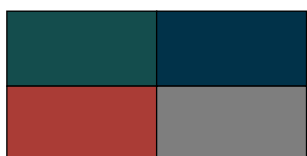
### process

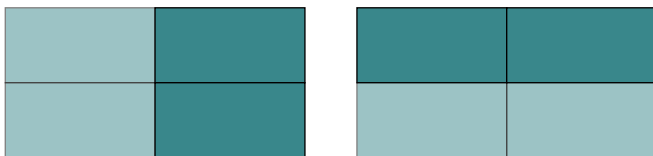
1. Draw four boxes on a whiteboard/chart paper as below:



Ask the participants how many boxes there are. Wait for a few responses to come in.

2. Shade the box in to show that beyond the four boxes immediately visible, the outline forms a box and the combination of two boxes each can also be a box. Show them that there are nine boxes in total





3. Explain that TB is represented by a larger box, and it will take more time to colour. However, if all four boxes are coloured, you are actually covering nine boxes,
4. Tell the participants that the boxes represent a course of TB treatment. If you only colour two boxes, it leaves the larger picture unfinished. The entire box should be coloured, for people with TB to have a complete recovery and complete the picture.

## activity 2: challenges of stopping midway



### objectives

The activity aims to draw the attention to the importance of treatment completion and the challenges of stopping midway via a small case study



### rationale

People with TB have a months-long course of treatment, which is often beset with side effects such as chills, nausea, weakness, which can lead to patients giving up medication. Patients also tend to give up medication after a few weeks, when they feel better, leading to an incomplete recovery and a rising risk of drug-resistant TB.



### equipment

None



### process

1. Narrate the following case study:

Imagine that one is driving a bullet motorcycle on an open road. It is nice and everyone on the bike is enjoying themselves. They come to an upward slope of 1 km. This is easy for a bullet motorcycle to climb. Halfway through the upward slope, the bike runs out of petrol. The people on the bike are upset. The rider tries to push the bike uphill for some time. The vehicle weighs over 200 kgs and is very difficult. The pillion also helps but even then it is difficult. They both get tired and the bike starts to slip back downhill. The bike is put in gear and halted.

2. Ask the participants what they should do next if they were in this situation
3. Listen to the responses which will primarily involve hitchhiking to get petrol. Now ask them to imagine if the rider is themselves, the pillion is their family, the bike is their body which has TB and the petrol is the medicine. Once they stop the medication (petrol), the bike stops and also starts sliding back which makes it difficult for themselves and their families.
4. Seek their thoughts and opinions and reinforce the need to complete treatment





# the Importance of nutrition



## objectives

To help patients understand the role of a healthy diet in recovery from TB, what constitutes a healthy diet, and their eligibility for nutrition support through the direct benefit transfer (DBT) scheme for patients.



## rationale

A nutritious diet has been linked to positive outcomes for TB patients. However, many recommended nutritious diets usually recommend the consumption of expensive fruits and vegetables which may not easily be available to TB patients. TB patients should know how to make healthy food out of local produce that is readily available and inexpensive. In addition, patients should be made aware that they are eligible for INR 500 per month during their treatment period under the government's Nikshay Poshan Yojana scheme.



## duration

60 minutes



## methodology

Group discussion, explanation using a flipchart and demonstration of the preparation of simple healthy foods



## equipment

Nutrition flipchart, ingredients for demonstration



## process

1. Start the discussion by asking the group of patients what they have been eating during treatment. Ask them if they have made any changes to their diet since they have started treatment.
2. Tell the group that it is important to eat healthy food to enable their recovery. Ask the group what they think constitutes healthy food.
3. Use the nutrition flipchart to tell the story of two different men's treatment journeys. One man did not feel like eating, and would not take his medication regularly. His reduced food intake resulted in him getting hospitalized. One man ate healthy food and took his treatment regularly, and was able to return to work quickly, even as he was on treatment. Use the questions in the flipchart to guide the discussion with the group while showing them the images depicting the story on the opposite side.
4. Give the groups examples of healthy food that they can access locally. If there is a medical officer present at the support group, ask him/her to give diet recommendations to the group.
5. Demonstrate the preparation of one or two simple dishes using easily-available ingredients, involving the members of the support group who are willing to participate. This session may also be conducted by members of community structures such as Self-help Groups. The recipes demonstrated may include salads, legume preparations, juices, buttermilk etc. Prepare enough so that each member of the group can try some, and ask them for some suggestions on what else they can prepare now they know that healthy food can be accessible.

6. Ask the patients if they have enrolled for the DBT scheme under the Nikshay Poshan Yojana. If they have not, tell them that every TB patient is eligible for INR 500 per month during the course of their treatment to allow them to buy nutritious food. Tell them about the documents required to enrol in the scheme and how to get the documents, such as identity proof, if they do not already have them. If the patients say that they have enrolled themselves in the scheme, but have not received the payment, refer them to health facility staff members such as the Medical Officer for further clarification.
7. Conclude the session with the message that healthy food will help patients gain weight, tolerate the medication better and that patients should consult the doctor about diet restrictions if they have other conditions such as diabetes, or kidney and liver conditions.



# stories from the field

## **A father finds PSG meetings a source of information and moral support**

PSG meetings not only serve as a platform for sharing and learning between patients, but also as an opportunity for caregivers to learn more about the disease. The stress of managing TB often hits caregivers, who may not fully understand the condition and how to best take care of their loved ones. When Polarao's young son was diagnosed with TB, the whole family was afraid and unsure of what would happen to him. Polarao, 38, was visiting the hospital in Visakhapatnam, Andhra Pradesh when he saw a PSG meeting in full swing, and was invited to join in. He heard doctors talking about side-effect management and thought the information could be useful for his son. Polarao began attending the monthly meetings, and learning more on nutrition, addressing fear and stigma, and the importance of regular follow-up visits. "I learned so much about TB prevention and importance of treatment adherence. With that knowledge only, I could help my son to take treatment regularly," he says. "I also learned how we can ensure the healing process through good nutrition along with medicine."

Even though Polarao has to give up a day's wage when he attends the meetings, he has found them useful for moral support and he now feels confident that the family will get through the treatment period. "The meeting has changed the situation at my home. Every time, we were providing rice and curries only to my son," he says. "But during the treatment process, my wife was taking all nutritional guidance through (health facility) staff, and she started giving him more water and protein-rich food."



# healthy habits: controlling smoking and alcohol consumption



## objectives

To ensure that patients understand that smoking and alcohol, while injurious to healthy people, are especially harmful to patients with TB, and to communicate that patients should reduce their consumption of narcotic and alcoholic substances during treatment.



## rationale

Alcohol consumption has been associated with an increased risk of TB, due to the impairment of the immune system, alcohol consumption being linked with malnutrition and liver disease, and the environment of such consumption being conducive to the spread of TB. Smoking is similarly harmful, affecting the immune system and damaging the lungs. While it is difficult to stop TB patients from consuming alcohol and tobacco, especially if they are habitual users, it must be communicated to them that they should stop consumption during the course of treatment.



## duration

45 - 60 minutes



## methodology

Group discussion, demonstration with BCC materials



## equipment

Weigh the consequences' flipchart, Idly-Vada poster



## process

1. Tell the group of patients that everyone knows that tobacco and alcohol consumption are injurious to health because they affect the immune system. Ask them if they know why these habits are especially harmful to TB patients?
2. Tell them that TB patients are already weak, and those who are smoking with lung TB are risking further damage to their lungs, which are already damaged by TB bacteria. In the case of alcohol consumption, mention that it worsens the effects of TB and that patients consuming it are more likely to miss their treatment doses, which will hamper their recovery. Mixing alcohol with any medication leads to harmful side effects. If a medical officer is present at the patient support group meeting, this information may be disseminated by him.
3. Use the 'Weigh the Consequences' flipchart which tells the story of an alcoholic man who chooses to continue consumption instead of looking after the welfare of his family. Tell the story of his descent into losing his job and house as his alcohol consumption prevents his treatment adherence, while using the guiding questions on the opposite side of the images. It is important to mention the effects of alcoholism on the family. As a contrast, the story of a person taking regular treatment after giving up alcohol shows that he is able to get back to work quickly and provide for his family. Answer any questions.

4. Use the idly/vada poster to talk about the harmful effects of using tobacco.
5. If you have identified a patient at the support group who has given up alcohol and tobacco consumption to focus on his treatment, ask him to share his/her experience. If his/her caregiver is present, ask them to talk about their role in helping the patient stop alcohol and tobacco consumption.
6. Conclude the session by telling the group about assistance available to them (such as Alcoholics Anonymous) and contact information for such groups.

## activity 1: avoiding unhealthy habits to improve the treatment experience



### objectives

The activity intends to make people with TB aware of the detrimental effect unhealthy habits such as tobacco and alcohol consumption can have on treatment adherence.



### rationale

Alcohol and tobacco consumption may worsen the side effects of medication and reduce their effectiveness. Alcohol and tobacco addicts frequently miss their medication, and this leads to the risk of developing drug-resistant TB. It is essential that patients reduce/stop the consumption of alcohol and tobacco during the treatment period.



### equipment

A plastic bottle, a tool to make a hole in it, water, a glass



### process

1. Take a plastic bottle and make a small hole at the bottom. Fill it with water, while keeping the hole covered with a finger. Ask the participants what they see.
2. Place a glass below the bottle and remove your finger, allowing the water to flow out. Into the glass. As the glass fills, continue to fill the bottle with water, allowing it to flow out.
3. Explain that the body is like the bottle, and the medicine is the water. If a person with TB smokes, drinks, or indulges in other unhealthy habits, the medicine flows out like water, without being effective.
4. Ask what a person with TB should do if he/she wants treatment to be effective? If a person with TB wants the treatment to be effective, he/she should stop drinking/smoking during treatment.



# keeping your family safe



## objectives

To help patients undertake healthy habits such as cough hygiene and regular hand washing in order to prevent the spread of TB, and to help them understand the importance of contact screening.



## rationale

To prevent the spread of TB to patients' close family, colleagues and friends, it is important to tell them that people they have been in contact with, especially children, should be screened for TB. They should also be proactive in preventing the spread of TB by covering their noses and mouths when the sneeze or cough, and should wash their hands and dispose of their sputum appropriately.



## duration

45 minutes



## methodology

Group discussion and demonstration of correct cough hygiene and handwashing



## equipment

Handouts for correct cough hygiene and handwashing practices, soap and towel if handwashing facilities are available for a demonstration



## process

1. Ask the patients what they thought about when they were diagnosed with TB. Did they think about their families and how to protect them? Do they want to know about how best to protect their families?
2. Tell the patients that once they are diagnosed, it is important that those close to them should be screened for TB as well. Ask them if this has been done by the frontline health worker/ medical office. If not, give them the contact details of the concerned person to conduct contact screening. If a medical officer is attending this session of the patient support group, he/she can explain the importance of contact screening and provide the contacts of healthcare staff who can do the screening.
3. Ask the patients how they cough when they are at home and demonstrate accordingly. Do they cough and sneeze openly? Do they cough and sneeze into their hands? Do they use a cloth and leave the cloth in the house?
4. Tell the patients that it is important to prevent the spread of the bacteria by preventing them from releasing into the air every time they cough and sneeze. Demonstrate coughing and sneezing into the elbow.
5. If they cough or sneeze into their hands, demonstrate the correct method of handwashing.
6. Tell them to wash their sputum away in water or bury it if they do not have easy access to running water.
7. Distribute handouts (see annexure) on correct cough hygiene methods, or pass it around the group if there are not enough copies.
8. Conclude by saying that patients can keep their families safe by the simple acts of practicing cough hygiene and correct sputum disposal. They can ask their family members to remind them until it becomes a habit. If the patients keep themselves safe, their families will also be safe.



# Annexure

# annexure

## i. Stigma and disclosure

### Stigma and disclosure flipchart



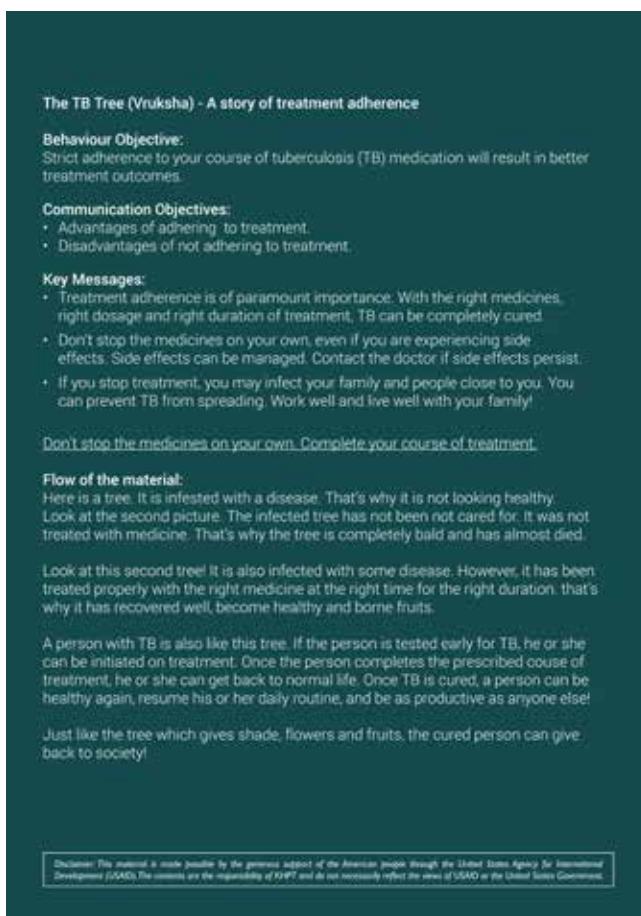


## ii. Treatment adherence

### Bullet



### TB Vruksha

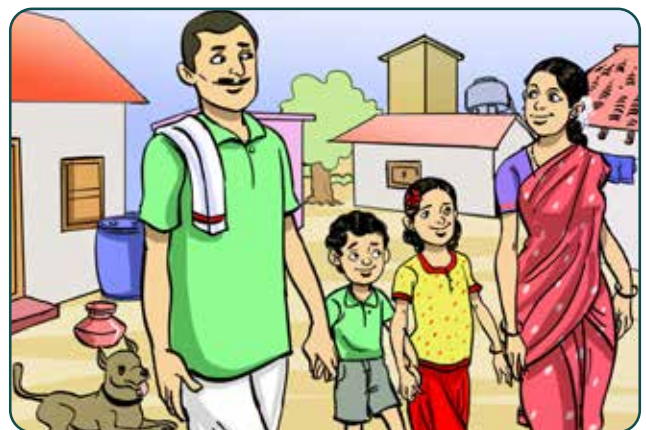
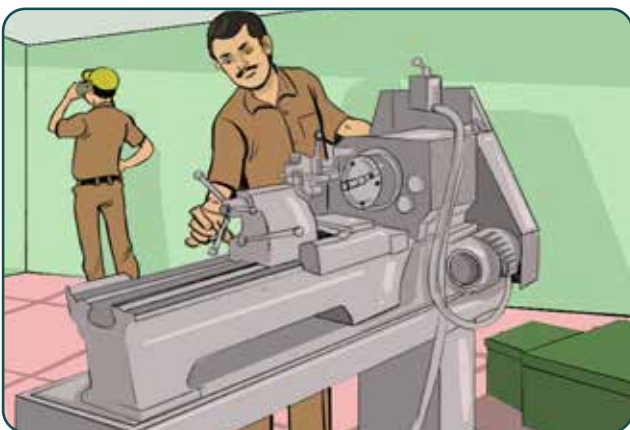
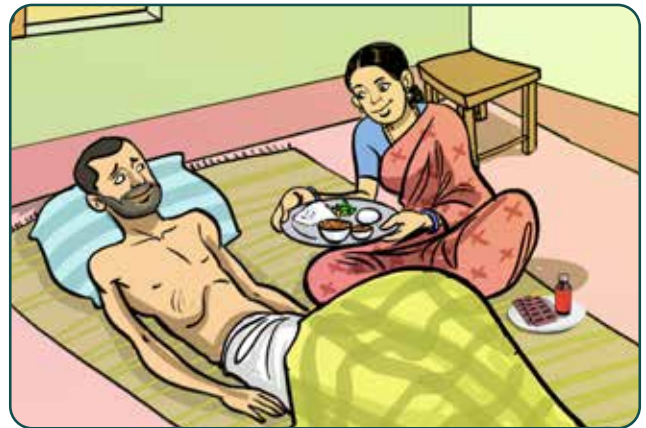


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### iii. The importance of nutrition

#### Nutrition flipchart





#### iv. Healthy habits: controlling smoking and alcohol consumption

##### Weigh the Consequences flipchart



##### Idly-Vada posters



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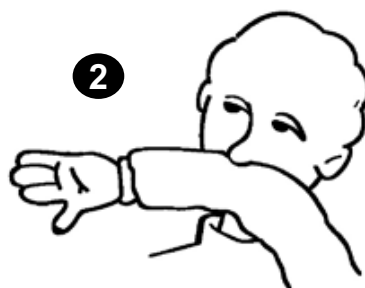
## v. keeping your family safe

### Cough Etiquette

#### How to prevent germs from spreading through coughing or sneezing?



1  
Cover your mouth and nose  
with cloth or paper



2  
Use your upper sleeve or  
elbow if there is no handkerchief.  
Do not use your hand



3  
If you cough frequently,  
use a mask



4  
Wash hands often.  
It is good to use soap



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