OVERVIEW

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सत्यमेव जयते

D.O. <u>Z- 28015/37/2020- TB</u>
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Dear STOs,

As you are aware that Karnataka Health Promotion Trust (KHPT) has been working in collaboration with NTEP as one of the key stakeholders in implementing community engagement activities.

This is to inform you that KHPT has prepared a toolkit which encompasses guidance on Community Structure Engagement and Patient Support Group.

This toolkit was implemented successfully in the states of Karnataka, Telangana, and Andhra Pradesh. The toolkit details the strategies involved in implementing these innovations and training modules to aid the process.

I am glad to share the toolkit with you all to substantiate your efforts in implementing community engagement activities. We encourage you to make necessary changes as per the local context and applicability.

Please contact us if you need any assistance.

Warm regards

Yours sincerely,

(Dr Nishant Kumar)

Encl: A/a

To

State TB Officer, (All States/ UTs)

OVER VIEW

The community engagement toolkit developed under the Tuberculosis Health Action Learning Initiative (THALI) features the strategies, training methodologies and field stories from three community centred innovations - Community Structure Engagement, Patient Support Groups and TB Champions. These models have been implemented and tested in the south Indian states of Karnataka, Telangana and Andhra Pradesh by THALI program staff and a cadre of outreach workers in urban and big city contexts with a high burden of TB. The booklets in the toolkit have been designed to be an easy-to-use resource for organisations and individuals wishing to build a strong network of stakeholders – including TB patients and caregivers, health facility staff and community organisations – to build increased ownership and sustained response towards TB control at a local level.

Structure	Content	Brief Description
Booklet 1 Community Structure Engagement	**Strategy Note** The strategy provides a detailed description of the intervention, including the rationale, the theory of changed envisioned by THALI, the stakeholders involved, and the process of engagement. The note also sets out the learnings and the impact of the intervention in THALI project geographies. **Training Module** The training modules have been designed to help facilitators to build capacities of patients and community members under each intervention through a set of structured, participatory and interactive sessions.	This booklet details an approach involving engagement with community structures that either reach or represent vulnerable populations in different geographies. It leverages the capacities of these grassroots structures to promote TB awareness and TB testing, mitigate TB stigma and offer linkages to post-diagnosis support including nutrition for TB patients in their local areas. It builds their perspectives, provided tools and motivates their leaders to integrate TB into their existing community welfare mandate and grow to be accountable and active community level organisations that work for people's health rights.
Booklet 2 Patient Support Groups	**Stories from the field** Stories from the field reflect the successes of each intervention through the experiences of a diverse set of stakeholders, and the qualitative impact that they have had in the communities of THALI's intervention geographies.	This booklet explains the concept of Patient Support Groups, an approach designed to make public health facilities patient friendly, while simultaneously providing patients a safe space to interact with healthcare providers outside the consultation room and to benefit from the experiences of other TB patients. Patient Support Groups (PSGs) served as a monthly platform for patient-provider engagement and experiential learning conducted at health facilities. They are intended to provide the correct information to TB patients and caregivers 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.
Booklet 3 TB Champions		This booklet explains the rationale and process of enabling a cadre of TB Champions based on the belief that patients have the responsibility of contributing to community health and showing solidarity by passing on the expertise gained during their treatment to other TB patients in the community. This process can encourage positive behaviour among TB patients undergoing treatment, as well as their caregivers, and help reduce feelings of mental stress and isolation, improving treatment adherence.

SETTING THE STAGE

Before the training

- Prior preparation is essential for effective facilitation. Give yourself sufficient time for this preparation.
- Gather as much relevant information as possible by interacting with co-trainers, program staff, and if possible, the persons participating in the training. This rapport building will prove very useful during the program.
- Be prepared for different skill levels of participants. Enlist the help of more proficient or literate participants to help those who are slower or who cannot write.
- Participate in the training programs conducted by other trainers and observe ways for skill improvement. This will also help you hone your time-management skills
- Prior to the training make an observational visit to the venue to know more about the available facilities. If you find something lacking you can bring it to the notice of the organizers or bring it yourself.
- If you need any aides or assistants, make prior arrangements for their presence and also ensure task allocation well in advance.
- Be aware that you will be the focus of attention during the training and be aware of your gestures and general conduct. Practice once in front of a full length mirror, if possible
- As a facilitator, you should be free from all prejudices or bias relating to people, ideas or issues.
- Develop the ability and skill to manage dissenting opinions, impediments and overcome confusion and chaos which may crop up during the course of a training program.
- During the training period, it is very important to get sufficient rest and sleep. Do not let any problems or worries affect your peace of mind. Keep away from other work pressures and mentally fortify yourself to focus on the scheduled program. Begin the session with confidence and self-belief. Have a good meal and carry a bottle of water.

At the beginning of the training

Starting the training program on a relaxed and positive note is an important first step. Many of the participants will have little or no previous experience of having attended any training program or workshop. Therefore it is only natural that they might be anxious or unsettled.

They should be given time to refresh themselves physically and to prepare themselves mentally. The facilitators should strive to create a warm, cordial and relaxed environment so that the participants can feel at ease with their surroundings and with each other. This is just as important as the actual training that will follow. The following activities could serve as an ice-breaking session to let participants get to know each other. The facilitator may either use these or any other.

Suggested Activity 1

Starting the training program on a relaxed and positive note is an important first step. Many of the participants will have little or no previous experience of having attended any training program or workshop. Therefore it is only natural that they might be anxious or unsettled.

They should be given time to refresh themselves physically and to prepare themselves mentally. The facilitators should strive to create a warm, cordial and relaxed environment so that the participants can feel at ease with their surroundings and with each other. This is just as important as the actual training that will follow. The following activities could serve as an ice-breaking session to let participants get to know each other. The facilitator may either use these or any other.

Suggested Activity 2

Each participant should be given a white postcard-sized piece of paper or card and a sketch pen or a ball pen. Tell each participant to imagine that the card is a mirror. Ask them to draw an image of their face and hair on the card making it as life-like as possible, with any distinguishing and individual features highlighted. Tell the participants that these cards will be collected and shuffled and then re-distributed to the group. The person getting the card should be able to recognize the picture and then find the depicted person in the group. Make sure that the cards are distributed so that pairs are formed. Once the two persons have found each other using the portrait cards, give them 15 minutes to introduce themselves and get to know each other by asking and telling about their home town, profession, family, or friends. Have each pair introduce themselves to the larger group and tell how they managed to recognize that person from the drawing.

In order to make the best of this time together during the training program, everyone should agree on some ground rules, or ways of preventing any group tensions or conflicts during the workshop. The facilitator should suggest certain topics which they may like to include such as: punctuality, respect for other people's views, politeness, being non-judgmental, giving everybody a chance to air their views, not using mobile phones, or making sure everyone participates and no one dominates activities.

At the end of the training

The facilitators must ask for feedback on the training methods, content and activities. They must ensure that allow the participants voice their frank opinions, without giving justifications or responding defensively to their feedback. One suggestion is to have a brainstorming session at the end of the module to gather insights from the participants regarding learning, the value of each session and how it changed their attitudes.

Feedback is also important to collect suggestions for future training sessions. The facilitators' skills can be reviewed from input by the participants and by each of the facilitators sharing notes and experiences between themselves.

Documentation of the feedback also allows program staff to modify the sessions on the basis of what has worked and remove sessions which may have not. If the training is to be scaled-up, these learning would be invaluable guidelines as different organisations work in specific contexts. Three aspects can be looked at: What went well, What did not connect, What could be done better.

USING
energizers

Energizers can be used to change the tempo of the day, keep people alert, help all participants mix with each other and make friends, revive interest levels and to help keep participants in a relaxed frame of mind. A list of energizers is included in the appendix to the toolkit. The facilitator may use energizers based on the context and the participant profile at intervals through the course of the day.

The facilitator should always ask everyone to participate, but stop the game or activity when the mood is still jovial, and make sure there is no feeling of having lost or won among the participants. Usage of energizers to be appropriate with session duration. Please avoid using long energizers if the session is short.

S.no	Energizer/ Game	When to be used	Materials required	Number of participants	Time required
1	Rhythmic Claps	This can be used to induce laughter among the participants and lighten the atmosphere	None	Entire group	5 minutes
2	Dancing Index Finger	This can be used to make the participants alert and think up ideas and names	None	30-35	10 minutes
3	Who is Your Favourite?	This can be used to break the monotony and helps the quieter participants to come out	None	30-35	10 minutes
4	Rani's Choice	This can be used in between post lunch sessions to energize the group	None	30-35	15 minutes
5	Idli-vada-chutney-sambar	This is most appropriate as an introductory game to help participants get comfortable. This can be used to mix the group and to break the monotony between sessions, or soon after lunch to enthuse the group. It also helps in the formation of small groups	None	30-35	10 minutes
6	Imitation Game	This can be used to form small groups, or to mix the larger group and also to break the monotony	None	30-25	10 minutes
7	Game of Rules	This can be used to mix the group and to break the monotony between sessions, or soon after lunch to enthuse the group	None	30-35	15 minutes
8	Gandhi Thatha Game	This can be used to induce laughter among the participants and lighten the atmosphere	None	30-35	5 minutes
9	Basket on My Head	This can be used to make the participants alert and think up ideas and names	None	30-35	5 minutes

10	**Follow the Leader**	This can be used to break the monotony and helps the quieter participants to come out	None	30-35	5 minutes
11	**In the River, On the Bank**	This can be used in between post lunch sessions to energize the group	None	30-35	5 minutes
12	**Number Acting**	This can be used in between post lunch sessions to energize the group	None	30-35	5 minutes
13	**Catch the Color**	This can be used to help the participants to get familiar the surroundings	None	30-35	5 minutes
14	**Chicken and Chimp**	This can be used to get the participants physically active and to break the monotony between sessions	None	30-35	10 minutes
15	**Blind Mice**	This can be used in between post lunch sessions to energize the group and break the monotony	None	30-35	5 minutes
16	**Chain Running**	This can be used in between post lunch sessions to energize the group and break the monotony	None	30-25	5 minutes
17	**Dance to the Beat**	This can be used to help the participants open up and break the ice	None	30-35	5 minutes
18	**What-ho, How-much?**	This can be used to form small groups, or to mix the larger group and also to break the monotony	None	30-35	5 minutes
19	**Chitty Chitty Bang Bang**	This can be used to make the participants alert and break the monotony	None	30-35	5 minutes

Rhythmic Claps

As a relaxation exercise, this can be used to prepare the participants for the sessions, or it can be used for calling the participants attention after a break, or to bring silence whenever the proceedings become too noisy. Begin clapping after saying, "OK one, two, three clap". The group will begin by clapping their hands twice followed by three continuous claps and repeat the latter three times. Conclude with two short claps: (Ex: Tuk tuk- tuk tuk tuk; Tuk tuk- tuk tuk tuk; Tuk tuk- tuk tuk tuk; Tuk tuk!)

Dancing Index Finger

Ask participants to stand in a circle. The facilitator will tell the group to do as she does and say what she says. She will then lift up the right hand and draw attention to the index finger by folding the remaining fingers. Now twist and turn the index finger and tell the group that the finger is dancing. The entire group will follow suit to the accompaniment of the thakadimi-thakajanu tune and others will provide the chorus.

Next she will unfold the thumb and tell the group that the thumb is also dancing with the index fingers. This should be imitated by the group, again accompanied by singing of the thakadimi-thakajanu tune. Follow on with the left hand, first with the index finger and then the thumb joining in. After the group follows suit, the thumbs and index fingers of both hands should be dancing. Gradually let the body dance to the rhythm of the thakadimi-thakajanu tune.

Who is Your Favorite?

The participants will stand in a circle and each of them will draw a smaller circle around themselves. One participant must volunteer to stand in the middle of the large circle while the facilitator takes her place in the outer circle. The facilitator must now ask the participant in the middle the question, "Who is your favourite?" The participant must choose her favourite by indicating something worn by other participants. For example, she can say, "Those wearing watches are my favourite.", and all those participants wearing watches must change their place and go into someone else's place. Other favourites could include red saris and glass bangles. Each time, one participant will be left without a vacant spot and will assume the role of the facilitator in the middle to continue the game. Encourage participants to be quick in thinking and responding. If chairs are available they may be used for participants to play the game while seated instead of standing.

Rani's Choice

Invite one of the participants to come forward and declare her for the role of the Rani or Queen. The facilitator will act as the Minister to the Rani. Draw a fairly large circle around the Rani and say that nobody is allowed to come inside that circle. The remaining participants will form 4 groups. They have to please the Rani by bringing simple objects desired by her and hand it over to the Minister. Each time the Rani desires something, the group bringing the desired object at the earliest will get a point. After playing the game for a while, analyze why a certain group got more marks while others got less. Explain the need for creativity combined with intelligence. Note: Before starting the game, the facilitator can brief the participant playing the Queen to start the game asking for simple things inside the room or hall. For example, one pink chart paper, four black hair clips, a pair of brown slippers and so on. Some of the commonly desired objects may be brought from outside the hall as well.

Idli-vada-chutney-sambar

Divide the participants into four groups and name the groups as Idli, vada, chutney and sambar, which are all types of south-Indian food. Ask the members of each group to hold hands and then form a circle. Now the facilitator narrates a story in which the names idli, vada, chutney and sambar are repeated randomly. Each time this happens, the particular group while continuing to hold hands, should also sit down and immediately get up. This should be repeated every time the name of the group figures in the narration of the story. This exercise is continued till the ice is broken and everyone is smiling. Note: This doesn't have to be a full fledged story but can also be a spur of the moment spiel. For example, "My wife, children and I went to a hotel and asked the waiter for the menu. He told us that they had idli, vada, chutney and sambar. My wife ordered idli, vada, chutney and sambar. My son ordered for two idlis, one vada and chutney, and my daughter ordered three vadas, but refused the idlis and asked only for the sambar, but not the chutney, while I ordered two idlis and chutney."

Imitation Game

The participants will form a circle and the facilitator will count off each participant from 1 – 6 giving each a name of an animal or a bird. Tell all the participants to start moving around the room and to imitate the cries and movements of the animals or birds they have been named after. For example, if it is fish, the participants must imitate swimming; in case of frogs, the participants will jump and so on. Now the participants will be asked find a partner belonging to the same group of animals or birds. For example, the facilitator will announce that all frogs must form themselves into pairs and participants with that name will jump like frogs towards other frogs and become pairs. Similarly the facilitator can ask different kinds of birds to form pairs and so on. Ensure that participants imitate the appropriate cries and movements throughout the period of exercise till pairs and subsequent groups are formed.

Follow the Leader

Select a leader from among the participants. She will start the game with an action or sound or both. Ask the remaining participants to imitate their leader. When the facilitator calls out "change", someone from the group will assume leadership and continue the game. Actions commonly include: dance steps, hunting gestures, or applying makeup. Stop the game after a couple of rounds. Encourage those who come forward when the change is announced. Continue the game until a sufficient number of participants get a chance to play the leader.

Basket on My Head

All the participants must stand in circle. The facilitator should carry a basket on her head like a vegetable vendor and approach one of the participants and loudly announce her list of vegetables. The participant must instantly respond by naming the vegetables. If a participant fumbles while telling the names she has to carry the basket and continue the game. Now, she must go to another participant and announce that she is selling fruits and that participant will have to instantly come up with the right answers.

Game of Rules

Form two groups with equal number of members. Call two people from each group and ask them to stand on the spots already decided by the facilitator. Draw two lines a short distance away from the two spots and ask all other members of each group to stand behind these lines. Now ask the members on the two spots to stand facing each other and to then hold each other's hands and lift them up to form an arc wide enough to allow the other participants to run through it.

When the facilitator announces "start", one participant from each group must run through the arc. Each participant in the group must complete their run, running back to their group to give a pass to the next member, who in turn must follow the same procedure. Continue till the last participant has completed the run. All participants are required to follow the following rules in this game:
1. They must run the course in front of their respective groups.
2. They should not touch anyone while running.
3. They must give a pass to the next group member in line.
4. All participants must stand behind their marked starting line.

Gandhi Thatha Game

The group is asked to form a standing circle and the facilitator should join the circle. It would be interesting if the facilitator could share a few thoughts on Mahatma Gandhi before starting the game. The rules are that the group must follow the cue provided by the facilitator. For example:

"Gandhi thatha asks all of us to sit down."
"Gandhi thatha asks all of us to remain standing."
"Gandhi thatha asks all of us to do a slow jog."

In the River, On the Bank

The participants will stand in two parallel lines, facing each other. Explain that all are standing on the riverbank and one step forward is the river. Participants will have to respond instantly to commands of "River" and "Bank". Start the game slowly and then increase speed as you vary the commands. Those who take a false step in response to the command will be out of the game.

Chain Running

Let all the participants stand apart and ask one to volunteer to start the game by running and touching another member. Now the other members must avoid being touched. Those who have been touched will hold hands and try to touch others. The chain will keep getting longer until the last person has been touched. Once a complete chain of the participants is formed, get them to sing a song while holding hands and moving around in a circle.

Number Acting

Start the game by asking participants to speak aloud the numbers from 1 to 10. Next, the numbers will be written in the air by moving fingers, followed by arms, heads, and then the entire body, while both hands are placed on their waists!

Catch the Color

The participants have to stand in a circle. The facilitator must loudly announce different colors one at a time. For each color, the participants must rush towards their immediate surroundings and get something matching that color. Those who fail to bring anything will be out of the game.

Chicken and Chimp

Divide the participants into two groups called Chicken and Chimp. Members of the two groups should form two parallel lines, standing about 5 feet apart. When the facilitator calls out "Chimp", the members from that group must run after the Chicken and catch them while they try to evade being caught. To make the game more interesting, the facilitator must keep suspense alive by starting with Chi.Chi.Chi…before saying either Chicken or Chimp! This not only creates confusion, but also makes participants more alert as they eagerly wait their turn either to catch or to run.

Blind Mice

Ask all the participants to close their eyes and slowly walk around like blind mice. They should not bang into each other. The facilitator must then ask the group to speed up their walking and finally ask them to run. Note: While playing this game, ensure that there are no obstacles on which participants can fall or hurt themselves.

Dance to the Beat

Ask the participants if they would like to sing a song. Tell them that you will first start singing these words very softly: daguchuku daguchuku daguchuku daguna dam dam dara dara dara dara dara dara dara dara. Then ask the participants to raise their voice while singing these words. Then repeat the tune while holding their hands to be followed by head shakes. The activity should end with each member taking vigorous steps to the tune. All will join in the dancing and jumping with enthusiasm.

Chitty Chitty Bang Bang

The participants stand in a circle and start saying numbers starting from 1. When it is the turn of the fifth participant, instead of saying 5, she has to say "Chitty Chitty Bang Bang", accompanied by a clap. This should be followed by every fifth participant (i.e., 5th, 10th, 15th, 20th and so on). If anyone just says "5", or "Chitty Chitty Bang Bang" without a clap, they have to leave the game. In that case, the next person is considered as the 5th person and is expected to follow the rules of the game.

What-ho, How-much?

The participants will first stand in a circle and then jog clockwise. While they are moving, the facilitator in the middle should repeatedly ask them "What-ho, How-much?" while they respond with "As-much-as-you-say" while continuing to jog in the circle. Suddenly, the facilitator should say a number, for example 3. Instantly the participants have to break the circle and form a group with three members. Anyone who fails to do so will be out of the game before it starts again with a new number. Note: Try variations by saying "two and half" so that three members come together with two standing and one sitting.

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COMMUNITY
STRUCTURE
ENGAGEMENT

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Strategy note

introduction

Tuberculosis (TB) is the world's most infectious killer[1], and India accounts for a quarter of the 10 million cases which occurred globally in 2018. While TB is curable with the right dosage of the right drug given at the right time, the months-long treatment course and side effects often deter patients from completing the course of treatment.

These barriers are compounded by the socio-economic repercussions of having TB; patients are often stigmatized by their families, colleagues and the surrounding community, sometimes losing their jobs, their family support systems and their will to complete treatment. The underlying factors that result in these repercussions for TB patients are:

- A lack of knowledge about TB

- The absence of nuanced efforts to reach marginalized communities

- Inadequate social mobilization efforts to provide support such as nutrition and linkages to welfare schemes for TB patients

A study conducted by KHPT in 2017 among 480 adults in the urban slums of Bengaluru, the capital city of the south Indian state of Karnataka, found that only a third of the population surveyed had a 'comprehensive knowledge of TB', i.e., knew that TB is spread through air, that cough is the most common symptom, that sputum tests are confirmatory, and that TB is curable. Only 29 percent knew that TB treatment lasts for six months and only 17 percent knew that treatment is available for free in government run health facilities. This lack of knowledge has implications on health seeking behaviour in communities, especially in urban slums, where populations are

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[1]WHO, TBAlliance.org

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vulnerable to developing and transmitting TB. While the Government of India has designated health staff from community health facilities to provide services through community visits, time and resource constraints prevent them from offering patient-centred care and sustained outreach outside the confines of the facility. For vulnerable populations, which are more at risk of developing TB due to their crowded living conditions, hazardous occupations, or pre-existing health conditions, the potential lack of access to health facilities - due to factors such as lack of public transport or problems with affordability of transport - is an additional barrier to diagnosis and treatment initiation.

In response to these challenges and gaps, KHPT developed an approach complementary to that of the government to address underlying barriers and push the National Tuberculosis Elimination Programme (NTEP) to greater success. This approach involves engagement with community structures that either reach or represent vulnerable populations in different geographies. It leverages the capacities of these grassroots structures to promote TB awareness and TB testing, mitigate TB stigma and offer linkages to post-diagnosis support including nutrition for TB patients in their local areas. The approach builds their perspectives, provides tools and motivates their leaders to integrate TB into their existing community welfare mandate. The model encourages community structures to actively engage with patients' issues in their unique contexts and sustain efforts against the spread of TB, paving the way for increased ownership of the 'End TB' agenda among communities.

The approach was developed and implemented by KHPT and TB Alert India in three South Indian states of Karnataka, Telangana and Andhra Pradesh, reaching a population of approximately 25 lakh under the Tuberculosis Health Action Learning Initiative (THALI), supported by the United States Agency for International Development (USAID). THALI frontline staff implemented the approach on the ground and adapted their interactions on the community structures' involvement to the structures' capacities and interests. The staff's experience with patients and caregivers, including understanding stigma and the need for social support, also helped shape the interventions.

what
is a
community
structure?

A community structure (CS) refers to a semi-formal or formal/ organized and decentralized network of individuals representing a certain group (men/ women/ transgenders/ youth from marginalized or vulnerable communities/ informal workers) in a defined geography, having a shared agenda and a welfare mandate, with its own operational systems and leadership.

These include Self-help Groups, labour unions (both formal and informal workers' unions), Youth groups, Dalit groups, Faith-based organizations (FBOs), Residential communities and Community-based organizations (CBOs) of vulnerable groups.

community structure engagement: the approach

KHPT and TB Alert India engaged with select, existing and fully functional community structures with the aim of demonstrating a successful model of community engagement which would be a) cost-effective, b) have a significant reach in the community, c) avoid creating a parallel or new structure within the community and d) sustain by creating a sense of community ownership.

The goal of the engagement was to enable community structures to play a catalytic role in driving the health and TB agenda within communities. We aimed to empower members of these structures to take charge of community health, and work with the government frontline healthcare workers not only to increase awareness about the disease, to build an enabling environment for TB work, but also to take steps towards quantifiable change through referrals of patients to testing centres, helping them complete the course of treatment through support and follow up and linking them to patient benefits and government services.

objectives

The objectives of working with community structures were:

- **Creating awareness and mitigating stigma:** To strengthen social accountability towards mitigating stigma and discrimination, promoting gender equality and increasing community participation in health decisions, generally, and TB, specifically
- **Promoting health seeking behaviour and TB detection:** To enhance social mobilization efforts towards improving health seeking behaviour and TB detection among vulnerable communities
- **Supporting TB patients and families:** To complement support (post-diagnosis support) for TB patients and their families to help them in their journey towards treatment completion

activities

Community structures have immense potential to collectivize efforts and initiatives in order to conduct activities that strengthen TB awareness in the community, improve the recognition of symptoms, and promote appropriate health seeking behaviour. Due to their significant influence as organizations with social welfare as part of their mandate, they have the ability to help TB patients in a variety of ways, starting from one-on-one counselling and patient visits to mobilizing resources to support them with monetary and/or nutrition support through the treatment period. The activities can be tailored in accordance with the organization's mandate, coverage and capabilities; some activities can be carried out by individual members of the community structures as well. This will create an enabling environment in the community to foster TB control initiatives and support TB patients through stigma mitigation and resource mobilization efforts.

The activities below have been aligned with the objectives listed in the previous section.

objective 1: creating awareness and mitigating stigma

1. **Conduct campaigns / events to promote non-negative messaging around TB:** Members of community structures can play a leadership role in organizing awareness drives, events and activities such as health camps on important occasions where communities get together to provide correct information on TB, dispel myths and misconceptions, and help mitigate the stigma associated with TB. They could also include TB into the agenda of their regular events and programs.

2. **Act as community influencers / community resource persons:** Leaders from the various community structures can be identified and capacitated to influence the opinions, attitudes, beliefs, motivations, and behaviour of others in the community. They could be individual members of the structures who are popular and respected within the community owing either to their social status, positive attitude or altruistic nature. The leaders could also include individuals who experienced TB either directly or have seen it in their families. These community influencers, who particularly show keenness to support TB programs, can play the role of Community resource persons or Community Resource Team (CRT) who will act as THALI's link to the community structures. They will:

   - Facilitate capacity-building sessions for members of their community structures
   - Lead community engagement and awareness activities
   - Influence family members for stigma mitigation (particularly against women)
   - Convey health messages and support the needs of individual TB patients
   - Act as a link between the TB patients, families, communities and the structures to which they belong.

objective 2: promoting health seeking behaviour and TB detection

1. **Establishing Health Information Centres (HIC) in communities:** HICs were established under the THALI project as easily accessible sources of information on TB within communities, owned and operated by members of existing community structures in the area. The main goals of HICs were to:

   - Sensitize community members about TB and help improve their health seeking behaviour
   - Refer people showing TB symptoms for testing and treatment

   HICs are equipped with communication materials on the basics of TB, details of the community health workers and nearest health facilities and a register to log referrals from the HIC. They are most often positioned within the office of the community structure or in a common space identified by them.

2. **Conduct health camps and other health promotion events:** The community structures will also play both lead and support roles to conduct health screening camps or other health-related events (both TB and non-TB) to address the needs of the groups they represent

objective 3: supporting TB patients and families

1. **Advocacy and networking:** Members of the community structures will help actively network and collaborate with other community structures operating in the geographic area to:

    • Mobilize resources to provide support for TB patients and families (nutrition, counselling and other forms of social support)

    • Attend patient support group meetings, and facilitate sessions such as the preparation of nutritious food.

    • Support advocacy efforts by TB patient advocates/TB Champions to improve the quality of services

    • Develop a feedback loop with the NTEP at facility, district and state level to ensure patient friendly and quality services

    • Collaborate with and help other community structures to support patients, especially those at higher risk.

stories from the field

Sri Sai Mahila Sangh, Bellary, Karnataka

A Self-help Group Federation takes ownership of TB control in an occupationally-vulnerable community
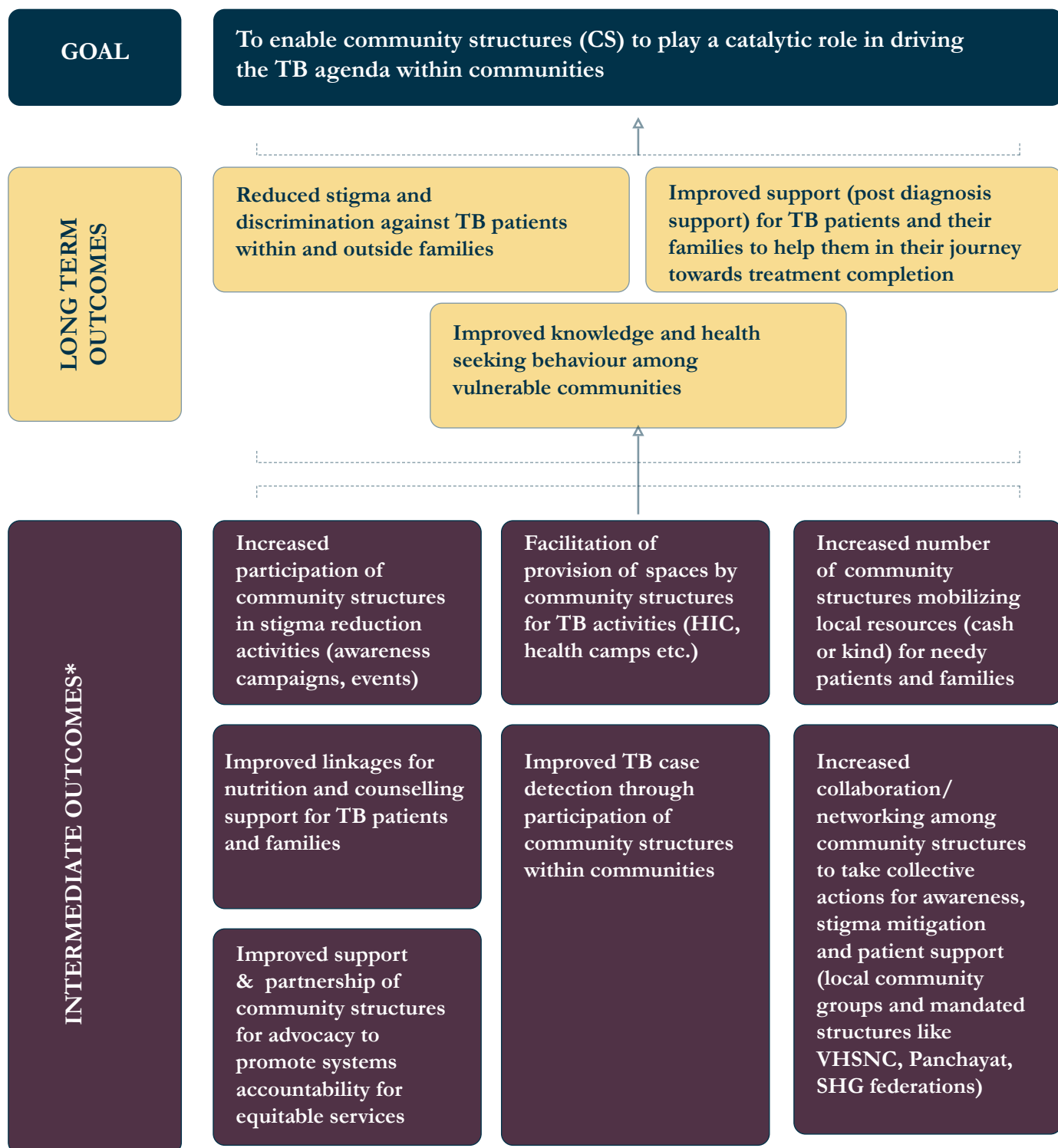
Community structures often engage in welfare activities in their areas, and integrating TB and general health activities into their agenda helps the community accept awareness, screening and testing-related activities. The Sri Sai Mahila Sangh in Bellary district of Karnataka is a federation of 20 Self-Help Groups in the urban slum area of B D Quarters. The organization is well known for initiatives such as collecting and distributing leftover food from social functions to the hungry and destitute, providing study materials and clothes to HIV-affected children, and facilitating night classes for the illiterate in their area.

Ms. Ratnamma, President of the Sangh, met the THALI Community Coordinator (CC) on her rounds of the area, and enquired about the work she was doing. When the CC enquired about SHGs working in the area, Ratnamma introduced herself as the head of the federation and facilitated a meeting with representatives of the SHGs to discuss THALI's objectives and potential support from the SHGs. The THALI team was invited to conducted sensitization session and screenings in the community. During one of the sessions, the THALI team found four women of the Sangh exhibiting symptoms of TB. Two of them tested positive. This news helped the SHG members understand the vulnerabilities of the population in B D Quarters, which is home to bidi makers, rag pickers, waste sorters and carpenters. Repeated sensitization sessions for the SHG members also cleared misconceptions that TB cannot spread, and once contracted, cannot be cured.

The Sangh members leveraged their community networks to gain support for awareness and screening activities in their locality. Leaders of other structures such as the Ambedkar Sangh stepped forward to conduct awareness campaigns through auto announcements in the area. Mahila Sangh members conducted house to house campaigns, accompanying THALI CCs who would explain the symptoms of TB, the need for testing and provide sputum cups in case samples were to be collected. Such household campaigns served two purposes, to lend credibility to the CC and to enable SHG members to learn how to carry on awareness campaigns on their own. During one household campaign, the 16 people with symptoms were referred for treatment, of which 11 were tested, and four diagnosed as TB-positive. Sangh members were trained on counselling skills and to conduct follow-up visits for patients to ensure they were taking their treatment.

Mahila Sangh members continue to conduct awareness activities on a smaller scale in B D Quarters and are now able to identify symptoms of TB and advise community members to be tested. In addition to their other welfare activities, they mobilize nutrition support for TB patients from local donors.

theory of change

GOAL

To enable community structures (CS) to play a catalytic role in driving the TB agenda within communities

LONG TERM OUTCOMES

Reduced stigma and discrimination against TB patients within and outside families

Improved support (post diagnosis support) for TB patients and their families to help them in their journey towards treatment completion

Improved knowledge and health seeking behaviour among vulnerable communities

INTERMEDIATE OUTCOMES*

Increased participation of community structures in stigma reduction activities (awareness campaigns, events)

Facilitation of provision of spaces by community structures for TB activities (HIC, health camps etc.)

Increased number of community structures mobilizing local resources (cash or kind) for needy patients and families

Improved linkages for nutrition and counselling support for TB patients and families

Improved TB case detection through participation of community structures within communities

Increased collaboration/ networking among community structures to take collective actions for awareness, stigma mitigation and patient support (local community groups and mandated structures like VHSNC, Panchayat, SHG federations)

Improved support & partnership of community structures for advocacy to promote systems accountability for equitable services

OUTPUTS

- A standardized checklist to identify CS that represent/ reach vulnerable population
- No. of sensitizations for CS
- No. of CS members trained
- No. of regular monthly meetings held with CS
- No. of learning visits organized for members of CS
- No. of IEC tools created for CS
- No. of advocacy meetings conducted by CS collaboratively with TB patient advocates with the department/ practitioners

- No. of CRT members trained
- No. of awareness campaigns and events conducted by CS
- No. of HICs set up by CS and # of people who accessed information at HICs
- No. of persons identified and referred through CS
- No. of persons tested positive for TB who were referred through CS
- No. of patients received nutrition support through CS
- No. of patients linked to social entitlements and other support through CS

- No. of PSGs supported by CS (space, sessions, facilitation etc.)
- No. of CS who mobilized local resources to support TB patients and families
- No. of events/ efforts conducted collaboratively between local community structures and with NTEP

INTERVENTIONS

- Identify suitable community structures that both represent and reach the most vulnerable populations
- Sensitize CS
- Develop IEC materials for CS
- Conduct monthly handholding meetings with CS
- Learning visits for community structures
- CS conduct advocacy meetings with department officials along with TB patient advocates
- Identify and train CRT members/ community leaders within CS

- Support CS to conduct awareness campaigns and community events
- Setting up of HICs through CS
- Conducting health camps and other events related to women's health, TB through CS
- Follow up with patients referred by CS to ensure that they are receiving all services as per guidelines
- Facilitate engagement of CS with Patient advocates and Patient support groups
- Facilitate mobilization of local resources (cash and kind) by CS for supporting TB patients and families

- Facilitate linkages for nutrition and counselling support for patients/ families by CS
- Facilitate collaboration and networking among local community structures and the NTEP for addressing gaps in quality and access

ASSUMPTION

Engagement with the community structures that reach the most vulnerable populations will help mitigate stigma associated with TB and in turn, increase demand and access to TB detection and quality patient care and support services

BARRIERS

Poor knowledge about TB among vulnerable populations

Stigma and discrimination associated with TB is high

Negative gender norms are deterrent to women's access to knowledge on TB and TB services

Lack of family and community support for TB patients

Marginalization (both physical and social) of certain communities deprives them of health and TB services more than the others

Absence of patient-friendly systems of service delivery

Absence of a community-led feedback loop to improve access and quality of services by the department

PROBLEM

Poor knowledge of and increased stigma associated with TB hinders case detection and proper management of TB for complete treatment and cure among communities in general and vulnerable populations specifically

community structure engagement: the process

Community structure engagement is an intensive process that involves the

i. participation of community members, in-treatment and cured TB patients to understand their perceptions of the existing community structures in their areas,

ii. the assessment and identification of the most suitable community structures,

iii. developing a checklist/ tool for shortlisting structures,

iv. focused perspective-building sessions

v. grading of community structures and tailoring handholding support to them

vi. documentation of successes such as their increased involvement and support to TB control activities through awareness building in the community and referral of persons with symptoms, as well as de-stigmatizing TB in their communities.

vii. Regular discussions with members of these structures to plan activities within communities

i social mapping

objectives

The social mapping exercise was conceptualized for community health workers (CHWs) to consult with the community about their perceptions of well-functioning structures in their areas, and to identify fully-functional, active, visible and well-regarded organizations best suited for community structure engagement in a particular area.

process

- The THALI CHWs had been working in the areas where community structure engagement was to be initiated. They interacted with leaders of community structures identified during earlier community engagement events, as well as other community level frontline health workers including ASHA workers, Anganwadi workers and school teachers to arrange a day and time for the social mapping activity to be conducted. Community structure leaders spread the word about the activity within the community. This activity is intended to build rapport in the community, and ensure that the process of identifying community structures is collaborative and consultative, involving the people who will support, as well as gain benefits by this initiative. This groundwork is essential to build trust and ownership for the initiative.

- In case the area in which social mapping is to be conducted is new or unfamiliar territory for CHWs, it is recommended that they approach community leaders such as the local corporators, ASHA / Anganwadi workers and heads of influential organizations such as local faith based / youth organizations to explain the initiative and get them involved in the process.

- The social mapping exercise can be conducted in an open area, such as a school playground or an open ground or a community gathering spot which is easily accessible by the community and can attract the attention of passers-by. The CHWs, with the assistance of the key opinion

leaders, mobilize the population and explain the activity to them. They tell the participants that they are part of a community health initiative, and wish to understand their area so that they can better work with them on improving community health.

- Some participants, men, women and children are given coloured chalk and asked to draw a map of the community, with major landmarks such as health facilities, schools, places of worship, community associations, youth associations, as well as features such as roads and parks. The other participants are encouraged to instruct them on where to place certain landmarks and on missing landmarks, if any. The CHWs facilitate, asking questions about the landmarks as they are drawn.

- After the community map activity is complete, the CHW asks them about community structures in their area, specifically about self-help groups (SHGs), slum associations, youth associations, labour unions, faith-based organizations and other community-based organizations such as associations for different communities. The CHW asks them about the most active organizations, i.e., which meet periodically and conduct regular activities.

- The CHW notes their response after the discussions with the community in order to create a list of organizations in that area.

community structure consultations

objectives

To visit the community structures identified during the social mapping process and assess their interest in getting involved in TB and health-related activities conducted in the community.

process

- After the identification of the structures, the CHWs create a list of community structures in the area. They visit the organizations one after the other , introducing themselves and the planned community health initiative, with a brief introduction to TB. They prioritize their visits by the burden of TB in the slums; structures in areas with more patients are visited first and more frequently.

- Through discussions with the heads of the community structures, the CHWs understand their goals, objectives, the number of members and their reach. These conversations also help them

assess their willingness to work for TB awareness and community health, and whether they will be able to raise funds, mobilize resources and engage with the local NTEP staff and the government.   This engagement allows them to gauge a community structure's suitability for the initiative, prior to running them through a selection checklist.

applying the selection checklist

objectives

To finalize the list of community structures that will undergo further sensitization and induction into the TB and community health initiative.

process

Based on these preliminary visits, the CHWs validate the information collected through a selection checklist to see which structures fulfilled the engagement criteria. This simple checklist will help the program team working on the field to identify the most suitable community structures once the initial mapping process is complete.

community structure identification checklist

S.No	Criteria	Yes	No
1.	Does the community structure have a goal or vision?		
2.	Does the community structure have proactive and involved leadership?		
3.	Does the community structure currently work on health and related issues?		
4.	Does the community structure have regular or registered members?		
5.	Does the community structure have resources like its own office, volunteers, staff and financial resources?		
6.	Does the community structure conduct regular meetings?		
7.	Does the community structure have the support, trust and goodwill of the larger communities where they operate?		
8.	Do they represent any vulnerable population group?		
9.	Is the community structure willing to collaborate on TB and health-related activities?		
	Total score		

If there are more than five ticks under the 'yes' column, frontline workers may proceed to engage with that community structure.

the criteria

- Vision and goals: The CHWs may find it easier to engage with community structures which have a vision and goal aligning with the principles of community well-being and ownership of community welfare initiatives.

- Initiatives for social welfare: A history of the organization's events and initiatives in the community will help CHWs understand their capabilities, their interests and the sections of the community they are likely to engage with. For example, a labour union may be likely to engage only with its members rather than the entire community, while a slum association is more likely to engage with the residents of that particular area.

- Leadership: Strong leadership qualities of the heads of the community structure determine their willingness to participate and the frequency of their participation.

- Regularity of meetings and membership: The regularity of meetings and a body of members indicates a sense of organization and discipline within the community structure. The meetings serve as an opportunity for members to be sensitized on TB, for them to discuss on how to integrate TB and community health into the agenda, as well as assign responsibilities for activities and events.

- Representing vulnerable groups: Community structures which represent occupationally vulnerable groups or are engaged in the welfare of particular castes and communities which may not have knowledge of or access to healthcare services could serve these high-risk groups. Activities conducted by these community structures could have greater acceptability.

- The checklist is not necessarily a means to exclude community structures from participation in the initiative, if they are willing. The checklist serves as a useful tool to identify community structures for further systematic engagement through perspective-building to streamline and sustain their involvement in TB control activities.

iv perspective building workshop and training of members and planning

objectives

To inculcate a sense of collective responsibility for community health through a participatory and activity-based training using a module (available in the toolkit)

process

- Once the community structures agree to work with the CHWs on community health and TB control in their areas, the CHWs arrange for a two-day perspective building workshop. The workshop is conducted for all community structure members to ensure a common understanding of the goals and rationale behind this initiative and to build an understanding of the need for community leadership.

- The training includes sessions on the basics of TB, the importance of active listening, the need for ownership of community health and the strengths of collective action. The sessions also illustrate the barriers that TB patients face on the journey to recovery and emphasizes the importance of teamwork and leadership to support them. The training culminates in a

planning session that builds on what they have learnt to create an action plan for the next year. (see community structures training module for details)

- The plans of the community structure may contain the following action points:

    a. Establishing HICs in communities such that anyone can access TB-related information
    b. Referring persons with symptoms of TB to frontline health workers
    c. Helping TB patients access patient benefits and arranging support such as nutrition locally
    d. Attending patient support group meetings at health facilities and teaching them skills, such as the preparation of healthy food
    e. Organizing awareness activities and health camps
    f. Supporting the government health staff during active TB case finding campaigns and other health programs

v linkages and trust building

objectives

To provide handholding support to community structures as they begin their engagement in the communities.

process

- After the workshop, the CHW visits the community structures 1-2 times a week to continue the momentum built by the training. They attend the meetings of the community structure, talk about TB and how to recognize the symptoms and refer the patients.
- The CHWs introduce community structure members to NTEP staff in the area, such as the TB Health Visitor, creating contacts, networks and a pathway for referrals.
- The CHWs also help the community structures refine their plans. They provide hand-holding support for the initial activities. If the community structures are conducting a health camp, they provide linkages to the health facility and if they are visiting patients for nutrition or any other form of support, they sensitize them on the importance of confidentiality and accompany them for visits.
- Once the community structures are constant in their engagement, the CHWs may link them to district and state officials as a valuable community resource for programs such as the Active Case Finding campaigns for TB and other activities such as dengue surveys etc.

vi self-assessment

The community structures will be provided a visual format to assess their strengths and performances once in 4-6 months. On the basis of the self-assessment, they may reach out to CHWs to help them build certain capacities or conduct certain activities.

self-assessment by CS

The self-assessment tool is aimed at helping the members' community structures to objectively assess their involvement in the project activities and also understand how well the structure is functioning for achieving their overall mandate. The specific objective of self-assessment is to help CS assess their own involvement in the Health and TB initiatives in their area. Once every four months of engagement, each of the CS will be encouraged to undertake self-assessment process

The outcome of the assessment will help the CS to understand the areas where they need further support from the project in the form of capacity building, handholding or education materials etc.

COMMUNITY STRUCTURE SELF - ASSESSMENT TOOL	
Date of self-assessment	
Name of the community structure	
Type of community structure	
Location/ Address	
President of the community structure	
Key members involved in the self-assessment process	
Total number of members	

	Visuals	Visuals	Criteria 🙂	Score ☹
		SECTION 1: GENERAL		
1		We are conducting monthly meetings regularly		
2		More than 50 % of our members are attending meetings		
3		Our female leaders also participate in the meetings (wherever applicable)		
4		All our office bearers / leaders are available for the meetings		
5		We record and also take action on the decisions made in the meetings		
6		We have the systems to ensure that all the money is accounted for and used properly		
		TOTAL		

		SECTION 2: ROLES	🙂	☹️
1		Our CS is involved in activities to support the communities (sanitation, health, savings, charity, education etc.)		
2		We conducted discussions specifically on health and related issues in our CS meetings		
3		Our CS responded actively to opportunities to support the local communities		
4		We involve the local people in the our area in festivals and other important events		
5		Our members discuss injustices prevalent in their area and act on them		
		TOTAL		

		SECTION 3: TB ACTIVITIES	🙂	☹️
1		Members of our CS have information on Symptoms of TB and TB services		
2		Our CS members referred people with TB symptoms regularly for testing		
3		Our CS conducted Awareness /sensitisation programs on TB for the community		
4		Our CS supported TB patients and their family with nutrition		
5		Our CS members visited TB patient's house and provided moral support		
6		Our CS members also shared information with families on Govt. benefits		
7		We have documented TB related activities we have conducted by		

8		Our CS attended Patient Support Groups		
9		Our CS involved TB champions to educate their members on TB		
		TOTAL		

TOTAL	🙂	
TOTAL	☹️	

overall scoring

🙂 🟢 ☐

More than 15 (15 to 20)   =   (We are doing excellent. Let us keep it up)

😐 🟡 ☐

Between 8-14   =   (We are making the effort, but we can do much better!)

☹️ 🔴 ☐

Less than 8   =   (We did not do that well. We can do much better with some support)

Follow-up action by the CS members:..

....

....

Signature and CS leader:

....

stories from the field

Navajyothi Network of HIV/AIDS Positive People, Koppal, Karnataka

An organization working with HIV patients extends its support to the larger community

While anyone can get TB, certain populations are at higher risk of developing the disease due to pre-existing medical conditions, occupational hazards or living conditions. THALI has engaged with groups that represent these vulnerable populations, such as slum associations and labour unions, sensitizing them on the vulnerabilities of their members or constituents and helping them plan activities to promote positive behaviour change.

The Navajyothi Network of HIV/AIDS Positive People, based in Koppal district of Karnataka, is a unique example of THALI working with a population with a pre-existing disease condition at risk of developing TB. Navajyothi is a community-based organization of 1500 members which has been working in Koppal for 15 years to represent the rights of persons with HIV/AIDS. Many of the office bearers of the network were aware of the link between HIV and TB, and had referred some of its members for TB testing. THALI program staff approached Navajyothi, and was invited to an internal meeting with the President and the Board to discuss expanding their work to the general population. The organization was responsive, and involved itself in microplanning activities, which were carried out by the THALI team to map its intervention areas and identify clusters of TB patients in order to better plan program activities.

Navajyothi's knowledge of the area and its reach in the community helped ease the THALI CCs into their community activities. The network's members themselves conducted TB awareness meetings in the area and at gatherings of the local Self-Help Group (SHG) federation, reaching out to 550 people in the area. They conducted mass communication activities as well, including two door-to-door campaigns for TB awareness, covering 750 residents, and arranging for auto announcements with TB messaging on four occasions in a locality of 6000 people. Representatives of Navajyothi also conducted in-person visits to counsel families of TB patients, who often do not fully understand the disease and isolate the patient out of fear, hindering their recovery.

Navajyothi's experience with TB-HIV, and KHPT's sensitization of its members, resulted in consistent efforts to refer TB symptomatic cases for treatment. The network referred 73 cases in a six-month period, which is the highest number of referrals of any community structure in the district. The organization now regularly attends patient support group meetings, and helps to link TB patients to care and social support. The experience has also taught them about the benefits for which TB patients, including TB-HIV patients are eligible, allowing them to spread this information among their own members.

monitoring and evaluating the community structures initiative

THALI monitored community structure engagement through a rigorous system of data collection and evaluation. While the initial concept of community structures was firmed up in October 2018, the CHWs began the mapping process in January 2019, followed by an exploration of establishing HICs in community structures before broadening the concept to conducting awareness campaigns, mobilizing resources in the form of financial assistance and nutrition for TB patients, and facilitating health camps in the community.

THALI's monitoring data shows promising results pointing towards the success of the initiative in the longer term. In the July 2019-March 2020 period, THALI CHWs mobilized and supported 395 community structures. Of these structures, 50% conducted awareness campaigns, while 75% of them referred patients for testing. Community structures referred 2730 patients in the July 2019- March 2020 period, of which 2230 were tested and 237 were found to be positive, indicating that community structures are increasingly making quality referrals for testing based on their knowledge of TB. The graph and table below indicate the total number of community structures, including the different kinds of organizations mobilized, as well as their performance.

total community structures identified = 395

220	SHGs
40	Slum association
36	Youth organisation
37	Labour union
18	FBOs
44	Other (auto union, NGO / CBO, timber depot)
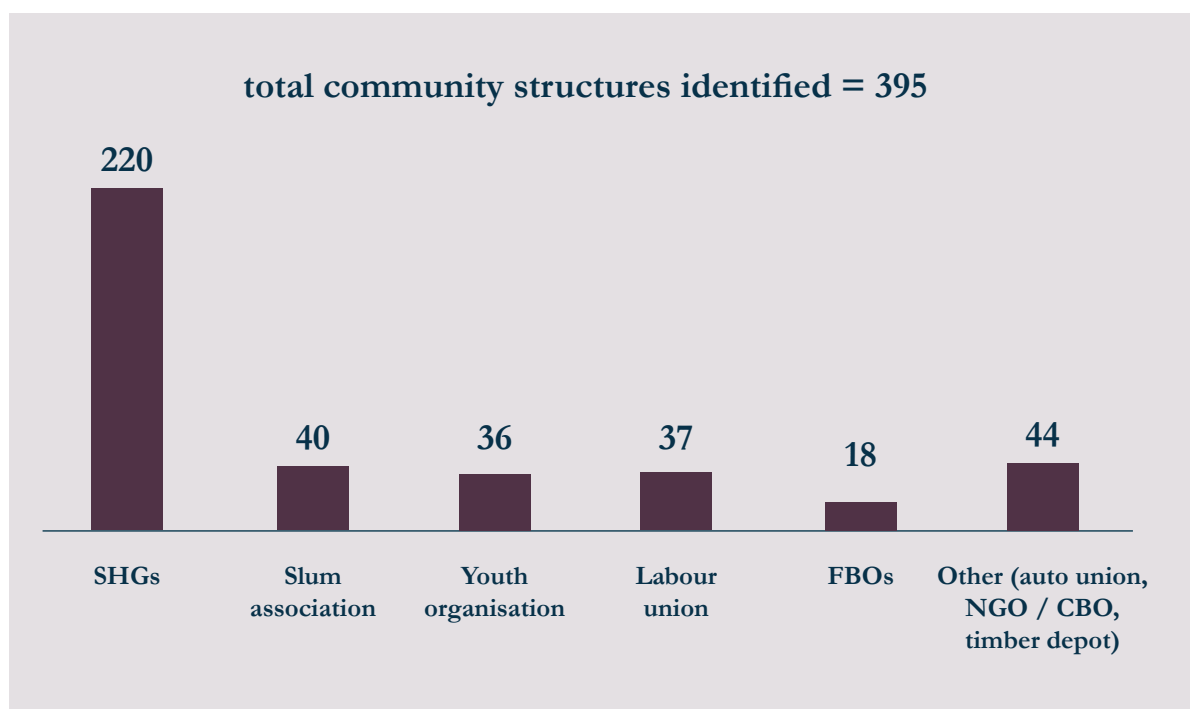
	Cumulative Achievements (July 2019- March 2020)
Number of members of community structures trained for health - related issues during the reporting period	1383
Number of handholding meetings conducted with community structures during the reporting period	1444
Number of Health Information Centres (HICs) functional by the end of reporting period	235

key learnings

The months-long process of community structure engagement yielded rich learning and experiences, which were channelled into refining the model of engagement. These included:

- **Situating TB within the wider mandate of community health:** The CHWs set out with the goal of integrating TB into the agenda of community structures. However, they realized that to maintain their commitment and interest in community welfare, the focus had to be broadened to community health beyond TB. The CHWs engaged the technical team at KHPT to advise on issues of general health, and helped community structures organize health camps which not only included TB screening, but also eye care and diabetes consultations.

- **Enabling community structures beyond sensitization on community health:** While sensitization on the topic of TB and the need for community leadership and ownership were essential components of community structure empowerment, the CHWs realized that certain organizations also needed assistance before they could integrate TB into their agenda. For example, in the Koppal district, an association of physical labourers (hamalies) was willing to set up an HIC in their office, but revealed that a majority of members did not have bank accounts, making it difficult for them to receive benefits if they were diagnosed with TB. The CHW organized a meeting between the associations' heads and a bank which sensitized them on setting up small savings accounts. This helped the members as well as potential TB patients among them, and led to a better buy-in to the concept of community ownership of TB control.

- **Sensitizing community structures on confidentiality:** The concept of confidentiality received emphasis during the sensitization of community structures, especially during sessions on understanding the TB patients' experience. While the importance of de-stigmatizing TB was a key point of the training, it was important to ensure that patients' wishes for confidentiality were respected, especially among the larger membership of community structures.

- **Importance of self-assessment:** This process encourages community structures to assess themselves using a tool. This is not an external review, and because it encourages community structures to reflect on their abilities and capacities, it creates ownership of the process and imposes no judgment. They can seek support from CHWs to develop their capacities, if required. They may choose to strengthen their organization independently as well.

- **Incentivizing community structures:** The THALI project was unable to incentivize community structures for their work on TB, which called the long-term sustainability of the initiative into question. CHWs were careful to position community structure initiatives such as house-to-house campaigns as, being led by the structures for community welfare, raising their profile in their community and helping them to continue raising their profile through social work. KHPT is also advocating this issue with the government to help incentivize community structures which refer TB patients and follow up until treatment completion.

sustaining impact

THALI's approach to community structures was designed to be transitioned to the NTEP at state level. The team met with staff at state and district levels to discuss the concept and get their support for rollout of the activities. Health facility staff were invited to be part of the activities conducted by community structures to create an opportunity for introductions and to strengthen linkages.

KHPT continuously shared the progress of community structures at meetings of TB officials at the state level. They expressed interest in engaging community structures in the two-week active case finding campaigns organized for high-burden districts thrice a year. KHPT continues to work with them to expand the engagement and is planning to include it into their Project Implementation Plan (PIP). Although this initiative doesn't call for additional resources, KHPT used the following opportunities to leverage funding from the government for building the ownership of the community structures towards TB elimination:

- As per the Government of India guidelines, an incentive payment of 500 INR per patient detected and 500 INR for every patient cured is being made available to treatment facilitators. KHPT is facilitating the issuance of a circular by GOI to transfer the amount to the community structures if members help in case detection and treatment completion. KHPT is advocating for its inclusion into state and district Project Implementation Plans (PIP).

- KHPT is advocating for the unlocking of funds for community structure engagement from the National TB program as per the Advocacy, Communication and Social Mobilization (ACSM) guidelines. This will help recognize community structures as mandated bodies that will potentially work with government functionaries to support TB elimination efforts.

- In addition to enabling community structures to contribute to timely diagnoses and treatment outcomes, the approach aims to mitigate the stigma against TB patients in the community by sensitizing community influencers who can normalize TB and stand up for patients facing discrimination, especially female TB patients who are doubly stigmatized owing to their gender and their lack of decision-making capacity.

2

Training module

The training for community structure members is a multi-faceted process. The process involves a series of sessions that sensitizes members on tuberculosis, helping one's community members, collective participation and the equal access to healthcare for all. These sessions are designed to build and activate a sense of responsibility within community structure members, and contain activities that empower them to formulate an action plan tailored for their communities that most need their support.

KHPT has designed the sessions to be activity-based and participatory in nature, involving storytelling and simple exercises. These illustrate the main objective of the session to make it simpler for participants to understand, retain information and spur into action when the need arises. This was done to counterbalance the more technical

sessions on understand the symptoms, testing and treatment of TB with equality, self-esteem and leadership, and to move away from a lecture-based approach which is usually considered uninteresting and reduces attention span on the important matter at hand i.e. managing TB. Discussions with the participants during the sessions is also an integral part of keeping the participants engaged and allows facilitators to tailor their messaging in real-time to the responses from the participants.

The training is designed for two full days. The first day sets the tone of the training, appreciating the community structure for taking initiatives to come for the training. The day also showcases key community structure actions, an overview on TB and the rights of a patient. The second day enables them to apply their learnings from the first day towards formulating a usable plan of action.

Topic	Duration (in hrs)	Equipment Required
Objective and expectation setting	0:45	Blackboard/Whiteboard/chart, markers/ chalk, laptop and projector (if available)
All points of view are equal and important	0:30	None
Each of us have the potential to play multiple roles	0:30	A pen or a glass / metal bottle
The importance of listening and sharing	0:30	None
Lunch Break		
Building motivation and self esteem	0:30	None
Understanding the basics of TB	1:00	Fully charged Laptop, IEC and BCC materials (one copy per attendee plus 5-10 extras) (About TB and Basics of TB will be attached as annexures) , Projector, if available
Understanding the experience of TB patients	1:00	Three chits of paper per participant, pens/ pencils for each participant, a red marker
Health as a right	0:30	Flyer of government schemes

Session 1: Objective and expectation setting

objectives

The objective of the activity is to help community structures understand the purpose of the training and what is expected of them during the two days, and for the facilitator to understand what the structure members think about the training initiative. The session will also introduce the organization conducting the training and include a brief introduction to TB.

rationale

This step is important as it is possible that many of the community structure members will have come for the training at the request of the head of the structure, not fully understanding the scope of the training. This session will bring about a common understanding of why the training is being conducted, who the trainers are and what is expected of them over the two day period.

duration

45 minutes

methodology

Presentation and discussion

equipment

Blackboard/Whiteboard/chart, markers/chalk, laptop and projector (if available)

process

1. Welcome the participants to the training and introduce yourself as being part of the organization.
2. Give a short introduction about the organization for about 2-3 minutes. Talks briefly about this new initiative to engage community structures to help improve TB control and the general health of the community. Appreciate the community for coming to an important discussion
3. Ask the participants why they think community engagement is important. Respond to the participants' answers by appreciating their participation and using the opportunity to emphasize that you are earning from them.
4. Add that the support of community structures is needed because they have a greater reach than the organization and they know what their community needs, especially their health needs.
5. Ends the session by asking the participants what they expect to gain from the training, and writing their expectations on a whiteboard/chart to be kept for later. If the participants raise questions about why it is important for them to attend the training, acknowledge their questions and tell them that some of the following sessions will help address their questions. They are welcome to bring up their concerns again after the first few sessions.
6. Before moving on to the next session, lay out your expectations from the participants, which are as follows:
   • Everyone shall be allowed to speak, participation is encouraged
   • There are no right or wrong responses, so no one should hesitate to speak.
   • Participants should not engage in their own discussions when others or the facilitator is speaking.
   • Participants shall be punctual when it comes to attending sessions.
   • Participation on both days is necessary for effective training.
7. Share an example from previous work and share a story of the experiences working with the community, in different fields, and tie that into the importance of having community involvement and leadership.

Session 2: all points of view are equal and important

objectives

To assure all participants that their points of view are valid and that they should not hesitate to share their views with the other participants who are from the community.

rationale

The participants at the training may be a mix of leaders and members, genders, professions and castes. The power dynamics raised by these factors may prevent some participants from speaking openly. This activity is designed to reassure people that they are free to speak in front of the other participants.

duration

30 minutes

methodology

Storytelling and group discussion

equipment

None

process

1. Divide the participants into five groups, if possible. Each group to be as similar as possible (Ex: all leaders in one group, all women in one group etc.)

2. Tell the participants of the story of the fingers of one hand:

> One day, the fingers of one hand begin to fight about which is the most important among them. They each give a genuine justification for why they are more important. The thumb says it is the most important, because everyone needs a thumb to hold things or work with skill like cooking or construction. The index finger tells the thumb that it is bigger than the thumb and necessary for signatures. The middle finger says that it is the tallest and most attractive. It has two fingers to protect it on either side! The ring finger interrupts to say that everyone puts their ring on it and it is the most sacred finger. The little finger joins in to say that when we fold our hands in prayer to God, it is always in front and the closest to God. Therefore, it is the best.

3. Ask the participants and groups which finger they think is the most important, asking for more responses until you receives a response that all the fingers are important as they each have their own role.

4. Once you receive that response, say that the fingers are like human beings. We are not all the same. We come from different backgrounds and professions. However, each of us have a unique role to play. We are all important.

5. Tell the participants that because everyone is different, everyone will have different and helpful perspectives to offer in the training and in life. They should be free to speak and share their views. They will represent their communities better, to help them, and their voices should be as strong as anyone else's. Indicate an example that the five fingers are strongest when they come together as one hand and in one community.

6. Before ending the session, ask if they understand and agree, and then move on to the next session when they respond in a positive manner. If they disagree, ask them to explain their position. If the disagreement is story-related, try to draw them back to the core objective which is to understand that everyone is important in their own way.

Session 3: each of us have the potential to play multiple roles

objectives

To facilitate introductions and help each of the participants understand that their community structure can play multiple roles and serve multiple purposes, including in the field of community health.

rationale

The community structures involved in the training (whether one or more) have a core purpose, such as saving and lending (Self-help Groups), employee welfare(labour unions) or enabling the practice of faith (faith-based organizations). The activity is designed to ease community structures into the idea that while they have a fixed mandate, it is possible for them to play multiple roles in the community's welfare, especially when it comes to community health.

duration

30 minutes

methodology

Activity based on engaging all participants.

equipment

A pen or glass / metal bottle

process

1. Ask each participant to introduce themselves by giving their name and profession. If there are multiple community structures present at the training, ask them to also specify which structure they are from. Start at one point of the gathering by handing a pen or bottle to a participants.

2. Ask the participants what the object is and then ask them what else can the object do? What other purpose can it serve? If the participants seem unsure, you can give an example. (If it is a pen, you can say it can be used as a pointer in the classroom for the blackboard. If it is a bottle, you can say that it can be used to roll out dough.)

3. The participants begin to introduce themselves and hand off the object to the next participant. There may be some repetitions if there are a large number of participants.

4. After the round of introductions is over, emphasize that they, as individuals, as the pen or the bottle, and as community structures, can play many roles. Even if the organization has its own agenda, it can integrate into that agenda a health promotion role, since a healthy community is a functional and productive community. The community structure has the potential to use its strengths to benefit the community much beyond just its membership.

Session 4: the importance of listening and sharing

objectives

To help participants understand the different types of listening, the need to listen and share their learning with others to help the community.

rationale

This activity is meant to highlight the need to take away their learning from the training and actively use them, instead of forgetting them or doing nothing about them. It is meant for participants to understand the value of sharing information with, and working for, the community.

duration

30 minutes

methodology

Storytelling and questions and answers

equipment

None required

process

1. Tell the story of three dolls. Each doll is priced differently, even though it looks the same. However, if you insert a thread into the ear of one doll, it comes out the other. For the second doll, a thread inserted into one ear goes down into the stomach. And for the third doll, the thread comes out of the mouth. The first doll is priced at Rs 10, the second at Rs 30 and the third at Rs 50. Asks the participants why these dolls are priced differently.

2. If the responses relate to the look of the doll, or the material, or the size, repeat that the dolls are exactly the same in those aspects.

3. Tell the participants that the third doll is the most expensive because what goes into its ear comes out of its mouth. It is able to share what it hears with others. That makes it the most valuable. The others are not as valuable because the Rs 30 doll internalizes what is said, what goes into its ear stays inside. The cheapest doll does not listen at all. What goes into one ear comes out the other without any retention.

4. Ask and confirm if the participants understand. If they do not, repeat point 3.

5. Briefly discuss the following scenarios:
   In an army there are 5 captains, only one of them gets information that the enemy's arrows can be stopped by wearing an extra chain armour. He does not share this with the other captains. What do you think will happen?
   The ration from the ration shop is only given to a few people instead of all the people. What do you think will happen?
   While building a wall, the mason sees that the foundation is getting weak. He decides to just cover it and build the wall. What do you think will happen?
   A driver on duty is feeling sleepy. He doesn't tell his passenger that he is sleepy. What do you think will happen?
   If you knew that washing hands can improve hygiene but you don't tell your family members, what do you think will happen?
   Ask the community to share stories on how sharing information has helped them

6. Conclude the session, saying that it is important for the participants to pass on and actively use their learning instead of keeping it inside them or forgetting it. That is what is expected from them.

stories from the field

Rakshana Welfare Association, Hyderabad
A slum association forms close ties with outreach and health facility staff

The Rakshana Welfare Association is a slum association in Rasoolpura, one of the largest urban slums in Hyderabad. The 12-member strong organization's women are particularly interested in women and child welfare initiatives. In the course of their activities, they had encountered TB patients, but hadn't been able to help them, unsure of what they should do or where they could tell them to go.

When THALI approached organization, which has been rooted in the community for 16 years, the conversation about TB and potential role that the association could play turned to the a discussion of the cases they had encountered and the persons they knew with similar symptoms. THALI staff facilitated a discussion with officials from the National Tuberculosis Elimination Programme, who spoke to them about linking symptomatics in the community to healthcare through them. NTEP officials would visit association members regularly, and formed a rapport which only strengthened when symptomatics referred for testing were diagnosed and given appropriate care.

The Rakshana Welfare Association was motivated to organize awareness activities for women in the community, as the male population, largely daily-wage workers, were away at work during the day. They conducted 11 meetings with 250 women to raise awareness on TB. Through their efforts, they have referred eight persons with symptoms, of whom three were diagnosed with TB and put on treatment. They continue to liaise with NTEP staff to link persons to testing, treatment and patient benefits.

Session 5: building motivation and self-esteem

objectives

The aim of this exercise is to motivate the participants to do good for others, thank them for the work that they are already doing for their members and communities and emphasize that there are rewards that may be non-monetary in nature, but are no less significant.

rationale

This activity is designed to simultaneously appreciate the work that the community structure members have already done, as well as inspire them to lead by example and enjoy the rewards in terms of respect, self-esteem and satisfaction for helping a social cause.

duration

30 minutes

methodology

Story telling

equipment

None required

process

1. Tell the story of a community leader who is visited by an angel.

> The angel comes to the community leader and asks him/her to direct her to the houses of three social workers. When the community leader asks who these three workers are, she says that they are on a list of people who love God and that she has come to reward them with a gift.
>
> The community leader's name is not on the list, despite him having done much work for the social welfare of people in his community. He feels troubled that God does not think he loves him, especially when he has worked so hard for God.
>
> The next day, the angel comes back with a list of more people. The community leader is upset and he tells the angel that he is not a courier company employee whose job is merely to direct people. He asks why he should when his name was not on the list of people who love God. The angel said that she has come with a different list with people whose efforts God appreciates. His name is the first on the list because of the service he does.

2. Conclude the story by saying that whatever each of the participants is doing is great work. Whenever they get involved in people's lives, they will definitely get a gift from God in some form or the other in future. This gift may be in different forms- satisfaction, good will of people, blessings of people, and are not necessarily monetary. Depending on the audience, (if everyone is of the same faith)a faith based example may also be added.

3. Ask the participants what they mean by success and being rich. They may respond by referring to wealth in monetary terms. Tell them that true success is measured by the number of people who will live by their example and who desire to be like them. Wealth is not just money, taking the example of Gandhi, Vivekananda, Karna, Red Cross and Red Crescent, Mother Teresa.

Session 6: understanding the basics of TB

objectives

The aim of this session is to explain the basics of TB, including symptoms, testing and treatment, so that all community members have correct information on the disease before leading health initiatives, especially those related to TB awareness.

rationale

This session serves as a bridge between the previous sessions that were more general in nature and the following sessions, which narrow the focus to health and well-being, and the experiences of TB patients. It is through an understanding of the disease and the available healthcare services that participants will be able to understand how they can support TB control, a sense that will be built through the sessions that follow.

duration

1 hour

methodology

Presentation and discussion

equipment

Fully charged Laptop, IEC and BCC materials (one copy per attendee plus 5-10 extras) (About TB and Basics of TB will be attached as annexures), Projector, if available

process

1. Ask the participants if they know about TB and probe into what they know through further questions.
2. Respond to the participants' answers with which are correct and which are not correct and then go on to give them the basic information on TB, including:
   • Cause of TB
   • What are the symptoms?
   • How do persons get tested? (including information that testing is free in the government facilities)
   • What is the treatment for TB? Emphasis on curability of TB
   • How can TB be prevented (Cough hygiene)?
   • Patient benefits made available through the government (nutrition support, direct benefit transfer payments)
   • This information may be communicated using IEC materials, on a whiteboard or through a PowerPoint presentation.
3. Ask the participants if they have any further questions.
4. If there are any participants who have had TB and are willing to share their experience, or who have known someone closely who had TB, and can talk about what they know of that person's experience, they may be invited to speak.
5. Close the session by telling the participants that they may ask questions about TB at any time during the training, and hand out TB materials to them, if available for each person. The materials need to be in a language that is understandable by the audience.

Session 7: understand the experience of TB patients

objectives

To help community structure members to understand what are the socio-economic pressures facing a TB patient and helping them visualize that experience to reinforce the need to help them.

rationale

While the basics of TB explain the medical aspects of the disease and treatment, it is important to explain the social and economic impact of the disease which can affect a patients' recovery. Stigma is discussed as an important force affecting patients' quality of life. The knowledge of these forces in impeding a patient's recovery will help them understand later how they can help a patient beyond connecting them to health facilities.

duration

1 hour

methodology

Activity

equipment

Three chits of paper per participant, pens/pencils for each participant

process

1. Each participant is handed three chits of paper and a pen/pencil and are told to write down the following:
   - 1st chit- What is their most favourite thing?
   - 2nd chit- Who is their most favourite person, the person whom they don't want to ever lose?
   - 3rd chit- What is their dream in in life? Or what do they want to become?

2. Give them 5-7 minutes to write it down. In case some of the participants cannot write, you or other assisting staff can write it down on chits for them.

3. Ask 4-5 participants to read out their responses for each question.

4. Ask participants to hold up their chits. Walk around the participants, randomly pulling away one or more of their chits, marking a cross on it and giving it back.

5. Tell the participants that you are playing the role of destiny, which comes one day without being invited and snatches things away from people. It could be their favourite person, their belongings, their house or their livelihood. Destiny doesn't give them a choice and takes away whatever it feels like. Then, ask a few persons what they have lost, and let them respond after checking their chits.

6. Ask them how they would feel if something they love is really taken away from them. To their responses, say that this is just an activity, but people experience it in their daily lives. Think of how it must feel for them.

7. Link their responses to TB, saying that people lose these things to TB, their family support, their livelihoods, especially due to stigma from the community. The community has the ability to support the family and create an enabling environment for the recovery of TB patients.

8. While the community can contribute in many ways such as short-term loans / donations or food distribution, it has the ability to have more far-reaching effects because of its knowledge

of the area and its needs. It is the community that can create long-term change by creating an atmosphere in which TB prevention and support to TB patients takes priority, for the benefit of the whole area.

9. The activity can be concluded when people spend 10 minutes to walk around, see each other's chits, erase the crosses (Xs) and then discuss in a group how they can help each other

10. Share an example from the case studies deck on how this program has helped another community
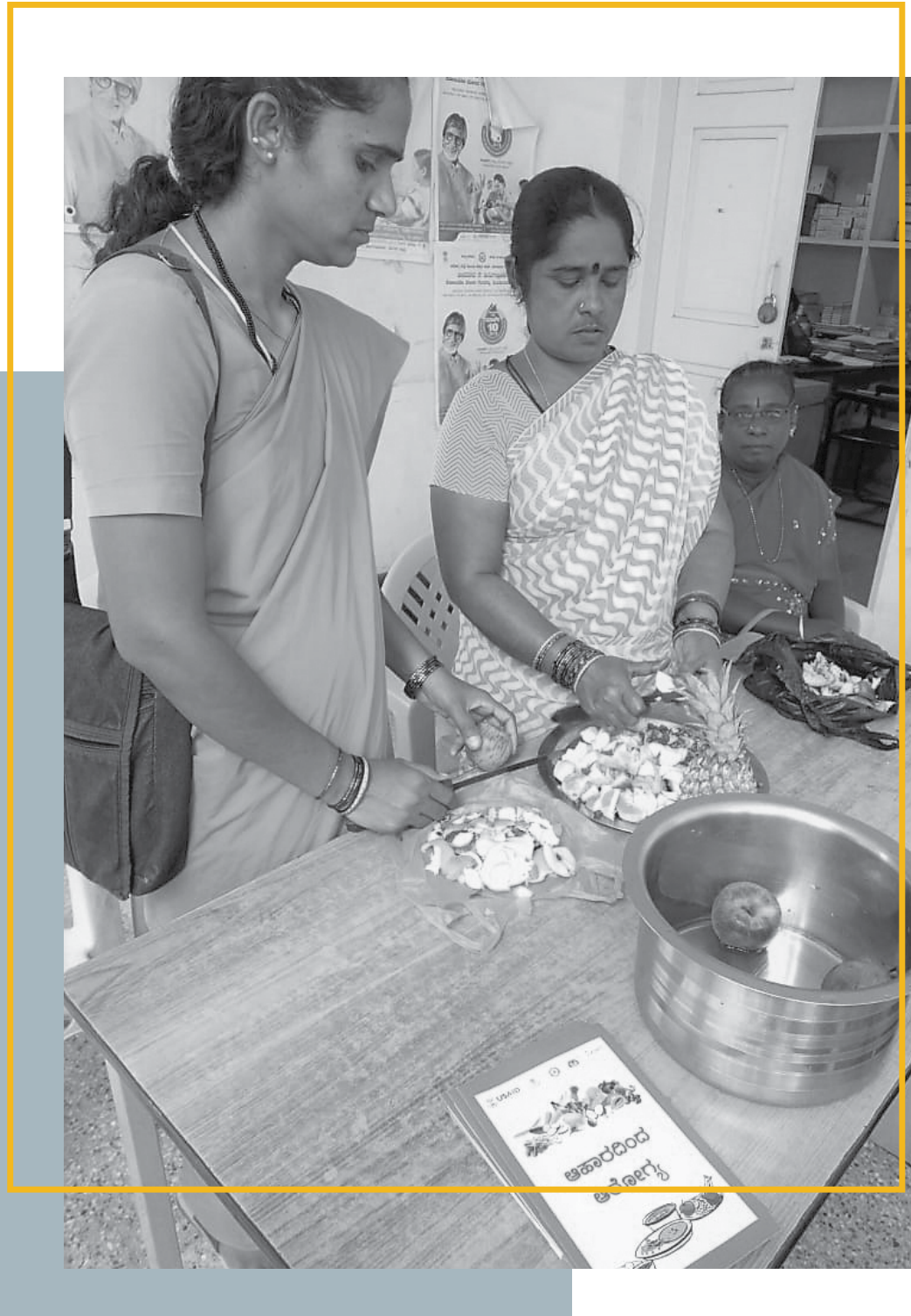
Session 8: health as a right

objectives

The objective of this activity is to make community structure members aware that they have a right to health.

rationale

Very often, communities view health as a service and not as a right. This builds their perspective that the healthcare is a right and they have the right to demand it. It is the government's responsibility to protect their right, and the responsibility of the community to demand it. Not only that, it is also the individual's duty to protect their health.

duration

30 minutes

methodology

Discussion

materials

Flyer on government schemes

process

1. Ask the participants-Who is your life partner?
- Some may say wife, friend, lover, parents, children etc.
- Listen to them respond and agree that 'yes, these are people who we value in life but who is the one that always remains with you?'
- Tell them that 'It is your body! It is a life partner. We are alive only as long as our body is. It is an instrument for us to live.'
- If you are really in love with your partner, you should take care of it. Healthy bodies are so important.
2. Ask the participants-Who is the life partner of our nation? PM? President? It is the people, because they earn and they give back to the nation. People are the strength of the nation. The nation has the responsibility to protect its resource and that is why we have the right to life and right to health.
- We all have a right to health.
- The nation's responsibility is to protect the health of its people and an individual's responsibility is to protect his/ her body.
- The community's responsibility is towards the health of a community.
- Irrespective of who you are, health is your right
3. Explain the right to health in the following manner:
- The right to health for all people means that everyone should have access to the health services they need, when and where they need them, without suffering financial hardship
- No one should get sick and die just because they are poor, or because they cannot access the health services they need
- Good health is also clearly determined by other basic human rights including access to safe drinking water and sanitation, nutritious food, adequate housing, education and safe working conditions

4. Explain to the participants that the Government of India has taken this mandate of protecting the health of citizens seriously. It offers free diagnostics and treatment, schemes such as free nutrition support (Nikshay Poshan Yojana), insurance schemes such as Ayushman Bharat etc. It employs a large cadre of frontline health workers like the ASHA and Anganwadi workers, runs the world largest immunization program free of cost, and has set up primary health centres and sub-centres where free services are provided etc.

5. End the session by saying that our role as the community is to be aware of these services, and ensure that we access them and also demand quality services. It is our right and our responsibility as the community to help people make health a priority and link them to these free services, where required. We have a major role to play in ensuring that disease is kept at bay (by adopting healthy practices). Health is our right. The government has a responsibility to ensure that the right to health is realised and we all, as community have the responsibility to cooperate with the government.

day 2

Topic	Duration (in hrs)	Equipment Required
Which communities should you help?	0:30	20 Small paper balls, a bucket or basket
The importance of community influence	0:45	None
The role of community leadership	0:30	A dupatta/cloth that can be used as a blindfold, a small object that can be picked off the ground, a watch for timing
Preparing for real life scenarios	1:00	A copy of the case study set for each group in a language that is easily understood, markers/pens, whiteboard/chart paper with stand
Lunch Break of upto 1 hour		
Support system available to patients	0:30	Handouts / Posters from the guest speaker
Formulating action points and way forward	0:45	Paper and markers for each participant group, whiteboard or chart paper with stand and markers for the facilitator, Pre-prepared thank you cards
Understanding the experience of TB patients	1:00	Three chits of paper per participant, pens/pencils for each participant, a red marker
Health as a right	0:30	Flyer of government schemes

Session 9: which communities should you help?

objectives

To help community structure members understand that there are particular sections of the population which are vulnerable and may have a lack of access to healthcare. These should be the focus of their activities.

rationale

The community members are told that there are particular sections of society that are vulnerable to developing TB due to pre-existing health conditions, their occupation or their living conditions. This activity is designed to help them keep these sections in mind when they make their action plans later on.

duration

30 minutes

methodology

Activity

equipment

Small paper balls, a bucket or basket

process

1. Ask for volunteers from the participants and select 5-6 participants. They are made to sit in a line one behind the other and are given a paper ball each.
2. Place a bucket or basket a small distance ahead of the first participant and instruct all the volunteers, one by one, to throw their balls into the basket/bucket.
3. The ones sitting further away from the bucket will have more difficulty getting their ball into the bucket.
4. Ask the participant why this happens. Once they respond about the long distance, tell them that some people are closer to accessing healthcare, while others, due to various vulnerabilities such as being elderly, having a lack of transport, having no one to accompany them to health facilities, cannot access it.
5. There are also external factors and situations which prevent certain types of people from getting access to healthcare or the correct information required for them to make decisions. Those who have power often have better access to services, whereas the uneducated, lower castes, and economically backward are often marginalized. The influential by virtue of caste, profession, qualification, gender are usually positioned as those who have better access to services and schemes. The ones that are usually marginalized are the ones who need these schemes but often face barriers in accessing services. Give examples such as how rich and connected people receive better services at shops and government offices. These examples can be tailored to their contexts, for example, if transport services are better in an upper-caste village, that may be attributed to an imbalance of power.

   TB patients may already be bearing the burden of such vulnerabilities and external factors, however, having the disease only compounds their troubles. They need support, and it is the community structures who are well-positioned to reach out to them, because it is them who can best understand how to help them. It is the community's responsibility to raise the powerless among their own and help them access services to improve their condition.

Session 10: the importance of community influence

objectives

To help community structures understand the strength of community support and trust over that of external parties.

rationale

Community members in positions of leadership wield considerable influence in their areas, and could be key to influencing TB patients and their families, especially if there is a distrust of the health system or external support.

duration

45 minutes

methodology

Storytelling and activity

equipment

None

process

1. Tell the participants of the story of the flies.

> There were two flies which landed inside a glass jar which contained a few crumbs of sweets. While they were busy eating the sweets, someone came and put the lid on the jar. The male fly tried to leave, but hit the lid several times. The female fly also tried, and was also unable to leave. The flies soon stopped trying to leave. They made the jar their home and raised a family. Soon there was a full community of flies in the jar. This society had a rule, no one must try to leave, as there were evil spirits preventing them from leaving. Some flies did try to leave, but were stopped by the lid. They were ostracized by the other flies for breaking the rules of their society.
>
> One day, someone opened the lid of the jar. None of the flies tried to leave. However some flies from the outside came in and told the flies in the jar about life outside, and the abundance of food and facilities outside. No one believed them, and they stayed inside their cramped jar.

2. Ask the participants why they feel the flies in the jar did not want to engage with the flies from the outside. If they raise the point of not trusting outsiders, ask them what they had missed by not going outside, such as access to more food and facilities.

3. Tell the participants that there are benefits of engaging with outsiders and external stakeholders. Education, experience and exposure can be beneficial to the community, but only if there is community acceptance.

4. As leaders of the community, they can be influential in linking community members to health care and services provided by 'outsiders'. Even outsiders can have the interest of the community at heart.

5. If time permits, you may conduct the 'knot' activity. Ask the participants to make a circle and ask three volunteers to step out of the circle. The participants must then entangle themselves in a group, while holding hands, by putting their arms around each other in different ways to create a 'knot' of people.

6. Ask the three participants outside the knot to try and untangle this knot by gently manoeuvring people away from each other. This will be a very difficult activity for them.

7. Then ask the persons in the knot to disentangle themselves from the group. This will be a much easier process as they will know how to manoeuvre their arms and legs to get out of the knot.

8. Ask the group to be seated. Explain to them that the knot represents a close-knit community. They are fully aware of their problems. While an outsider may try to help, only an insider can allow that help by opening up to them.

9. Close the session by re-emphasizing the importance of opening up one's mind and allowing other people to help the community.

Session 11: the role of community leadership

🎯 objectives

To show that the community is best equipped to lead its members towards health and well-being.

🧠 rationale

The community has its own welfare at heart, and it is the community leaders who can help direct the community's response to interventions for their health and well-being.

⏱ duration

30 minutes

✅ methodology

Game-based activity

📐 equipment

A dupatta/cloth that can be used as a blindfold, a small object that can be picked off the ground, a watch for timing

🔀 process

1. Split the participants into two groups and blindfold one member of each one.

2. Keep a small object on the ground some distance away from the blindfolded person and then ask the rest of the group to direct the person to the object. Time how long it takes for the blindfolded person to reach and pick up the object.

3. Repeat the action with the second group and then declare the winning group as the one which has taken the least time in directing the blindfolded member to pick up the object.

4. Conclude the session by saying that the community is best led by the community itself and as community leaders, they can direct their communities to be healthier and more prosperous.

Session 12: preparing for real-life scenarios

objectives

The objective is to prompt responses from the participants on how they as a community structure would deal with real-life situations of TB patients, drawing from their learning in the previous sessions.

rationale

The participants are given the opportunity to apply what they have learnt in activity-based sessions to situations that simulate a real life incident that they might face in their day-to-day workings with TB patients. It will allow them to contextualize the situation and make decisions on how to work with TB patients as an organization.

duration

60 minutes

methodology

Discussion and presentation

equipment

A copy of the case study for each group in a language that is easily understood, markers/pens, whiteboard/chart paper with stand

process

1. Divide the participants into groups, preferably with members of the same structure in each group (this will be useful for the later sessions) and give each group a copy of the case study. Alternatively, if the group is not comfortable reading, read out the situation to the group, twice. The following are sample situations, which can be modified to take into context the setting in which the training is conducted.

- **Situation 1 (Problems with Alcoholism and Treatment Adherence):** A 40-year old TB patient who lives with his wife and three children is not taking tablets at all. He is an alcoholic, so he stops his medicine half-way through his course of treatment, even though his family and the healthcare workers are trying to convince him to complete his medication.
  What can you do?

- **Situation 2 (Stigma):** A 30-year-old male TB patient who lives alone and works as a mechanic in a garage is asked to vacate his home by the residents' association and is also refused entry into shops to buy vegetables. What can you do to help him?

- **Situation 3 (Poverty):** A 35-year-old woman is the only earning member of a family. She works as domestic help and supports her two young children and aged parents since her husband's death from TB two years ago. She has now been diagnosed with TB, and can no longer go to work. The family has no money to buy food. How can you help?

- **Situation 4 (Lack of knowledge and stigma):** There is a family in the community, of which one 22-year-old girl is exhibiting symptoms of TB, including a persistent cough and fever. The family does not take her for testing even after repeated visits from health workers or community structure members. They are from an upper caste and they do not engage with health workers, denying that she can have such a disease. They also refuse to take her to the government hospital as they believe the quality of care is very low. The girl is to get married in a few months. What can you do?

2. Give each group a chart paper and marker and tell them to write down the major points from their discussion about what they can do in each situation. Encourage the groups to discuss with each other and make a plan of action for tackling the problem using the strengths of the community structure. They are given 10-15 minutes to discuss.

3. The groups each have five minutes to come and present their plan of action. Provide feedback to the group on the basis of feasibility, while emphasizing the importance of additional aspects such as patient confidentiality. Ask the other participants for their feedback.

4. Close the session by saying that these are potential situations that the community structure members have to deal with, and they will have to be careful while handling sensitive issues of stigma and disclosure.

stories from the field

The Salvation Army, Vijayawada
A faith-based organization scales up awareness to church congregations across Vijayawada

The Salvation Army has 12 churches in Vijayawada, with a congregation of about 3000 people. With its reach and history of taking up welfare activities in the slums of Vijayawada, THALI program staff believed that it could promote positive health seeking behaviour across the district. The team began with one church in Arul Nagar and spoke to the church pastor about the burden of TB in India and in the district, the activities of the THALI project and the need to for influential community organizations to help TB control response among their members and, consequently, the larger community. The pastor gave the THAI team a 30-minute slot during Sunday services, and they involved local officials from the National Tuberculosis Elimination Program (NTEP) to talk about TB, its symptoms, testing and treatment. After the meeting, the pastor's wife contacted THALI staff, and said that one of her relatives had all the symptoms of TB. The team swung into action and worked with the NTEP team to get her tested. She was diagnosed with TB and put on treatment. This incident caught the attention of Major Dr. I.D. Ebenezer, who is the Divisional Commander heading all 12 branches Salvation Army churches in Vijayawada. He permitted THALI to conduct sensitization sessions with all other churches.

THALI conducted awareness camps in the Arul Nagar church, Milk Project church, and Pezzonipet church. The Arul Nagar church facilitated a medical camp in December 2019 as part of its observation of World AIDS Day; more than 200 people attended and six presumptive TB cases were identified by a medical team from the Apollo Tyres Foundation and referred to the nearest Designated Microscopy Centre for testing. The Pezzonipet church supported 12 patients in the community with nutrition packets. Through this network of Salvation Army churches, THALI could reach about 2500 people in different slums and mobilize nutrition support was provided for 25 TB patients.

The Salvation Army has been open to conducting awareness camps in their churches and communities and were recognized for their efforts at a training meeting for NTEP staff organized by THALI, where they shared their experience working in TB control and working alongside the NTEP for the benefit of their communities.

Post lunch small activity/energizers to be used to break lethargy

Session 13: support systems available to patients

objectives

The aim of the session is to introduce patients to the working of the government health system and the public benefits and schemes that patients are eligible for.

rationale

Since community structures will be linking patients exhibiting symptoms to frontline workers or health facilities for testing, it is important that they understand how the health system works and what benefits patients are eligible for.

duration

30 minutes

methodology

Information session

equipment

None

process

1. This session may be conducted by a staff member from the TB elimination program at Tuberculosis Unit/district/state level, if available. Keep the participants in the groups as these groups will continue in the following session.

2. Introduce the participants to the different levels of the National Tuberculosis Elimination Program (NTEP), detailing the facilities (the Designated Microscopy Centre, the Tuberculosis Unit, etc.) and the health staff (the TB Health Visitor, Senior Treatment Supervisor, Senior TB Laboratory Supervisor (STLS).

3. Talk about the benefits that patients are eligible for in public health facilities, including free testing, free treatment and nutrition support.

4. Ask the participants if there are any questions, and conclude, saying that the information is important for the participants to remembers, as they will be passing it on to potential patients. Prepare a few pre-prepared questions, in case there are no questions. These questions can be compiled from earlier discussions / modules in the previous day.

Session 14: formulating action points and the way forward

objectives

To engage the participants in putting down actionable points on working towards TB elimination and general health in the community.

rationale

It is important to get the participants to come together and make a collective decision on activities they can undertake in an individual and group capacity to improve community health. This session provides an opportunity for participants to have a collective agreement on activities, and a commitment to achieve them in a particular timeline, with feedback and support provided by the organizers.

duration

45 minutes

methodology

Discussion-based activity

equipment

Paper and markers for each participant group, whiteboard or chart paper with stand and markers for the facilitator, Pre-prepared thank you cards

process

1. Ask each group of participants to discuss five things they will do after the training to help TB patients and raise awareness in their communities. Give them ten minutes to make their list. Discuss with them the various possibilities for community structure members to support TB programs and general health activities in their areas. The areas of activity for community structure members include:
   • Setting up health information centres at their offices and members' local businesses to serve as a point of contact for community members to get the correct information on TB and contacts to local frontline health workers.
   • Referring symptomatic patients to frontline health workers for TB testing.
   • Mobilizing nutrition support through local donors
   • Supporting activities conducted by health facilities such as health camps and patient support groups
   • Helping TB patients one-on-one through counselling and garnering family support, while maintaining confidentiality.
2. Give the groups 20 minutes to discuss their planned activities and note down the points.
3. Each group reads out their list. Note down their actions on a whiteboard and consolidate the most feasible actions into a formal action plan. Run them quickly through their plan, and make changes if necessary. Tell them that the frontline health workers or project staff will be following up with the community structures after the training and help them to develop a detailed plan based on their points. If possible, set the meeting dates at the conclusion of the activity. If the actions can be converted into a chart, the community structure can take it back with them and display in their common area / office location.
4. Thank them and congratulate them for their thinking and ideas. Gives them a small card of thanks, welcoming them to the fight against TB, and for community health, as change makers.

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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 he 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 he'd never met shared how they had been cured of TB by taking treatment regularly, giving him confidence that he 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 his family could not attend these meetings, Jojamma would return home and share what he 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," he 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 his 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

GOAL	**Enabling a better TB treatment experience for the TB patients through Patient Support Group (PSG)**

LONG TERM OUTCOMES

Improved treatment outcomes amongst TB patients who participate in PSG	**Improved stigma redressal for TB patients**

INTERMEDIATE OUTCOMES

Increased participation of TB patients in PSG meetings	**Regularisation at DMC level** **Regular interaction between TB patients and caregivers with the doctor**	**Improved treatment adherence among TB patients who participated in PSG**

INTERMEDIATE OUTCOMES

• No. of patients whose weight is recorded every month • No. of TB patients who participated in the PSG • No. of TB Patients under a Differentiated Care Model (DCM) category/categories who attended PSG meetings	• No. of TB Champions identified and trained • No. of PSGs formed in Intervention districts • No. of patients who have been linked to medical support. • No. of PSG meetings conducted every month	• No. of patients who received nutrition support • No. of stigma cases reported • No. of stigma cases addressed (qualitative and quantitative documentation)

INTERVENTIONS

• Formation of PSGs at DMC level • Conducting PSG meetings on a fixed day every month • Regular BCC sessions • Ensuring participation of DCM category patients and caregivers	• Regular monitoring of patients' weight and treatment adherence • Creating a platform to have interaction amongst TB patient and caregivers	• Capacity building of TB Champions for experience sharing and support • Provision of nutrition support to needy patients • Addressing concerns related to stigma

ASSUMPTION	PSGs potentially help patients and caregivers to deal with psychosocial and medical challenges they face during their treatment period

BARRIERS

Negative attitudes towards treatment	Stigma and discrimination associated with TB	Irregular patient support meeting at facility level
Lack of knowledge on the importance of treatment adherence	Lack of knowledge on how to cope with side effects	Absence of patient-friendly systems for service delivery
Less interaction between TB patients and their family members with medical doctor	Under-nutrition hindering treatment response	Psychosocial issues related to TB

PROBLEM	Factors like self-stigma, low level of confidence and self-esteem, side effects and adverse drug interactions, and stigma among family members contribute to unpleasant treatment experiences. This results in poor treatment adherence and negative outcomes among TB patients.

patient support groups: the process

Engaging with staff at health facilities to assess feasibility of establishing PSGs

Mobilizing patients with the help of frontline health workers

Working with community structure and local leaders for nutrition and other forms of support

1. **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 >=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	**3:** 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	**2:** 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.

i 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. Adds 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.
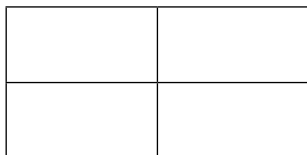
equipment

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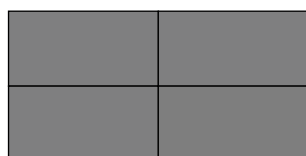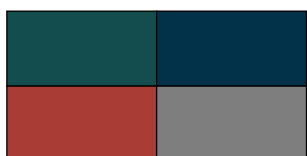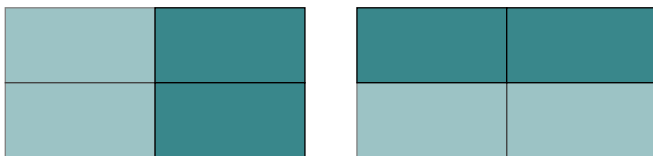
process

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."

iv 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 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.

v 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

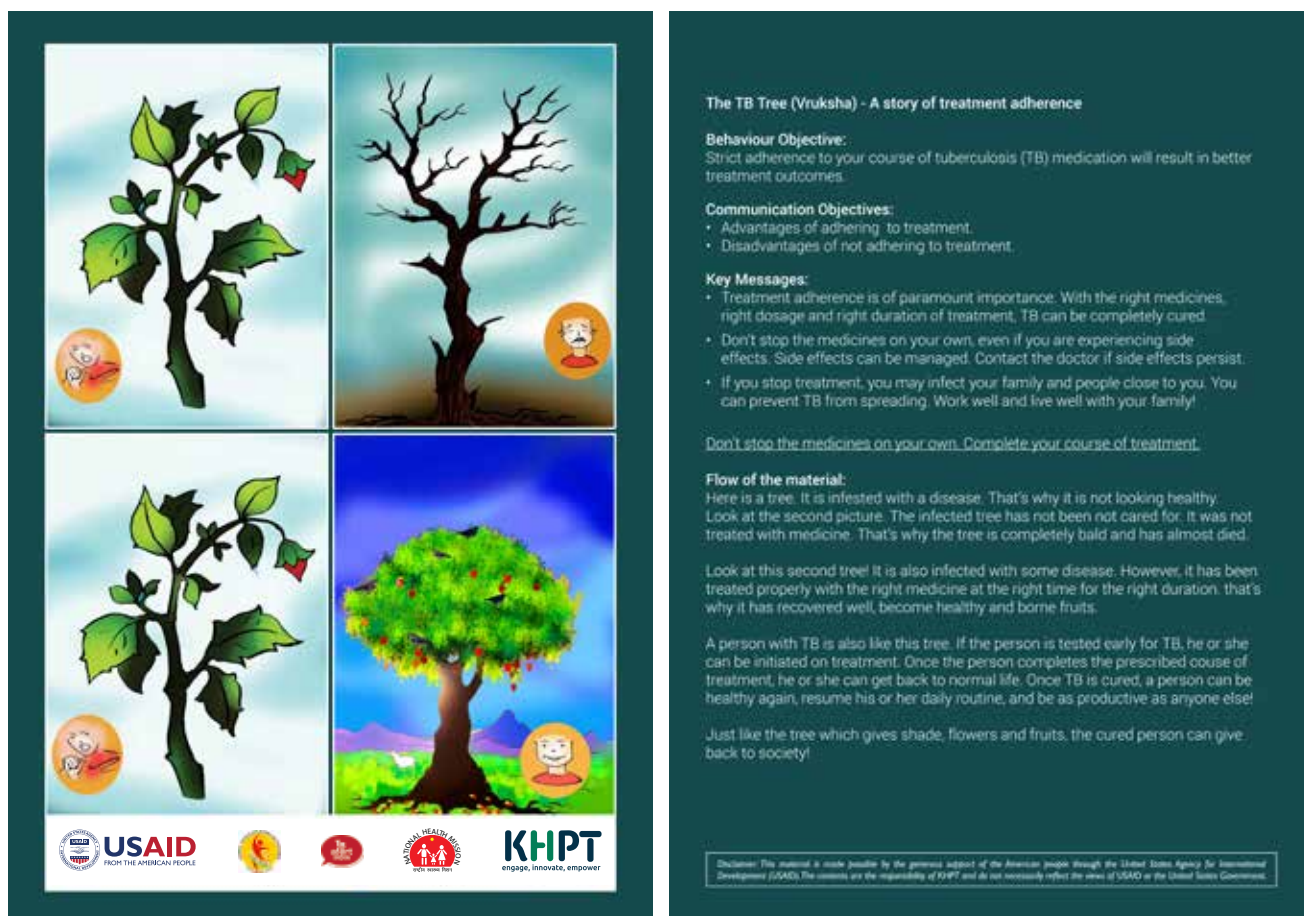**Stigma and disclosure flipchart**
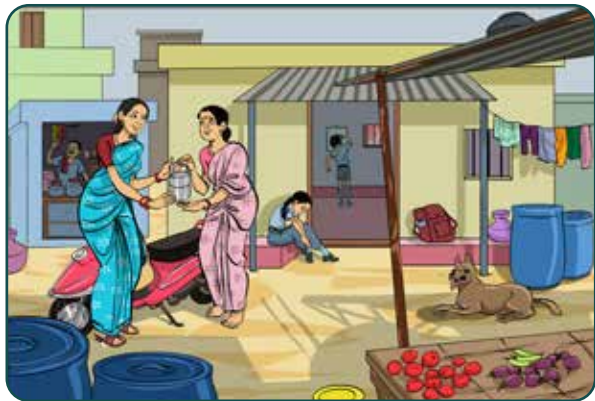
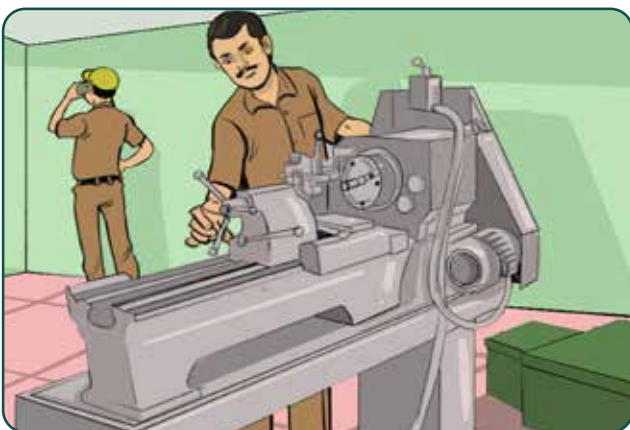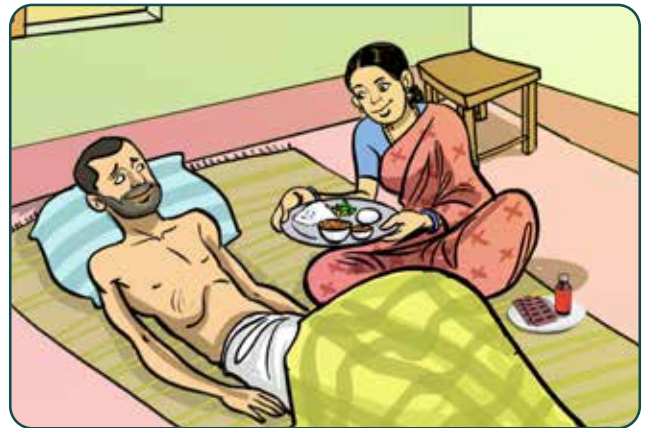## ii. Treatment adherence

Bullet

TB Vruksha

These BCC materials are accompanied by guidelines for usage by frontline workers. To access or adapt these materials, please contact us at kmunit@khpt.org

iii. The importance of nutrition
Nutrition flipchart

iv. Healthy habits: controlling smoking and alcohol consumption

Weigh the Consequences flipchart

Idly-Vada posters

These BCC materials are accompanied by guidelines for usage by frontline workers. To access or adapt these materials, please contact us at kmunit@khpt.org

Cough Etiquette

How to prevent germs from spreading through coughing or sneezing?

1 Cover your mouth and nose with cloth or paper
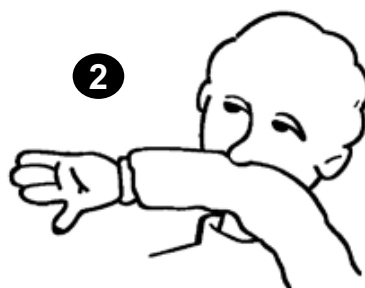
2 Use your upper sleeve or elbow if there is no handkerchief. Do not use your hand

3 If you cough frequently, use a mask

4 Wash hands often. It is good to use soap

These BCC materials are accompanied by guidelines for usage by frontline workers. To access or adapt these materials, please contact us at kmunit@khpt.org