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

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
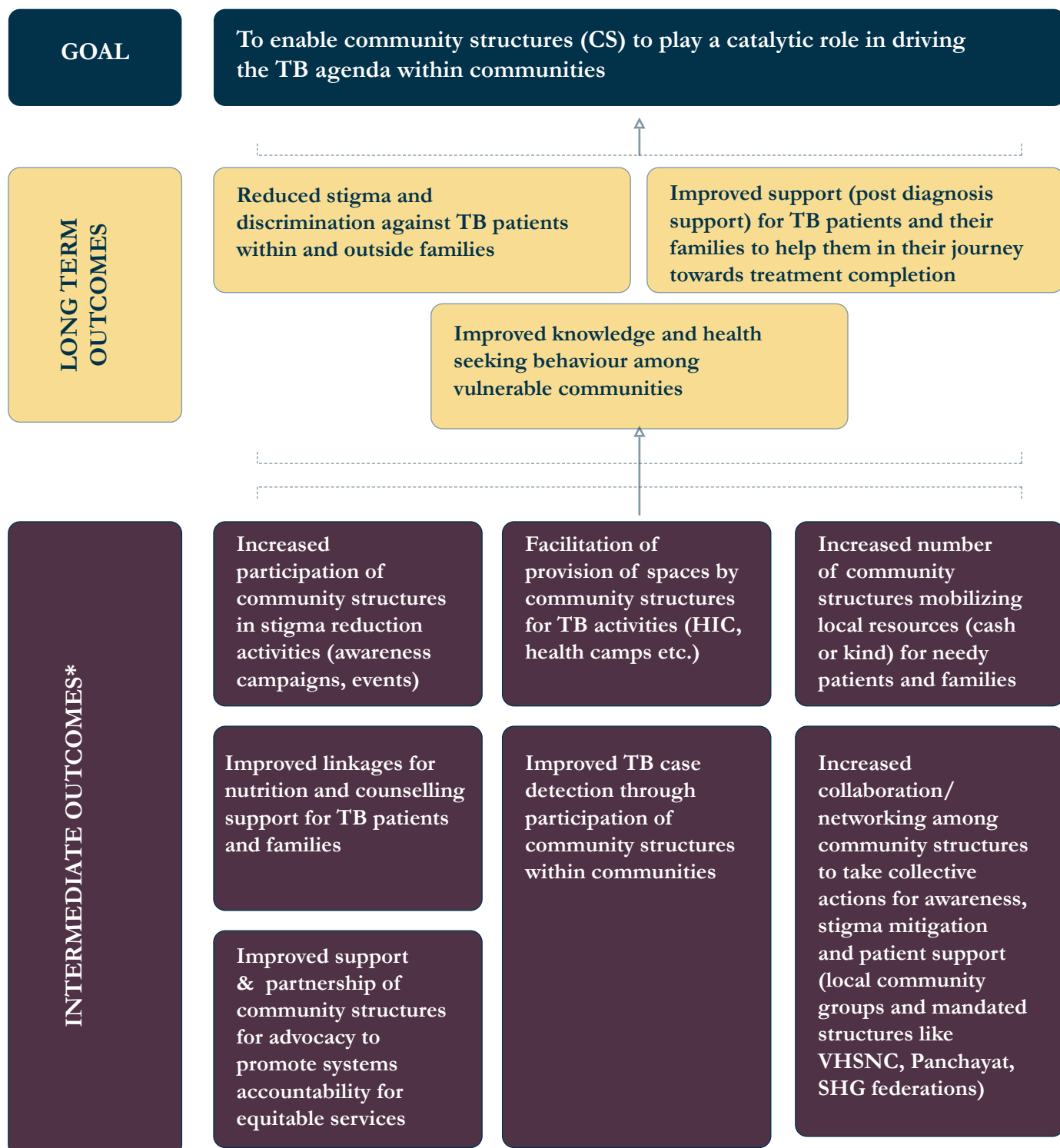
Community structures often engage in welfare activities in their areas, and integrating TB and general health activities into their agenda helps the community accept awareness, screening and testing-related activities. The Sri Sai Mahila Sangh in Bellary district of Karnataka is a federation of 20 Self-Help 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

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

SHGs	220
Slum association	40
Youth organisation	36
Labour union	37
FBOs	18
Other (auto union, NGO / CBO, timber depot)	44
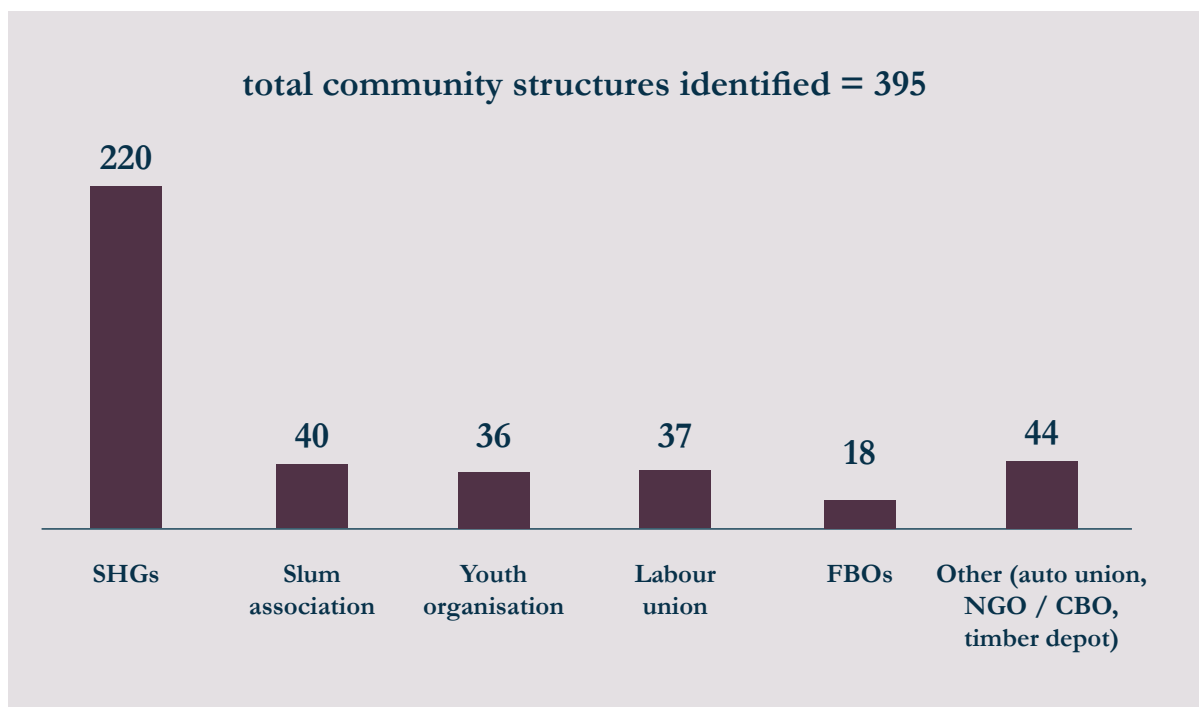
	Cumulative Achievements (July 2019- March 2020)
Number of members of community structures trained for health - related issues during the reporting period	1383
Number of handholding meetings conducted with community structures during the reporting period	1444
Number of Health Information Centres (HICs) 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
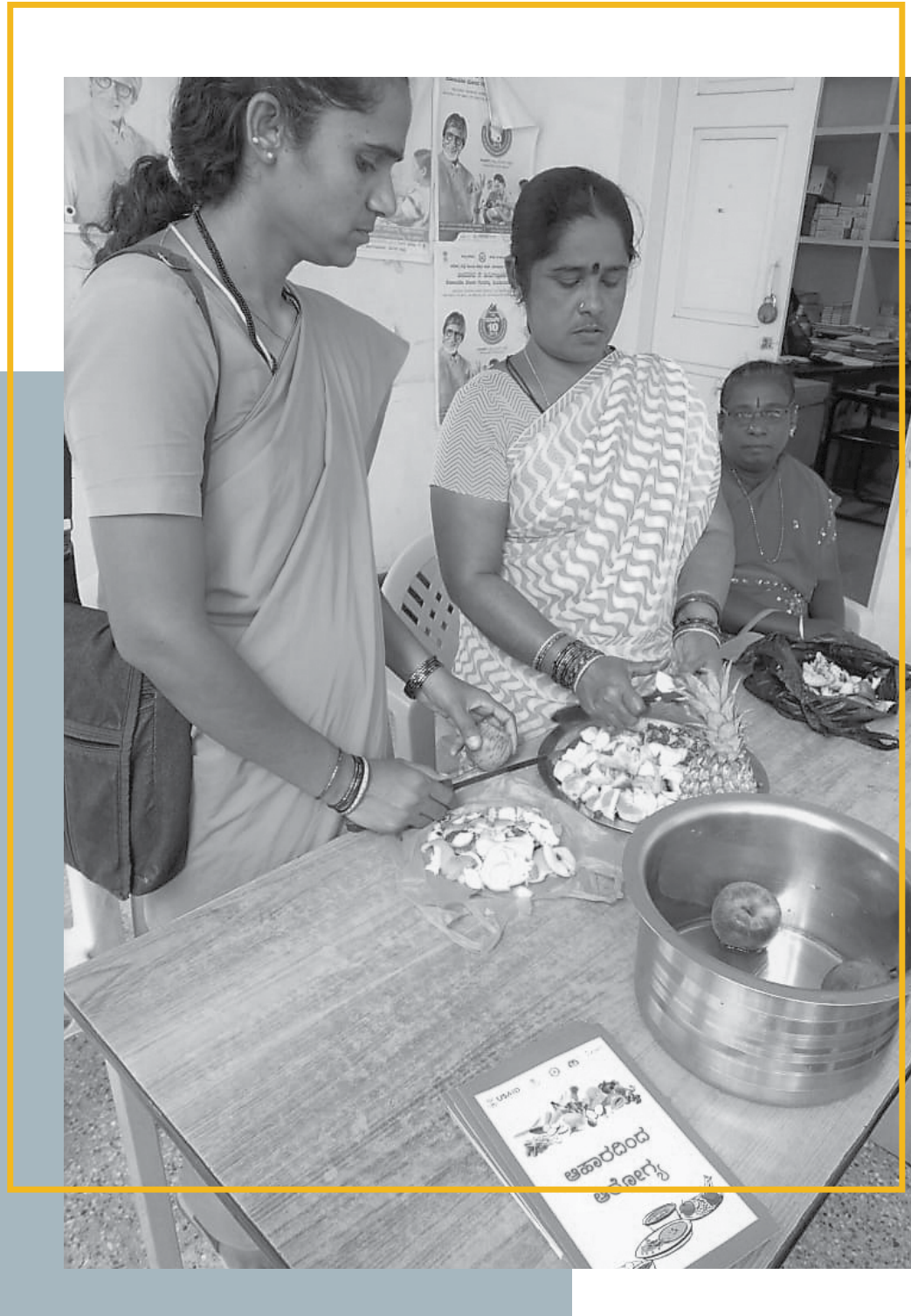
Session 8: health as a right

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.

d a y 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?

- **Situation 5 (Stigma and privacy):** A 35 year old mason has TB. He is trained to manage his condition well and take care to not spread it to his wife and two children. Whenever his wife / children are seen outside, few people call them names such as "TB Family / TB Children" and create an environment of disgust and mistrust, even though the family has tested negative for TB. 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.